Enhancing the post-stroke patient experience at mealtime through participatory design: Eliciting, connecting and supporting multi-voicedness

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Declaration

The research reported within this thesis is my own work except where otherwise stated, and has not been submitted for any other degree.

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Abstract

Context/issue

Stroke is the major cause of disability in both Scotland and Portugal. It is estimated that each year stroke affects 15,000 people in Scotland and approximately 21,000 in Portugal, and possibly one-third of these individuals require rehabilitation. Research (Ekberg et al., 2002; Wright et al., 2005) has identified that the quality of the mealtime experience for patients affected by stroke in rehabilitation is poor, which may be demotivating and a factor in influencing recovery.

Questions and previous studies

Is there an opportunity for design methods and approaches to help understand and improve the patient mealtime experience and if so, how? In previous studies, Cottam and Leadbeater (2004), Murray et al. (2006) and Boyle and Harris (2009) suggest that the integration of multi-stakeholders' participation into the design process can be valuable. Bate and Robert (2007) suggest directly taking account of patients' and healthcare professionals' experiences – "the real virtuosos of the experience" (Sanders, 2001) – as the basis for designing service improvements and, consequently, better experiences. So, can design approaches help elicit patients' and healthcare professionals' "voices" and can these voices be used to help enhance the quality of the mealtime experience for patients undergoing stroke rehabilitation and if so, how?

Methodology

This thesis adopts a participatory design (PD) approach to play a role in engaging and structuring the direct participation of patients and healthcare professionals in research. This method encompasses socialised and materialised situations in time and space with a focus on understanding the reasons behind current experiences while also exploring desirable futures. The analysis is based on translating and interpreting those patients' and healthcare professionals' voices, using the principles of framework analysis.

Subjects, methods and activities

This pilot study included 11 participants comprising 6 healthcare professionals: a nurse, speech therapist, occupational therapist and dietician; and 5 patients who had a clinical diagnosis of stroke and eating difficulties. This research employed the following data collection techniques within a participatory design (PD) framework: i) integrating 4

interviews with observations, ii) 5 interviews combining a tool (storyboard) and a technique (nurse verbalising), and iii) 2 workshops acting as games. This chosen study design facilitated the aligning of different design situations where patients and healthcare professionals were temporarily engaged in discussing the present experiences, and, subsequently, in two different groups, suggesting ideas for future experiences. In this research study, PD methods were adapted to permit patients to participate, so that tools and techniques become connected, flexible and adapted to better accommodate their individual needs.

Findings

This study found that socio-cultural differences highlight different perspectives: what patients imagined as desirable experiences differed from the views of the healthcare professionals. The study found that the current mealtime experience largely reflects a pre-occupation within functional rehabilitation issues, such as swallowing, but both patients and healthcare professionals highlight issues of subjective well-being which were not well-catered for. However, both patients and healthcare professionals emphasised complementary concerns about the mealtime, such as: experiencing positive socialisation; sensorial stimulation in ways that evoke well-being; and environmental factors designed to accommodate individual needs. The "*What if*" situations allowed patients and healthcare professionals to imagine a desirable design of the mealtime experience. These findings highlight the reconsidering the idea of the mealtime as one which offers a desirable and temporary break from the clinical "mechanistic" routine to create an opportunity to celebrate life and influence the patients' emotional state in positive ways.

Discussion

In this study, eliciting multi-voicedness through a process of inquiry by engaging patients and healthcare professionals has brought forth new insights and issues. The method enabled the building of scenarios, not only to translate both the patients' and healthcare professionals' voices into visual narratives of both what happens presently and their desirable future experiences. This process made information-sharing between different individuals and the two groups possible.

Originality of contribution, implications of findings and future work

This is the first study to consider the voices of the patients and healthcare professionals in the mealtime experience for people affected by stroke. Here, some of the participants involved were at the extreme end of their ability to participate due to being fatigued by their condition. The work has shown how methods derived from PD can still be applied in these conditions but they must be adapted and evaluated in ways that do not cause tiredness for patients. The combination of methods has opened up new possibilities for patients, those affected by stroke, and their therapists, to actively engage and participate with their own experiences and ideas. By eliciting these voices, this research study has made a contribution to knowledge by obtaining an understanding of the patient experience at the mealtime.

While PD methods have helped to evaluate the way the International Classification of Functioning (ICF) model is currently being applied in this context and have helped to show what issues are not being addressed, this study has further developed and tested new PD approaches and methods in this setting and has provided insights on the modifications required and their implications for participants. The adoption of a PD approach revealed a novel and valuable way to highlight the pre-occupation with functional restoration in rehabilitation and revealed the absence of certain aspects of the ICF model from practice that are important to patients, such as attention to subjective well-being. In this way, this study has revealed how employing a PD approach can potentially improve the delivery of the ICF model.

The approach and techniques used here may be appropriate to be employed in other healthcare settings. This study will therefore be of interest across healthcare communities looking for new and useful ways of improving the patient experience.

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List of Abbreviations

ICF   The International Classification of Functioning

NHS   National Health Service

SA   Stroke Association

WHO   World Health Organization

TMF   Textured Modified Food

PD   Participatory Design

BDA   British Dietetic Association

SIGN   Scottish Intercollegiate Guidelines Network

ISWP   Intercollegiate Stroke Working Party

OECD   Organisation for Economic Co-operation and Development

DGS   Direcção-Geral da Saúde

1

Introduction

Stroke, a chronic disease, affects 15 million people worldwide each year (WHO, 2011a). The impacts of stroke show people facing physical, cognitive and psychological difficulties, and demonstrate how health services are required to treat and assist patients to recover from the effects of stroke (Stroke Association, 2012a). Furthermore, evidence shows that, in the United Kingdom (UK), stroke has been the biggest single cause of major disability (WHO, 2011a, b and c), where Scotland presents the highest incidence each year (Stroke Association, 2013). It is estimated that each year stroke affects 15,000 people in Scotland, and possibly one-third of these individuals require rehabilitation.

Stroke is also the major cause of disability in Portugal. It is estimated that each year stroke affects approximately 21,000 people in Portugal (DGS, 2001). My interest in this area was initially influenced by the context of stroke in Portugal where I observed that healthcare organisations such as rehabilitation centres faced challenges to promote quality of life for patients affected by stroke throughout the recovery process. In particular, I carried out a study, for my post-graduate degree (Neves, 2008), addressing various aspects of the food service in a Portuguese hospital. This initial experience suggested to me, as a designer and as someone who was interested in food, cooking and the social aspects associated with enjoying food, that 'Design' might be able to play a positive role at the mealtime in this context of stroke rehabilitation, which goes beyond enhancing the patient's physiological functionality to one which promotes enjoyment and pleasure in eating in order to promote emotional and social restoration.

Due to my interest in Design, and thinking about what it might offer in this context, I began to think about pursuing a doctoral study, and began to read more widely. In the UK, and elsewhere, it is clear there has been, and continues to be, a significant interest in utilising design approaches to discuss and explore healthcare issues, including those associated with the treatment and recovery of people with chronic diseases. In the context of the mealtime in healthcare, various studies reveal that attention has been focused on enhancing food service provision and eating in hospital and care homes through design approaches. More on this topic will be discussed in Chapter 3.

Because of the nature of, and approach to, the research being done in this area in the School of Design at The Glasgow School of Art, I developed a proposal for an in-depth doctoral study of the patient mealtime in the hospital stroke rehabilitation setting which would highlight the role of design practices in exploring, revealing and improving the patient experience.

1.1 The mealtime as a day-to-day patient experience

Those affected by stroke typically go to hospital to receive treatment and undergo rehabilitation in a "Stroke Unit" (Intercollegiate Stroke Working Party, 2012). Stroke units are clinical services that involve the collaboration of a multidisciplinary team with multiple skillsets to treat and aid those patients in their recovery. Initially, patients follow the care pathway of "acute services" to receive treatment in order to stabilise the degree of severity of their clinical condition. In other words, the priority of this treatment is to help the patient to survive. After they become clinically stabilised, the treatment focus shifts to rehabilitation in order to assist the patient to recover from the impacts of stroke.

Recovering from stroke involves the patients having either a short or long stay in hospital (SIGN 118, 2010). However, patients who present with eating difficulties need a longer hospital stay (Westergren et al., 2002b). The mealtime is an everyday activity where experiences, such as swallowing, transporting food to the mouth, and handling the cutlery have been identified as some of the elements of patients' eating difficulties during rehabilitation in hospital (Westergren et al., 2001a). Swallowing problems require specially-prepared food as treatment (Wright et al., 2005). In other words, patients have to undergo a process of having to functionally rehabilitate their swallowing function while eating Texture Modified Food (TMF). Thus, (re)learning the everyday, taken-for-granted act of eating becomes central to both the survival and recovery of people affected by stroke.

Initial review of literature and the mealtime service revealed two main issues. Firstly, there was very little evidence of the patient's voice in this context at the mealtime in hospital. Secondly, the quality of the mealtime experience for patients affected by stroke in rehabilitation presented some problematic issues, which may be demotivating and a factor in influencing recovery. However, in hospital, the mealtime involves two groups in inter-connected roles; the healthcare professionals who plan and deliver, and the patients who receive and recover. These roles provide two distinctly different perspectives and experiences of the world. For example, healthcare professionals might hold experiences

that can be relevant to make significant contributions from the clinical perspective. In contrast, patients might possess their own personal experiences associated with their individual health circumstances at the time that can be essential to make significant contributions from the self-perspective. These two views of the world can be relevant to obtaining an understanding of the patient experience but also to explore new ways of thinking about it.

In this line of thinking, this research then suggested that using Participatory Design (PD) approaches to explore issues and ideas by patients and healthcare professionals arising from the status quo. On one hand, this involves exploring with patients and healthcare professionals how improvements could be made. Eliciting these contrasting "voices" is considered significant and valuable, as they can be seen as a source to bring forth new insights on how to enhance the patient experience. Additionally, by placing a focus on creating opportunities to engage those patients' and healthcare professionals' voices in this research, involving dialogues to reflect, think and talk about the mealtime experience, it might reveal new directions on how to contribute to the future patient experience at the mealtime in stroke rehabilitation with the aim of facilitating the recovery of the patients. On the other hand, using PD in this context of stroke in hospital would pose particular opportunities and challenges, as it did not appear to have been done in this setting before.

1.2   The healthcare model

In the UK, the National Health Service (NHS), like comparable healthcare services in other countries, is a large-scale system, involving a complex variety of forms of service provision, both in terms of primary medical care and support services, both inside and outside the hospital environment. The growth in incidences of chronic diseases and conditions places a demand on healthcare services to respond to the treatment of such conditions, but also to provide improved quality of life throughout the treatment regime, addressing the issue of patient-centred care as it has been deemed to be important to deliver the most effective care for individual patients (ISWP, 2008), or, in other words, by providing more personalised care, individual health needs can be supported (Department of Health, 2005).

In the context of stroke, the health policy-makers and medical researchers have highlighted the significance of the International Classification of Functioning (ICF) model in order to deliver the most effective care for individual needs (ISWP, 2008; Scobbie et al., 2011). The ICF model integrates two views: the medical and social. The medical view is to

respond to the patient's disability caused by a health condition in terms of treatment and/or cure. The social view is related to the quality of the social and environmental conditions that allow people to conduct their everyday lives with as few physically barriers as possible (WHO, 2001). The applied ICF model in the context of stroke rehabilitation at the mealtime has developed into one with a predominant view; the medical, while issues around social views are left poorly addressed despite the explicit recommendations of their importance in the ICF model. What this shows is that the mealtime is delivered under the application of an unbalanced rather than a balanced ICF model.

1.2.1 The patient experience

The former NHS Institute for Innovation and Improvement in collaboration with medical researchers has developed an experience-based co-design (EBCD) approach, a model to improve the quality of healthcare that emphasises the direct participation of multiple views, in particular those of the patients and healthcare professionals, and considers these to be significant when implementing healthcare service improvements. PD potentially offers something useful as an approach to research in the context of stroke, as a deep understanding of the patient experience at the mealtime. PD models emphasise the importance of begining to understand what is currently happening (experiences) as the basis to gaining an understanding of what would be desirable, as experiences, in the future. In this way, PD emphasises a focus on the patient experience. Perhaps this emphasis might reveal the importance of participatory design models in this context of health to support healthcare models (Murray et al., 2006). By giving patients and healthcare professionals a voice through a "co-design" process, this approach might help to highlight views different from that of the medical. These might be valuable to elicit the kinds of evidence that can contribute to balanced rather than unbalanced healthcare models, in particular in this context of stroke rehabilitation at the mealtime.

1.3 Using participative co-design approaches to improve the quality of the patient experience

Improvements in NHS patient experience are being driven by a collaboration of patients, support and advocate groups, and healthcare professionals, often with different roles, conceptions and experiences in the use, utilisation and provision of health services. Involving patients in research can be valuable because they possess a different perspective from that of the healthcare professional due to their own knowledge, role and experience in healthcare. As I mentioned earlier, patients can be seen as care receivers and healthcare professionals as care providers. In this way, patients' involvement can provide distinct and

valuable insights in research (INVOLVE, 2012). However, the value of the direct participation of the patient can be even wider reaching in design research.

To drive meaningful change we have to create a partnership between healthcare professionals and patients. A partnership means to establish co-design practices where researchers, patients and healthcare professionals work together to design (Sanders and Stappers, 2008) or redesign (Cottam and Leadbeater, 2004; Donetto et al., 2014) health services for better future experiences. The nature of this partnership is based on the value of multi-voiced participation in the design process. Design into improvements in the quality of the patient experience at the mealtime demands collaboration, involving patients and healthcare professionals in design. In this way, patients and healthcare professionals are seen as the source to explore new ways of thinking about the mealtime experience. Think, for example, in stroke rehabilitation in hospital, how the mealtime becomes part of patients' and healthcare professionals' lives on a daily basis. Future design changes at the mealtime will affect their lives, and most importantly, their experiences. Therefore, involving patients and healthcare professionals in design research means being responsive to their lives, needs and experiences in their future. Moreover, an understanding of the patients' and healthcare professionals' experiences and ideas can provide valuable information, but also, this information can be useful to promote new ways of experiencing. Giving patients and healthcare professionals a voice in design can help to support desirable mealtime experiences in stroke rehabilitation in the future. In this way, this research will focus on eliciting patients' and healthcare professionals' voices, as this might be a significant way to bring forth new insights. In what follows, I will explain how to do this.

1.4 Eliciting patients' and healthcare professionals' voices

Design for experiencing has been considered important for the user because the value of products is not only in designing for their functionality and usability, but also in delivering pleasurable and enjoyable experiences (Norman, 2005). Although design researchers have become more interested in this idea of designing for the patient experience, what *is* the patient experience? And *who* participates within design practices? I argue that when aiming to generate active patient participation, design practices must always be adapted in order to accommodate the individual needs of the particular patients involved. Most importantly, it must allow for the generation of valuable dialogues, which integrate "the real virtuosos of the experience" (Sanders, 2001), and, consequently, contribute to obtaining new insights. Patients cannot only be seen as users or consumers simply because

they are those who receive care and treatment and/or are living with a health condition in their everyday lives (INVOLVE, 2012). This is particularly true for those affected by stroke who might face a series of everyday adjustments or adaptations to conduct their lives on a daily basis. Although design researchers, on the one hand, and medical researchers on the other, have previously involved patients in research, they involved them in different ways than those presented in this thesis. Here patients, those affected by stroke, had the opportunity to have a say by participating directly in the design process with an aim to obtaining an understanding of patients' experiences, aspirations and desires for their future experiences.

In this way, this research study adopts a participatory design (PD) approach to investigate the patient experience at mealtime in stroke rehabilitation in hospital. As Binder et al. (2011a) have argued, PD practices must develop strategies that allow people to participate, and consequently, enable their legitimate participation because when these strategies involve diverse skills, these "voices" are considered to be fundamental to design for desirable futures (Krippendorff, 20016). This approach is achieved by thinking of design as a process where social and material situations are orchestrated to deal with matters of concern in time and place. PD values are based on giving democratic voice to people; the growing emphasis on the social and material network of stakeholders; on putting people and tools together in interacting to design for change; and designing for and with people because this is seen as being a source of valuable information to create new products, services and, consequently, to enrich experiences. PD was adopted in this research to establish the direct participation with patients and healthcare professionals in the design process with a goal of eliciting their voices to explore opportunities to enhance the quality of the patient experience at mealtime. This idea of voices is related to how design practices can trigger patients' and healthcare professionals' interest, empower their capabilities and align their motivations (Manzini and Rizzo, 2011). Fundamentally, this research adapted PD tools and techniques that were able to support the particular nature of these patients' capabilities to enable the engagement of the "virtuosos" (Sanders, 2001) and not just those who are more able and advantaged (Boyle and Harris, 2009).

Contemporary views of PD consider the challenges to participation as "infrastructuring" (Bjögvinsson et al., 2012). *Infrastructuring* here suggests thinking of design research in this idea of a journey, involving social and material arrangements in temporary spaces to allow different "voices", views, opinions and ideas to emerge. What I will argue is that participation, in this thesis, is precisely a journey involving active patients and healthcare

professionals in social and material situations that enable their voices to be made "loud" in time and space. However, design research to involve patients, in particular those affected by stroke, means considering how to conceive and conduct these social and material situations in order to provide ways that inspire and support patients to participate despite the difficulties posed by their health conditions. PD practices involve tools and techniques to generate dialogue that allow people to express themselves in different forms; perhaps involving a dialogue that goes beyond words, for example, creating maps, sketches and/or prototypes. By involving patients, PD design practices require a focus on design connectedness in this interaction between the social and the material in order to facilitate patients' participation, or, in other words, support patients' well-being rather than influencing feelings of embarrassment (Perry and McLaren, 2003). This means that PD in this context of stroke requires adaptations to support and facilitate inclusiveness rather than influence exclusiveness. Fundamentally, PD needs to offer the possibility for these patients, those who live with a health condition, to participate in social and material situations. I argue for the consideration of such PD design practice strategies as being a valid way to support patients' participation.

Traditionally, design research with user experience suggests that an understanding of people's experiences should occur at the beginning of design to provide valuable information to proceed into design developments of products or services (Sanders and Dandavate, 1999). However, others have pointed out that a more appropriate way might be to engage in the cultural context of experience in order to understand how people make sense of their experience at that time (Wright et al., 2008) and in relation to each other (Battarbee and Koskinen, 2005). It is believed that using practices to know "the real virtuosos of the experience" (Sanders, 2001) is reflected in design that creates empathy. Empathy, in this context, refers to design practices that create direct contact with people within an attitude of respecting their views and ideas (Mattelmäki and Battarbee, 2002), but also, in supporting design research to gain an understanding of people's experiences (Segal and Fulton Suri, 1997). This is based on understanding of people's needs, aspirations and motivations as being a source of valuable information to support future desirable experiences.

However, design practices to obtain an understanding of the patient experience have required consideration about design practices, not only to create direct contact with the "virtuosos", but also to determine what kind of authority design has to engage these "virtuosos", particularly patients. What this research shows is how design practices at work

in the National Health Service ethical approval system have allowed the "virtuosos" to participate in the design process. In doing so, this research shows how to legitimise patients' and healthcare professionals' participation in design. Although design researchers point out the ethical issues and challenges to involving patients directly in design practices (Macdonald et al., 2010), I demonstrate that making design proposals that are focused on the significance of patients' and healthcare professionals' contribution to design into "desirable futures" (Krippendorff, 2006) potentially motivates the healthcare community to support and collaborate in their involvement. This strategy is not only considered valuable to design to support desirable experiences but also the outcomes delivered through design might be significant for health, in particular, in stroke rehabilitation and these patients' recovery.

1.5 The thesis structure

This thesis, exploring the patient experience of the mealtime in stroke rehabilitation, is detailed in the following nine chapters. A summary overview of the content of each chapter is presented below.

Chapter 2 provides a Contextual Review of the understanding of the impact and effects of stroke, focusing on clinical practice and rehabilitation in the stroke rehabilitation ward, and also on one aspect of the patient experience; their mealtimes. This reveals a model of healthcare practice which predominates in stroke rehabilitation, and how this impinges on the mealtime and on patients' experiences. This chapter identifies potential opportunities for design to introduce and explore a missing social dimension to complement the current predominantly functional restoration practice.

Chapter 3 presents a Literature Review with the intention of gaining an understanding of design for people's experience and how patients and healthcare staff can be involved in developing improvements to the status quo. It highlights the inclusion of a social agenda in design practices to explore opportunities to improve the quality of the patient experience in health services. It provides illustrations of how design models are utilised to support healthcare improvements and how design researchers handle the collaborative design process as a means of changing things for the better. It highlights, within the context of stroke recovery, how the direct participation of patients and healthcare professionals can be supported and harnessed in collective creativity as a means to obtain new insights.

Chapter 4 describes the Methodology which will employ a distinct participatory design (PD) approach to support the direct participation of the patients and healthcare

professionals. This chapter discusses the appropriateness of methods to involve these particular stroke patients considering that they can require a series of adjustments or adaptations to conduct their life on a daily basis. The specific design tools and techniques that are to be utilised in this study highlight the specific "adaptations" needed to accommodate individual needs, to support their participation and to promote social dialogues as a means to explore future possibilities.

Chapter 5, the Study Design, explains how the process of inquiry is planned and organised, using "infrastructuring" through a framework which will focus on eliciting the patients' and healthcare professionals' voices, involving three phases. Phases 1 and 2 will be used to start with explorations about the current experiences at the mealtime before proceeding towards Phase 3; an exploration of future improved and desired possibilities. As an approach to the enquiry, this chapter discusses the necessity and challenges of observing an ethics application process to gain access to and to legitimise participation of these patients and staff in this healthcare setting. It also discusses how adapting participatory design methods and creating connectedness through social and material situation "design games" is intended to better involve individuals, particularly patients in the design process. This will help elicit their "voice" and produce data and evidence which was found missing in the literature. Voices will be illustrated by using a framework method of analysis.

Chapter 6, Findings from Phase 1, demonstrates the present situation at the mealtime in stroke rehabilitation in hospital by eliciting four healthcare professionals' voices. Their voices allowed the obtaining of an understanding of work experiences, stroke, rehabilitation and the mealtime for patients in hospital. Fundamentally, this chapter highlights the emerging issues, revealing how the mealtime is problematic for the patients and their experience. Moreover, this research study aims to build a storyboard of the mealtime, and that process is outlined in this chapter. Building a storyboard proves to be a valuable tool to support further investigations about the present situation.

Chapter 7, Findings from Phase 2, illustrates what the five patients' voices revealed by conducting interviews and combining the tools and techniques discussed in Chapter 5. Through this research study it is possible see their individual experiences at the mealtime. Through these individual experiences it is possible to identify the main problematic experiential aspects at the mealtime. One of the aims of this research study is to build a scenario of the present situation. Thus, overlapping the healthcare professionals' and patients' voices allows us to see the contextual mealtime scenario of the present situation. Building this scenario is useful not only to reflect about the emerging issues, but also to

define what needs to be explored next and how using the scenario can support this exploration.

Chapter 8, Findings from Phase 3, provides the outcomes of conducting two separate, but connected, co-design workshops. The first was conducted with a group of three patients and the second with a group of three healthcare professionals. This research study aimed to explore possibilities for a desirable change at the mealtime in the future. The first workshop demonstrates the patients' ideas of what would be a desirable mealtime experience in stroke rehabilitation in hospital. Collecting the patients' ideas is considered to be a significant way to obtain an understanding of their aspirations. Thus, transporting these patients' ideas to the second workshop involving healthcare professionals is relevant to explore what can be done to address these patients' aspirations. Thus, these patients' voices were used to build a new storyboard to support further investigations. The second workshop illustrates the healthcare professionals' ideas based on the patients' perspectives for the future to explore what would make a significant difference at the mealtime in future patients' experiences. Giving healthcare professionals a voice is also important to turn ideas into concepts. Once again, by overlapping these patients' and healthcare professionals' voices, I illustrate a new contextual scenario of the mealtime. Building a new 'improved' mealtime scenario allows an important comparison with the current mealtime scenario and what directions need to be explored further.

Chapter 9, the Discussion, demonstrates the value of using participatory design in the context of stroke rehabilitation research. This chapter discusses that adapting participatory tools and techniques are essential to be both appropriate and valuable to inspire, facilitate and support patients' participation. A model for design connectedness demonstrates how the relationship between tools, techniques and people can offer the possibility for voices to emerge. A framework method of analysis is shown to demonstrate multi-voicedness and provide deep and rich information about the mealtime in the study's context. This chapter points out, on one hand, how PD has a role to play in supporting multi-voicedness in this context of stroke and healthcare. On the other hand, it emphasises how stroke rehabilitation might benefit from a PD approach in order to rebalance the omission of the social dimension in healthcare models. This chapter also discusses the achievements and limitations of this research study.

Chapter 10, the Conclusion, reflects on the three main contributions to knowledge that result from this study. Firstly, from a healthcare perspective, the approach provides evidence of factors other than the requirement for the patients' functional restoration which

may have an important bearing on their recovery. Secondly, it has shown how PD approaches were adapted and extended into a challenging and complex healthcare environment involving patients who have suffered significant trauma and found these to be effective in gathering new data and insights. Thirdly, it provides a means of enabling patients to articulate issues such that these could be shared through communication channels such as the Patients Association.

2

Stroke: Contextual Review

2.1 Introduction

In hospital, the mealtime, as a microcosm of the stroke care world, is a day-to-day patient experience. Patients affected by stroke present eating difficulties, which often necessitates a longer stay in hospital (Westergren at al., 2002a). A design research study in this context of stroke at the mealtime becomes significant when we aim to influence the patient's well-being during recovery, particularly as medical researchers have considered the mealtime to be "both an integral component of the rehabilitation process and markers of the relative 'normality' of life" (Perry and McLaren, 2003, p.368).

This chapter begins by exploring what a stroke is and what its effects are on individuals; understood through a discussion of the impacts of stroke, these can involve a range of physical, cognitive and psychological difficulties. In exploring the incidence of stroke with a focus on European countries, Scotland and Portugal have faced the highest annual incidences of stroke. When recovering from stroke in these countries, patients proceed through a care journey that begins at rehabilitation in hospital to recovery at home. In hospital, stroke rehabilitation in the UK, following National Clinical Guidelines for Stroke, has used the International Classification of Functioning (ICF) model with an aim to deliver the most effective care to respond in a timely and appropriate manner to each patient's unique needs (ISWP, 2008; 2012). The ICF model, developed by the World Health Organization, has indicated the integration of two viewpoints, the medical and the social, in order to reduce the complex notion of disability. This model places the focus on enhancing the functional capacity of the patient and on improving his/her performance in the contextual environment (WHO, 2001), for instance, the varying impact of different environments on the ability of the individual.

In exploring the medical model, research has been concerned with developing and conducting methods to assess, treat, restore or adapt the patient's bodily functions affected by stroke. This model has included a focus on identifying eating difficulties (Westergren et al., 2002b; Medin et al., 2010) and providing appropriate food (Perry, 2004; Wright et al., 2005) in order to promote patients' nutrition in rehabilitation. However, reviews will show how medical research has highlighted social concerns and how these social concerns are opening up opportunities for design interventions. Consider, for example, how medical

research has found that patients consider eating to be a relevant aspect of life (Perry and McLaren, 2003) and that it should be an enjoyable experience (Ekberg et al., 2002). How can design play a role in order to address quality of life issues for people who have had a stroke?

Stroke is a highly complex situation and health policy makers as well as medical researchers have been understandably pre-occupied with "pathologies" and with how to deliver the most effective treatment in order to cure and restore patients with the aim of getting them back to their "normal" lives. From a design point of view, this thesis will highlight that/how design can promote a sense of empowerment for individuals "to become normal". In other words, design can explore medical concerns about the social. Perhaps more interesting is that design can support the ICF model, helping, for example, to emphasise that the medical model is a good one, but that design can facilitate this model to become a "supra-medical" model. Think, for example, of the mealtime as eating, but eating as encompassing swallowing, socialising, enjoyment and pleasure. Reflecting on these issues will highlight the need to obtain a better understanding of the patient experience, in particular, when medical research has revealed that patients who are being assisted to eat in public can experience feelings of embarrassment (Perry and McLaren, 2003) and that patients who present swallowing difficulties may lose out on the social pleasure associated with food (ISWP, 2008).

2.2 What is a stroke?

Stroke, referred to by the World Health Organization (WHO) as a "chronic disease", is often considered to be life-changing (Stroke Association, 2012a) due to the physiological, psychological and inter-personal consequences it places upon sufferers. A stroke is defined as "a brain injury caused by sudden interruption of blood flow" (Stroke Association, 2012b, p.4). The Stroke Association (2008b) illustrates two main causes of stroke: a blockage, which occurs when a blood clot blocks an artery that carries blood to the brain (this is called an ischaemic stroke); and a bleed, which occurs when a blood vessel bursts, causing bleeding into the brain (this is called a haemorrhage stroke) (Stroke Association, 2012b, p.5) (see Figure 2.1).
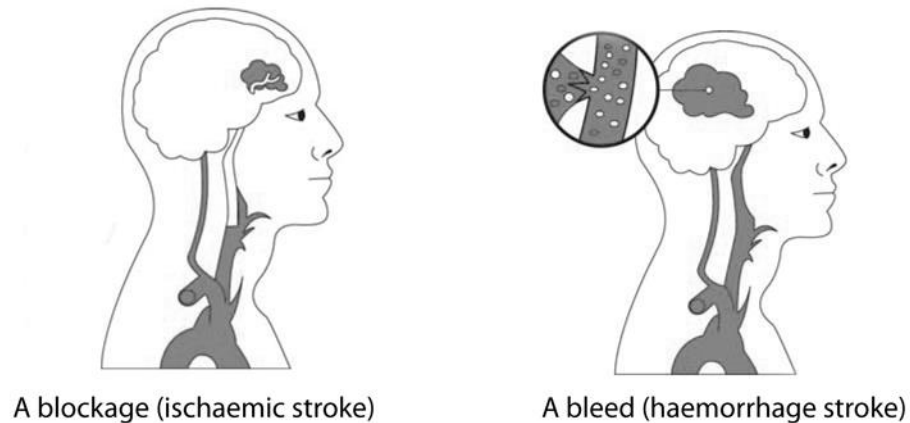
Figure 2.1 The main causes of stroke
(Source: Adapted from Stroke Association (2008b), What is a stroke? The stroke Association)

After stroke occurs, the affected area of the brain cannot function as previously. Such a brain injury affects how the body functions, preventing "normal" operation of the body and social interaction. Although a variety of symptoms have been reported depending on the part of the brain that is affected, the immediate symptoms of stroke have been described as: an inability to move one side of the body; an inability to understand and/or formulate speech; and/or an inability to see one side of the visual field (Stroke Association, 2012b, p.7). The following explorations will demonstrate the impacts of stroke.

2.3 The impacts of stroke

The main impacts of stroke can be categorised into the cognitive, physical and psychological (see Figure 2.2). For example, Losseff (2004) demonstrated these impacts by describing a patient's experience after stroke.

> *I was 42 years old when I suffered my stroke [...] Paralysed on my left side and unable to walk, I was confined to hospital for 3 months, then spent about a year recovering [...] stroke is an earthquake at the centre of who we are [...] our emotions [...] our body is no longer responsive to routine everyday instructions [...] I found myself wanting to tell health-care workers what it felt [...] but because my speech was slurred and my mind confused, I felt unable to articulate such thoughts. [...] The muscles on my left side were so weak that to sit in a chair [...] even with nurses to help me [...] was exhausting [...] slowness, of weeks lived [...] circumscribed by [...] new restrictions and limitations.* (Losseff, 2004, pp.63-65)

This patient's experience shows that stroke brings temporary disability at different levels, involving the patient's bodily functions and his/her participation in a day-to-day life situation. In other words, it reveals that a sense of self, of identity, and of a relationship to the world that is experienced in a different way after stroke. Consider, for example, the patient being in a sort of interior dialogue with himself/herself as a result of a set of combined impacts such as physical, cognitive and psychological experienced during his/her recovery. Recovering from stroke necessitates temporary medical intervention to "fix" the patient and return them to their normal lives. This emphasis on interventions to "repair" the patient opens up ways of thinking about how design might support the medical to bring a sense of empowerment to back to "normal". Explorations of the multiple impacts of stroke will be now made in more detail.

Cognitive impacts

Cognitive impacts are those associated with the patient's ability to think. The National Stroke Association (2014a), on its website, explains that stroke makes an impact on cognitive function in this way: "people use their brains to talk, read, write, learn, understand, reason and remember. Losing skills in this area may affect how you manage everyday tasks, take part in rehabilitation". The National Institute of Neurological Disorders and Stroke, on its website, adds: "Individuals also may lose their ability to make plans, comprehend meaning, learn new tasks, or engage in other complex mental activities [...] inability to acknowledge the reality of the physical impairments [...] the loss of the ability to respond to objects or sensory stimuli located on the stroke-impaired side". As a result of these consequences, patients can face difficulties in recognising objects and/or people. They might face difficulties in expressing verbally what they feel. These combined effects highlight a need to further investigate the mealtime in order to understand the patient experience in this context.

Physical impacts

Physical impacts are those associated with the patient's ability to voluntarily use their body to move, see and eat. The Stroke Association indicates that weakness or paralysis of an arm or leg can be one of the most recognisable and most common impacts of a stroke (Stroke Association, 2012b). Paralysis, as The National Stroke Association describes on its website, is "the inability of a muscle or group of muscles to move voluntarily". For example, paralysis can affect the throat muscles, those required for swallowing. According to them, more than 70% of stroke patients can experience swallowing difficulties (dysphagia). This has to be functionally restored to prevent, for example, choking.

Therefore, swallowing is inextricably linked to eating. Furthermore, visual disturbances can be experienced due to "the loss of half of each eye's visual field" and/or experiencing difficulty to "process what the eye sees" (National Stroke Association, 2014b website). According to the Stroke Association, stroke can cause "double vision, blurred vision or partial blindness" (Stroke Association, 2008c, p.10). Fatigue, described by the National Stroke Association as a physical impact of stroke, can affect between forty and seventy percent of patients. Fatigue, as they also note, is not the same thing as being tired; rather, the National Stroke Association reports on their website that "fatigue is usually linked to chronic dysfunction of some kind and can significantly impair a person's physical, cognitive and psychosocial (emotional and behavioural) functioning". What is illustrated here is also a set of connected effects, which require further investigation at the mealtime.

Psychological impacts

Psychological impacts are defined as those associated with the patient's emotions and state of mind. Negative feelings are described as a symptom of stroke in a variety of degrees, such as anger, frustration, anxiety, sadness and fear (National Stroke Association, 2014c; National Institute of Neurological Disorders and Stroke, 2011; and Stroke Association websites). These emotions have been associated with a diagnosis of depression. The National Institute of Neurological Disorders and Stroke defines post-stroke depression as a feeling of hopelessness that interferes with functioning and inhibits quality of life. The National Stroke Association states that these emotions affect more than a third of stroke patients and, if not treated and managed appropriately, they can slow down their recovery. These views prompt us to think about the patients' emotions at their mealtimes. Patients might be demotivated due to the effects of stroke. This highlights the need to look at the mealtimes to better understand the implications of this situation. Depression, as the National Stroke Association notes, can inhibit the progress of recovery and rehabilitation and can make a big impact on the patient's quality of life.
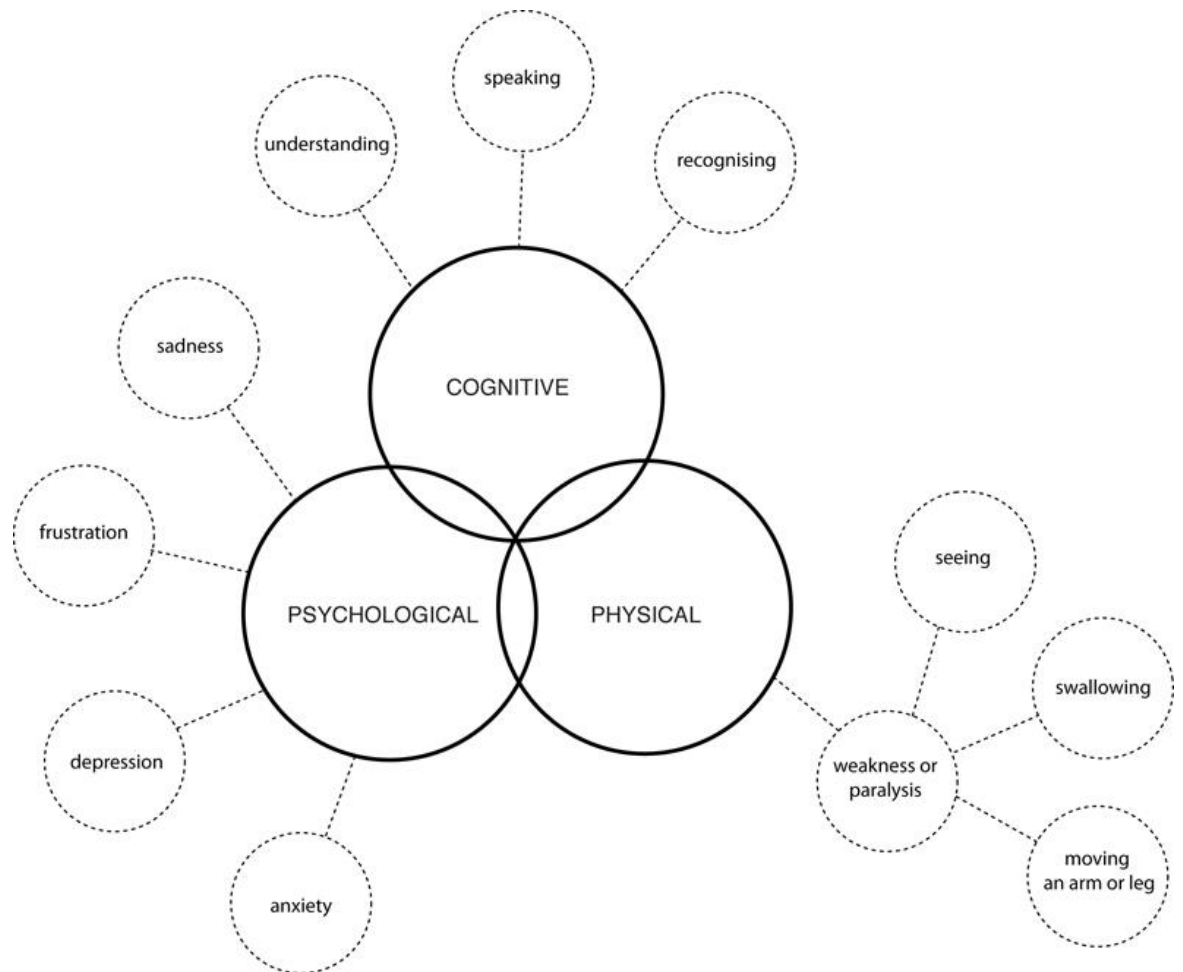
Figure 2.2 The effects of stroke

2.3.1   Social impact

Providing this initial understanding of the impacts of stroke demonstrates the manner in which patients can experience a complex set of problems to deal with during their recovery. In exploring the impacts of stroke, there seems to be a particular emphasis on the social impact (see Figure 2.3). Consider, for example, what happens in public situations such as the mealtime when these combined impacts, such as the cognitive, physical and psychological, are exposed. What seems to emerge here is the question of "how is the patient socialising"? In other words, how does the patient experience the social and/or contextual environment? What does it look like? Is it enjoyable? Socialising becomes part of our lifestyle in a variety of ways, such as eating a meal together with someone. In this chapter, explorations move beyond the patient's health condition, which requires treatment and recovery, to consider the social and/or contextual element as being an integral component of the patient's recovery (WHO, 2001), perhaps, exploring the possibilities for supporting subjective well-being (SWB). Adopting this perspective might also open up ways to explore the medical within this perspective that the medical model is a good one, but how can the medical become "supra-medical"? Think, for example, how

receiving treatment is essential for clinical reasons, but this can be taken further: how can receiving treatment become more than treatment? In what follows, the investigation will look further into how the incidence of stroke is becoming a concern for the National Health Service and how rehabilitation care has become fundamental in order to explore the deeper social and contextual issues.
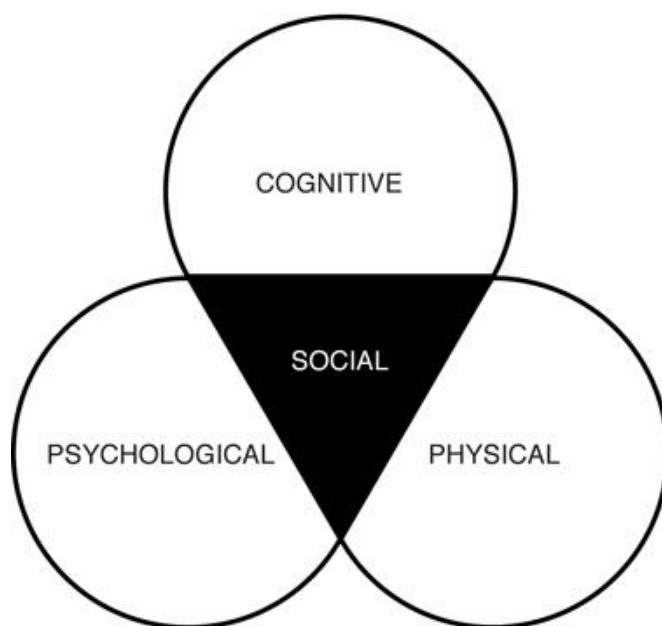
Figure 2.3 The patient socialising

2.4 The incidence of stroke

The incidence of stroke is a major concern for the National Health Service (NHS) in the UK. According to the World Health Organization (WHO), each year 15 million people worldwide have a stroke and, of these, 5 million die, 5 million survive but face a future life with multiple disabilities, and a possible 5 million will recover well (Stroke Association, 2010). In European countries, incidence of stroke is demonstrated to be one of the highest risks to health and life each year (WHO, 2011a, b and c). This view stresses concerns of "well-being" to society. Consider, for example, in Portugal, between 5 and 9 people have a stroke each day. Sá (2009) reported that stroke affects six people per hour in Portugal; she compared this situation to having the same effect as a crash of a large aircraft involving more than 500 people occurring each month. According to the Direcção-Geral da Saúde (DGS) (2001), these incidences add up to approximately 21,000 each year. In this context, Santana (2011) revealed that stroke is the main cause of disability among elderly people in

Portugal. Martins (2006) reported that 50% of stroke survivors will experience limitations in conducting their day-to-day activities and 20% will require assistance from others to conduct their lives. Here, Martins also reported that in 2004 in Portugal, 33,555 patients were admitted to hospital after being affected by a stroke, however, the incidence can actually be higher. This illustration draws attention to not only the social concerns but also to the implications that stroke can have in the organisation of health service provision and the costs involved in these logistics.

The WHO also states: "Stroke is the biggest single cause of major disability in the United Kingdom." The Stroke Association (2013) reported that "there are approximately 152,000 strokes in the UK every year. That is more than one every five minutes". According to the Stroke Association (2013), Scotland presents the highest incidence of stroke of all the countries in the UK. The Scottish Stroke Care Audit also reported that Scotland faces an annual incidence of stroke, affecting 15,000 people. According to the Stroke Association (2010), of these, one-third will survive with one or more impairments, including physical, sensory, neurological and psychological impairments.

From these views, the incidence of stroke seems to highlight multiple concerns, such as the social, medical and economical. Social concerns highlight attention related to people's quality of life after stroke. Medical concerns reveal attention to the health service provision to treat and recover people. In the organising of care for people affected by stroke, it would seem that it is important to understand this process with a special focus placed on patients during their recovery in hospital. Thinking, for example, in economic terms, stroke can bring challenges, especially when the care involves a large number of patients needing extended stays in hospital. What the Stroke Association (2013, p.5) reveals is that "Stroke costs the EU over 38 billion euros a year".

Moreover, there is the idea of seeing those patients affected by stroke as "survivors". The Organisation for Economic Co-operation and Development (OECD) reported, "Stroke patients who survive the acute episode are often left with some degree of disability" (Moon et al., 2003, p.27). The term, "survive", in this context, determines that remaining alive after acute treatment means that "survivors" become patients where others have died. Rehabilitation following acute treatment is an important component of the continuum of care (Moon et al., 2003, p.47). This can be conceptualised in patients affected by stroke as they are in a care process; from surviving, to getting better, and then returning back to their lives. In what follows, a more detailed discussion of what this means will be outlined, with an emphasis on demonstrating the patient care journey.

2.5 The patient care journey

Patients, those affected by stroke, can receive a variety of treatments at different places and times. As Moon et al. (2003) note, "these include acute care in a hospital setting, specialised care in a stroke unit, rehabilitation, and long-term support and care in a home-based or residential setting" (Moon et al., 2003, p.43). From this perspective, the Scottish Intercollegiate Guidelines Network (SIGN) (SIGN 118, 2010, p.5) outline the organisation of services in four key recommendations as follows:

1) Stroke patients requiring admission to hospital should be admitted to a stroke unit staffed by a coordinated multidisciplinary team with a special interest in stroke care.

2) In exceptional circumstances, when admission to a stroke unit is not possible, rehabilitation should be provided in a generic rehabilitation ward on an individual basis.

3) The core multidisciplinary team should include appropriate levels of nursing, medical, physiotherapy, occupational therapy, speech and language therapy, and social work staff.

4) Patients and carers should have an early active involvement in the rehabilitation process (SIGN 118, 2010, p.5).

As demonstrated earlier, each patient can present a variety of care needs as a result of stroke. To respond to the individual patient's needs, as SIGN 118 (2010) notes, an organised and expert service must be implemented to manage patients in efficient and effective ways. What SIGN 118 (2010, p.7) reveals is that "the organisation of stroke services must be considered at the level of the NHS board, acute hospitals, primary care and in the patient's own home or care home". In other words, the organisation of stroke services might involve hospital care, hospital or home-based care, discharge and post-discharge services and ongoing rehabilitation and follow-up.

In Portugal, the Direcção-Geral da Saúde (DGS) has implemented the program, "stroke pathway", in order to provide effective management of stroke patients but also with the hope of reducing mortality by stroke (Silva and Gouveia, 2012). The stroke pathway, as Silva and Gouveia describe, highlights the patient journey through the organised stroke services. According to them, a person experiencing the symptoms of stroke will dial the

emergency telephone number (112). The emergency is thus alerted at the pre-hospital stage, and the person with stroke symptoms then goes to the hospital. When the person arrives at the hospital, at the in-hospital stage, a number of examinations adhering to medical guidelines are performed. For those who survive but do not fully recover from the stroke episode there is a network of rehabilitation services available to them, intended to provide assistance to the patients after the in-hospital period and at the post-hospital/ rehabilitation stage (DGS, 2010; Silva and Gouveia, 2012).

In healthcare contexts such as Portugal and Scotland, patients follow a care journey that requires different care services at different times in order to respond to the individual patient's needs at the time (see Figure 2.4).
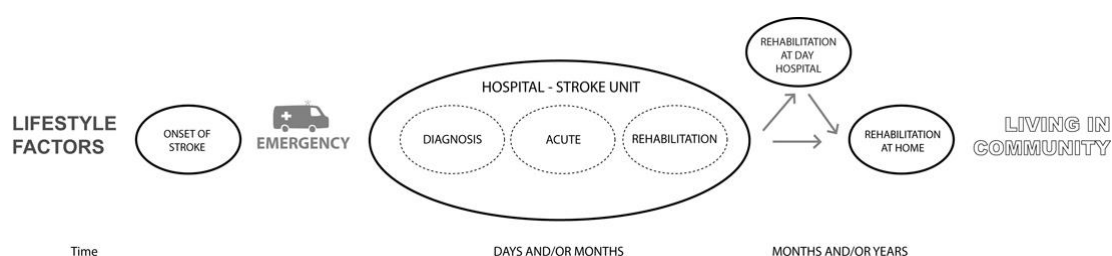
Figure 2.4 The patient care journey

From this illustration, it is possible to see that patients become involved in a care journey which is circumscribed by a diversity of health services related to treating and recovering from their current health conditions. At the same time, it highlights this idea that the patient's life becomes physically, emotionally and socially involved in a different contextual situation from previously. Consider, for example, how recovering from stroke begins by involving the patient in a ward environment in hospital, in which they can remain for days or sometimes months (ISWP, 2008). Because the patients' experiences in hospital are a temporary life situation, this highlights attention to the need to look at rehabilitation service. Hence, an understanding of stroke rehabilitation care in hospital will be further explored.

2.6 Stroke rehabilitation care in hospital

In hospital, stroke units, as Moon et al. (2003) describes, are health services that involve multidisciplinary teams such as doctors, nurses, physiotherapists and speech therapists dedicated to both acute and rehabilitative stroke care (Moon et al., 2003). In other words,

this shows that stroke care involves diverse and varied expertise. The Scottish Intercollegiate Guidelines Network (SIGN) (SIGN 118, 2010) reveals that multidisciplinary teams have an important role to play in health services, which is to provide multiple interventions with an aim to benefit "fewer patients dying or requiring institutional care or remaining dependent." To achieve this aim, healthcare professionals coordinate regular multidisciplinary meetings to discuss goals to improve the patient's health condition at the time (SIGN 118, 2010, p.8). Thinking in terms of this multiple expertise, how can design play a role here to focus on the quality of the patient experience in healthcare? Consider, for example, how healthcare expertise is relevant to the treatment and recovery of the patient. When combined with design, this expertise has the potential to significantly promote improved quality of life and enjoyment during the patient's recovery.

Rehabilitation, in stroke units, can be initiated as soon as the patient's condition has been stabilised (Moon et al., 2003). Here patients can remain for several weeks (SIGN 118, 2010). As I stated earlier, this shows once again that the patients are temporarily involved in a required rather than desired life situation, which draws attention to the need for further understanding of the patient experience, particularly at the mealtime. Furthermore, rehabilitation has been described as an intervention process involving the patients' assessment and treatment (Losseff, 2004). Fundamentally, as Alexander et al. (2001) underline, it is an intervention process, involving experts such as the physiotherapist, the occupational therapist, the speech and language therapist, the dietician and the nurse, as the most common professionals, in order to work with the individual patient's needs. Here the healthcare professionals present different roles, which require further understanding. For example, the SIGN 118 guideline explains these multiple roles in this way:

> *Stroke nursing focuses on the holistic needs of the patient and family, involving the physical, psychological, cognitive, emotional, spiritual and social care. [...] The nurse considers the individual's needs working collaboratively with the patient and their families to involve them in a meaningful way with decision making and their recovery. Stroke nursing is delivered within a context of multidisciplinary working enabling the sharing and integration of clinical practice. Stroke nursing is a continuous 24 hour process throughout the patient's journey of care.* (SIGN 118, 2010, p.56)

> *Physiotherapists are experts in the assessment and treatment of movement disorders. Physiotherapy involves the skilled use of physical interventions in order to restore functional movement, reduce impairment and activity limitations and*

maximise quality of life after a stroke. These interventions commonly involve exercise, movement and the use of electrical treatments. (SIGN 118, 2010, p.57)

Speech and language therapists are an integral part of the stroke care team. Their particular field of expertise lies in the assessment and management of communication disorders and dysphagia. (SIGN 118, 2010, p.58)

Occupational therapists treat people who have impairments, restricted activity levels and limited ability to participate as a result of injury or illness, in order to achieve the highest level of independence possible. [...] They will use purposeful activity to promote the restoration of function and to maximise participation in meaningful activities, i.e. occupations of self care, domestic, social and work roles. (SIGN 118, 2010, p.59)

Dieticians can offer specialist advice to patients with nutritional problems post stroke. This may include assessing patients who are deemed nutritionally at risk during an initial nutrition screen, advising on the nutritional adequacy of modified texture diets, advising on the transition from artificial nutrition onto oral diet, and addressing secondary prevention. (SIGN 118, 2010, p.61)

By demonstrating the roles these healthcare professionals have in rehabilitation care in hospital, it shows that patients will have to undergo a process to be functionally rehabilitated. In other words, this model represents the rehabilitation approach, involving a multidisciplinary team with multiple skills to treat and restore patients' functioning in order to allow them to return to normality or, in other words, their previous quality of life. This view of normality and quality of life opens up new ways of thinking; for example, could design play a role here? Could design support the rehabilitation process with the aim of promoting the patient's improved subjective well-being during his/her recovery (see Figure 2.5)?
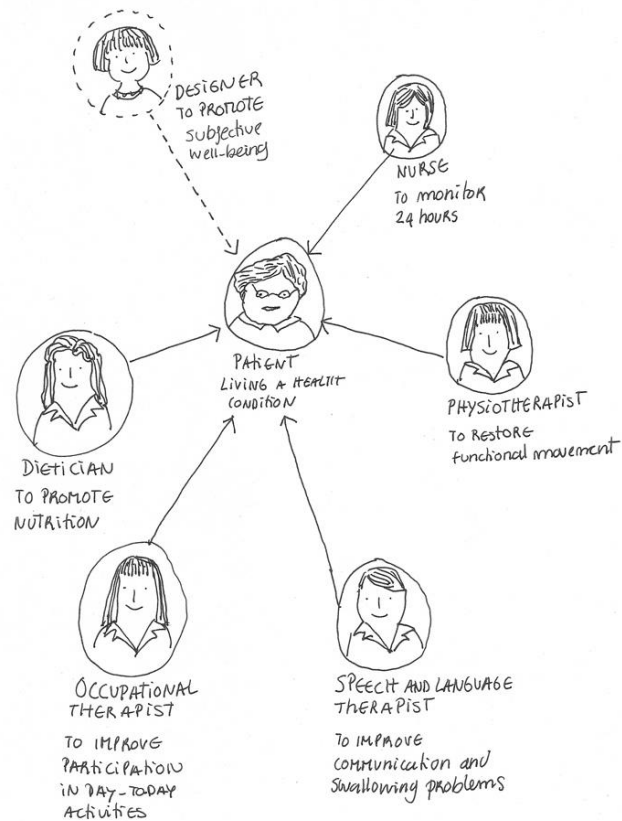
Figure 2.5 The role of multidisciplinary team in stroke rehabilitation care

Furthermore, this illustration shows that stroke rehabilitation care in hospital highlights two different roles; the healthcare professionals who plan care, and the patients who receive care and experience a temporary life situation. To obtain a better understanding of this situation, the following explorations will focus on how stroke rehabilitation care is planned when delivering care for patients.

2.6.1 An ICF model

In 2001, the World Health Organization (WHO) presented the International Classification of Functioning (ICF). The ICF is a model which classifies health into two parts, each with two components (see Figure 2.6). In the first part, classified as functioning and disability, functioning was defined as a term to encompass all bodily functions, activities and participation. Disability was defined as a term for impairments to circumscribe activity limitations or participation restrictions. In the second part, classified as contextual factors, environmental factors were defined as those associated with the physical, social and attitudinal environment in which people live and conduct their lives. Personal factors were defined as comprising features of the individual's life, such as habits, lifestyle, social background, education, profession, and past and current experiences.

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity Functioning	Activities Participation	Facilitators	not applicable
Negative aspect	Impairment Disability	Activity limitation Participation restriction	Barriers / hindrances	not applicable

Figure 2.6 An overview of ICF
(Source: Adapted from World Health Organization (2001), International classification of functioning, disability and health: ICF. Geneva: WHO)

In other words, the ICF model integrates two views: the medical and the social (see Figure 2.7) with a focus on enhancing the functional capacity of people with more or less of a disability and to improve their performance when experiencing the contextual environment.
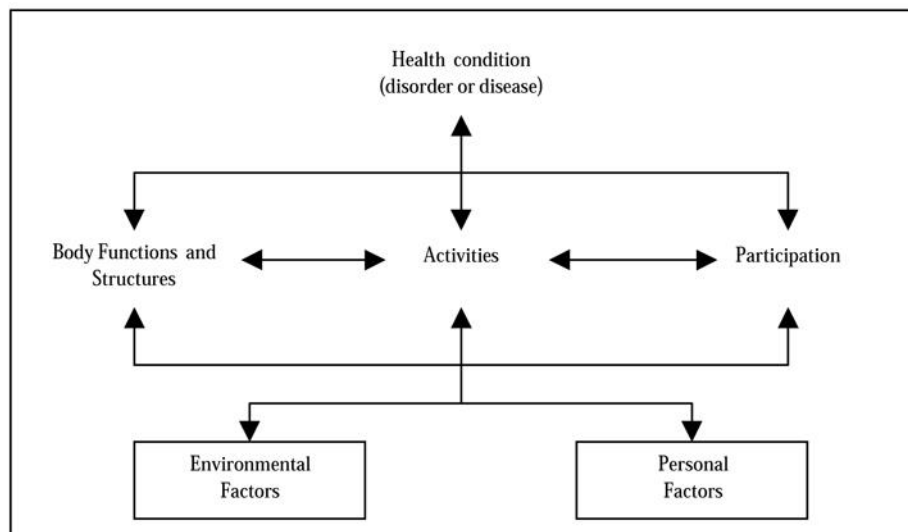
Figure 2.7 Interactions between the components of ICF
(Source: Adapted from World Health Organization (2001), International classification of functioning, disability and health: ICF. Geneva: WHO)

The medical view, as the WHO (2001) pointed out, is focused on a patient's disability caused by a health condition. Here individual treatment is central with an aim of providing a cure. On the other hand, the social view is focused on the contextual factors. According to WHO (2001), involving a social view allows social action to create environmental conditions to allow people conduct their lives without barriers. What this shows is that the ICF model involves multiple perspectives in order to achieve the best health service provision. But also, it highlights that achieving the best healthcare is taking into consideration the quality of life for people with some degree of disability. In terms of social view, this opens up new ways of thinking, for example, can design play a role in offering support to active social participation in order to discuss social concerns?

By exploring stroke in rehabilitation care in hospital, in the UK, the Intercollegiate Stroke Working Party (ISWP) (2008; 2012) developed the National Clinical Guideline for Stroke using the ICF model. This guideline, as the ISWP noted, proposes to lead to the delivery of the most effective care to individual patients (ISWP, 2008; 2012). This seems to highlight what the NHS Institute for Innovation and Improvement, on its website, considers essential to deliver a good patient experience, to consider the patients' views as being fundamental to provide better health services. In fact, rehabilitation, as the ISWP (2008) reports, is a problem-solving process with a focus on treatment and "restoration". Receiving treatment was emphasised through healthcare professionals' interventions. Here interventions were defined as those to support the patient safely, such as "keeping the patient stable" and treating the patient's disability with a restorative and/or adaptive goal (ISWP 2008, p.12). Although this guideline used the ICF model, rehabilitation seemed to lean more towards a single view; the medical. For example, recommendations here were centred on a range of goals and actions such as treatment, assessment, training, teaching, monitoring, modifying and adapting to involve the individual patients' body functions and structures (ISWP 2008; Stroke Association, 2008c).

Achieving goals, as Scobbie et al. (2011) point out, is fundamental to rehabilitation practice where healthcare professionals were described as the planners and deliverers of these goals in day-to-day work practices. Here the healthcare professionals' experiences in work practices were illustrated through a "goal-setting and action-planning practice framework", involving goal negotiation, goal identification, planning, and appraisal and feedback (Scobbie et al., 2011, p.477). What this research study proposes is to investigate the patients' experiences in this rehabilitation work process. In rehabilitation, healthcare professionals, as Monaghan et al. (2005) observed, are involved in a number of multidisciplinary weekly meetings to discuss each individual patient's problems and goals

for recovery. Here rehabilitation care was also underlined in a consecutive way; as patient assessment based on their individual goals and recovery action planning (Monaghan et al., 2005). Conducting strategies to improve the patient's functional ability has been demonstrated as a goal in health policy and rehabilitation care research in order to get the patient back to his/her previous quality of life.

Quality of life, as the ISWP (2008) defines, refers to the level of comfort, enjoyment, and ability to conduct everyday activities. Additionally, McKevit et al. (2003) pointed out that quality of life is important but a less easily defined outcome in health and healthcare research. By exploring the healthcare professionals' views, definitions of quality of life included categories such as social, happiness and physical. The social was associated with the patient's ability to engage in social interaction with family and friends. Happiness revealed views associated with the patient's enjoyment and satisfaction with life but also encompassed being able to make life choices. The physical category underlined the patient's functional ability to perform the activities of daily living, including feeding (McKevit et al., 2003, p.867).

From these views, the ICF model can be seen as the vehicle to deliver and promote quality of care and quality of life for patients in stroke rehabilitation. However, stroke rehabilitation care seems to emphasise a strong medical view. Thinking in terms of the ICF model, however, it proposes not only the medical element of care, but also the integration of the social. In what follows, a deeper investigation will look at how the ICF model is used at the mealtime.

2.6.2 The mealtime as a patient experience

In exploring the mealtime, research and its recommendations still appear to provide evidence of a single view, the medical, in stroke rehabilitation care. Consider, for example, in 2000, several studies in the field of rehabilitation care research were conducted with the aim of identifying the patients' eating difficulties (see Figure 2.8). Jacobsson et al. (2000, p.258) revealed that: manipulating food on the plate, swallowing, transporting food to the mouth, handling the knife, fork and spoon, spilling while transporting food to the mouth, and adjusting trunk and head during eating, were all difficulties experienced by patients in hospital. According to Westergren et al. (2001a), sitting position, aberrant eating speed (slow or forced), manipulating food in the mouth (leakage, hoarding, chewing difficulties), opening and/or closing the mouth and alertness were other difficulties that patients experienced during their recovery in hospital. In this study, the authors found that in 162 patients, 80% presented difficulties in their ability to eat, 52% were unable to eat without

assistance and 32% were undernourished. As demonstrated earlier in Section 2.3, stroke can affect not only the physical but also cognitive and psychological body functions. In another study, Westergren et al. (2001b) drew attention to the patients' emotions when they reported that these patients present low energy to eat. Furthermore, patients with swallowing difficulties revealed that they may not complete their meals and those who experience difficulties in preparing the food on the plate and moving it to the mouth might require individual assistance to eat (Westergren et al., 2002b).
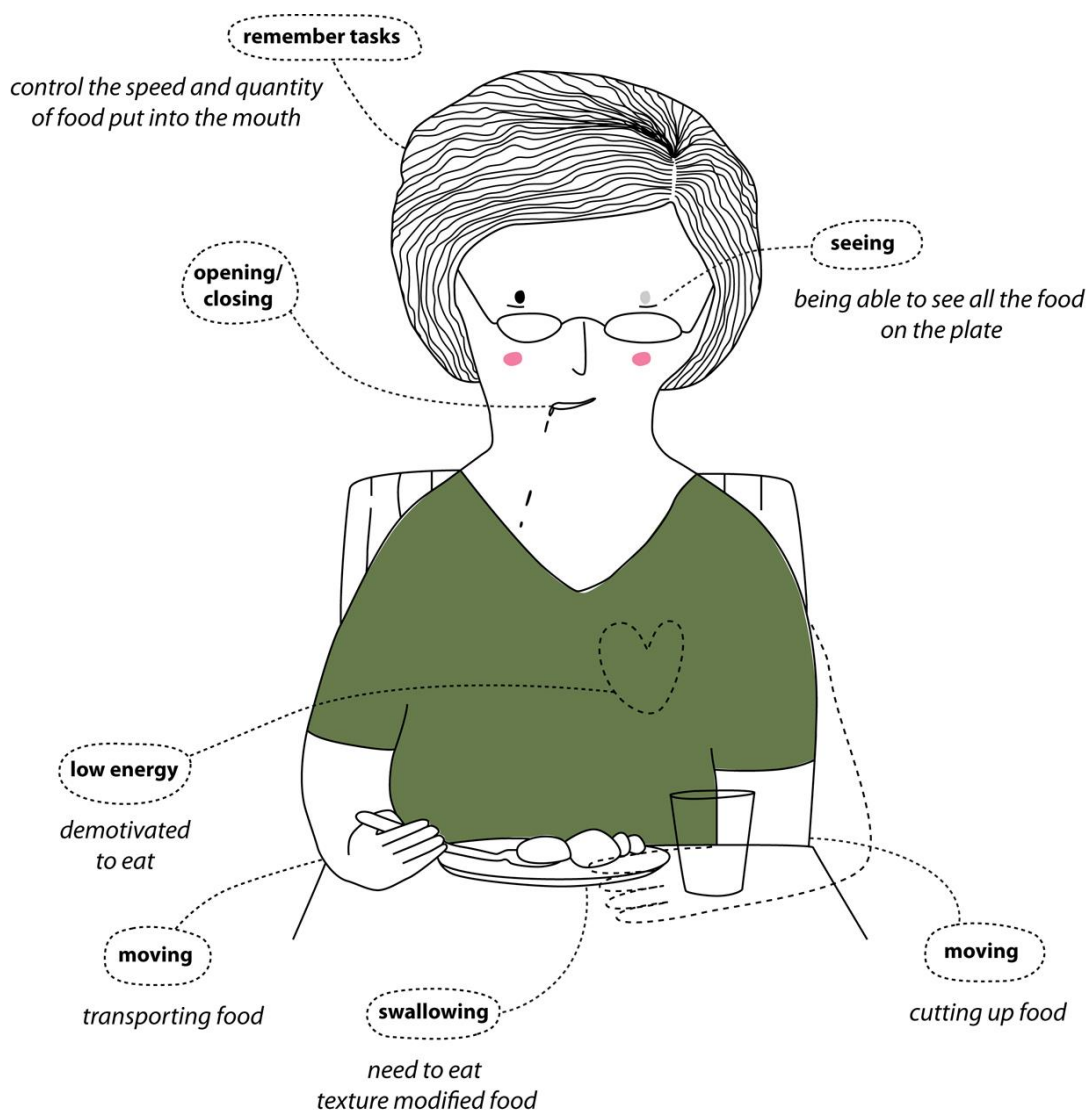
Figure 2.8 The patients' eating difficulties

As a result of these observations, recommendations were made to implement intervention strategies such as observing patients in order to maintain or improve nutritional status. These recommendations also underlined the importance of assessing and taking systematic

measures of the patients' ingestion, deglutition (swallowing) and energy levels in order to improve eating abilities. The mealtime as a day-to-day patient experience in rehabilitation highlights here a medical view focused on identifying the patient's disability caused by stroke in order to conduct and improve medical interventions to benefit the patient's recovery. What it accentuates here is also a need to understand the mealtime as a patient experience, not only from a single view, the medical, but also from a more social view, involving the patients' views. Think, for example, what do patients think of the mealtime as a day-to-day experience in rehabilitation in hospital? The following explorations will bring a focus on understanding the patients' experiences at the mealtime, in particular, when research studies have indicated that patients who present eating difficulties might require a longer hospital stay (Westergren et al., (2002a).

A smaller number of studies were found that explored the patients' experiences at the mealtime while in rehabilitation care in hospital. Ekberg et al. (2002) drew attention to the social and psychological impacts of swallowing difficulties, known as dysphagia, at mealtimes but their perspective still appears to be only from the healthcare professionals' views. Their focus was to determine the effects of dysphagia but also to explore the relationships between what they called "the psychological handicaps of the condition and the frequency of diagnosis and treatment" (Ekberg et al., 2002, p.1). This study identified that, in 360 patients, 84% of patients felt that eating should be an enjoyable experience. They also found that 36% of patients avoided eating with others because of their health conditions. What seems to be highlighted in this view is the significance of promoting patients' enjoyment at the mealtime. However, the authors' suggestions were addressed towards healthcare professionals' work practices rather than the patient experience. According to Ekberg et al. (2002), "clinicians need to be aware of the adverse effects of dysphagia on patients' self-esteem, socialization, and enjoyment of life" (Ekberg et al., 2002, p.139). What this observation shows is a medical view highlighting social and experiential concerns. Consider, for example, Perry and McLaren (2003) conducted a study to understand patients' perspectives of their eating experiences six months after experiencing stroke. Patients considered eating to be a relevant aspect of life. Here eating difficulties were highlighted as being not only functional but also social and psychological issues. For example, patients reported that requiring someone to cut up their food could be embarrassing, especially if they were eating a meal in public (Perry and McLaren, 2003, p.366). In another study by Carlsson et al. (2004) with a focus on exploring how people affected by stroke experienced living with eating difficulties, their results revealed people striving to live a normal life. Living with eating difficulties was reported as generating experiences of feeling dependent on others. More recently, Medin et al. (2010) conducted a

study to explore patients' experiences of eating three months after stroke. From this study we can see once again that the mealtime is experienced as a sense of striving for control to eat.

These views highlight the social and emotional issues around the mealtime, which are relevant to the concerns of this research. There is limited evidence of research that explores the patient's experience at the mealtime from the patient's perspective, in particular those patients affected by stroke in stroke rehabilitation care in hospital. As mentioned earlier, the patients' views can be significant to provide better health services. According to the NHS Institute for Innovation and Improvement, on its website, patients care about their health experience: "They want to feel informed, supported and listened to so that they can make meaningful decisions and choices about their care". In general, most explorations here were to investigate patients' experiences several months after stroke. But this research aims to explore the patients' experiences at the mealtime during their recovery in hospital. This setting has previously been explored from the medical view but what if it was explored by both the patients' and the healthcare professionals' perspectives? Furthermore, patients with swallowing difficulties seem to experience a complex situation at the mealtime, one which requires deep understanding. In what follows, the impact that swallowing difficulties might have on the patients' mealtime experiences will be demonstrated.

There is a relationship between swallowing difficulties and food that must be demonstrated. Perry (2004) underlined the importance of patients' nutrition in rehabilitation. In her study, following a group of patients through acute hospital admission and at six months post-stroke, she found that most of these patients required eating modified texture diets as nutritional provision. According to her, patients with a greater severity of swallowing difficulties (dysphagia) tend to present "reduced intake". This issue was related to an increase in stroke severity causing a decrease in energy to eat. What Wright et al. (2005) revealed was that those patients with swallowing difficulties require Texture-Modified Food (TMF). By exploring TMF, in 2009, the British Dietetic Association and the Royal College of Speech and Language Therapists published National Descriptors for Texture Modification in Adults. Here TMF is described in a scale of six different textures of food, from easier to swallow (e.g. puréed and free of lumps) to harder to swallow (e.g. regular food) (see Figure 2.9).

EASIER to swallow · HARDER to swallow

puréed free of lumps · regular food

Figure 2.9 Texture modified food scale

National clinical guidelines in the UK have recommended TMF as a treatment for patients who present swallowing difficulties (ISWP, 2008; The Scottish Government, 2008; SIGN 118 and 119, 2010). As the Intercollegiate Stroke Working Party (2008) noted, patients with swallowing difficulties are at risk of aspiration pneumonia. According to them, this can cause food, fluid and saliva to enter the airway. What it stresses here is that the patient's health condition under medical treatment is the recovery of swallowing. Eating is swallowing, but also enjoyment and pleasure. For example, Wright et al. (2005) found that TMF tends to influence malnutrition. Poels et al. (2006) reported that malnutrition is common in stroke rehabilitation. However, according to Wright et al., patients tend to eat less and consequently can lose weight. The reasons were related not only to eating difficulties but also to having less food choice and "poor" presentation (Wright et al., 2005, p.217). Once again, this medical view highlights attention to the patients' experiences at the mealtime. Here personalisation and aesthetic aspects at the mealtime seem to be issues that require further investigation. Within the concerns of patients' malnutrition, Naithani et al. (2008) also examined patients' experience of access to food in hospitals. Here contextual factors were issues that were highlighted, such as the physical environment. Repetitive sounds, unpleasant smells, uncomfortable eating position and concerns about food choice were also revealed. According to them, the patients' eating experience and nutritional care requires adherence to the principles of "Protected Mealtimes". This view of Protected Mealtimes was reported as "an initiative aimed at improving the eating experience for patients in hospital, from presentation of food to assistance at mealtimes". According to them, this should bring a focus on eating where other activities are not undertaken on the ward while meals are served or eaten with the aim of "identifying and addressing patients' needs for assistance" (Naithani et al., 2008, p.301-302). This view highlights attention to the mealtime as a sensorial experience. Once more, the authors' suggestions addressed directions focused on a single view, the medical, rather than on multiple views, involving both the medical and social. In what follows, these views will be highlighted in order to discuss in more detail what design can do in this situation.

2.7   Why design?

The ICF model inspires this research study. As demonstrated in Section 2.6.1, this model demonstrates the integration of the medical and social views in order to deliver the best healthcare service provision and promote quality of life for those who live with some degree of disability. Although the medical view at the mealtime highlights social concerns associated with the patient experience, healthcare providers tend to place their focus on treatment to restore function rather than on the patient experience. Consider, for example, how the studies outlined in Section 2.6.2 focused future research directions on the improvement of strategies to promote nutritional and functional improvement with less emphasis on experiential issues. However, the Intercollegiate Stroke Working Party (2008) noted that "patients with swallowing problems may avoid eating in social settings, and thus lose physical and social pleasures normally associated with food" (ISWP, 2008, p.97). This view shows that policy-makers acknowledge that issues around the quality of the patient experience at the mealtime need attention, in particular when recent survey on patient experience revealed "food/meals to be problematic" in hospital (The Scottish Government, 2014, p.7). Therefore, can design play a relevant role here to bring a focus on the patient experience? In doing so, can design support the ICF model at the mealtime (see Figure 2.10), and perhaps link multiple rather than single views? In other words, can design support this social/contextual view, which is missing in the ICF model at the mealtime? Consider, for example, how the medical view focuses on the patient's treatment and recovery while design can focus on how to promote the quality of the patient's experience with an aim to support the patient's enjoyment, socialising and quality of life during their recovery.
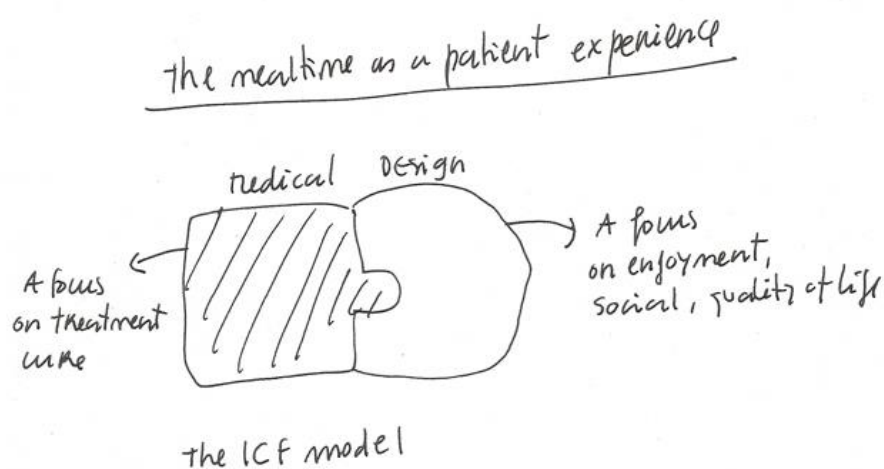
Figure 2.10 Design to support the ICF model

Thinking in terms of enjoyment, Apetito, a European frozen food company, reported on their website that Texture-Modified Food (TMF) can be unattractive, in particular when the different parts of food are unrecognisable (Apetito website). For example, the Scottish Intercollegiate Guidelines Network 119 (SIGN) (2010) recommends that TMF should be attractive. In addressing this issue, a European programme called "Performance", Personalised Food for the Nutrition of Elderly Consumers, concerned with these issues of nutritional and aesthetic needs, in its website, explains the idea of developing a 3D printer to create an aesthetic food experience (Performance, 2014). Although it shows an interest in promoting enjoyment at the mealtime, it also brings forth a focus on food. Consider, for example, patients affected by stroke, who can see their difficulty in dealing with emotional and bodily responses to day-to-day activities, as the patient revealed in Section 2.3. The mealtime cannot be only focused on food, but should also have an emphasis on the idea that enjoying a meal might make recovery faster. In this context, what seems to be relevant is to obtain a deeper understanding of the patient experience, considering issues such as how patients see an enjoyable experience at the mealtime during their stroke rehabilitation in hospital. What this research study proposes is an understanding of the mealtime from both the professional and individual patient experience in order to bring forth multiple rather than single views. In this way, design can support this view that these multiple voices can be important in stroke rehabilitation care.

The discussion of stroke within this contextual review of rehabilitation care has been valuable for this research because it was aimed at understanding how the mealtime as a day-to-day patient experience might be lived during stroke rehabilitation care in hospital. It has also been valuable for this research because it was aimed at identifying issues from a design point of view, in particular, how the mealtime as a patient experience relates to the integration of multiple views. In relation to the concerns of this research, this exploration focused on the mealtime in stroke rehabilitation shows opportunities for design interventions. As posed earlier, can design play a role to promote the quality of the patient experience at the mealtime?

In a review of the literature, three interesting elements were found that related directly to the purpose of this research. First, the ICF model used in stroke rehabilitation in hospital was discovered. In exploring the literature on the ICF model itself, it advocates the integration of multiple views, such as the medical and social. Integrating multiple views in healthcare was considered to be significant to deliver the best health service provision and to promote good quality of life. Second, views related to the mealtime in stroke rehabilitation demonstrated a focus on addressing the patients' functional eating

difficulties, underlining a medical approach. Although the medical view acknowledged social concerns at the mealtime, for example, it indicated issues related to the patient enjoyment, socialising and quality of life during his/her recovery, treatment tended to focus largely on functional restoration. In other words, it tended to reflect more of the professionals' and less of the patients' perspectives. Third, research studies tended to show eating with a focus on the issue of swallowing. Although patients with swallowing difficulties present a complex situation which requires medical attention, eating also encompasses social, enjoyment and aesthetic considerations as being important elements to promote quality of life in stroke rehabilitation.

This research study acknowledges that stroke is a highly complex condition and that health policy-makers as well as medical researchers have been understandably pre-occupied with how to deliver the most effective and individualised care for those patients. Achieving the best healthcare involves using the ICF model in stroke rehabilitation. Using the ICF model is acknowledging multiple rather than single views. In looking at the medical argument, it did provide an understanding of social issues and highlighted the need to address further investigations into the context of the patient experience at the mealtime. Eating is swallowing but it is also a patient experience, but what is the patient experience? Hence, central to this discussion has been whether or not or to what extent design can enable a deeper understanding of the patient experience within this context of stroke where patients moving through a recovery "acceleration" back to normality, and further, how such understanding of the patient experience can highlight opportunities to address improvements to the mealtime in stroke rehabilitation care in hospital. Ultimately, this thesis aims to explore how investigations that are focused on the patient experience can support the ICF model at the mealtime.

2.8 Summary

This chapter began by demonstrating that stroke is a highly complex health condition, revealing patients facing cognitive, physical and psychological difficulties. Using examples from both Portuguese and Scottish contexts, it indicated that stroke, as the main cause of disability in Portugal and Scotland, also presents the highest incidence in the UK. These countries, as examples, have allowed for an explanation of the "mechanistic" understanding of the world of stroke care. Afterwards, it revealed the National Health Service's concerns for the delivery of organised stroke services to respond to the individual patient's needs, which highlighted the patient care journey through a healthcare process. In exploring stroke rehabilitation in hospital, it revealed that a multidisciplinary approach is

co-ordinated to address the patients' disabilities in order to promote their quality of life after stroke during recovery. Here, stroke rehabilitation care used the ICF model and sought to integrate multiple disciplinary, professional or practice views in order to reduce the complex notion of disability, achieve the best healthcare service provision and promote quality of life. However, in an exploration of the patient's mealtime experience, the ICF model revealed an emphasis upon a singular view rather than multiple views, and so highlighted opportunities for design interventions. To conclude, this chapter asked the question, if design could help to better support the ICF model, by revealing the patient experience at the mealtime. In the following chapter, I will examine design and define how design will play a role in the multidisciplinary approach to the research in the context of stroke.

3

Design: Literature Review

3.1   Introduction

In the previous chapter, the current state of the mealtime in stroke rehabilitation care in hospital revealed the importance of the International Classification of Functioning (ICF) model. While the ICF model is balanced in terms of the medical and social aspects of care, its application in practice at the mealtime has been shown to be unbalanced, highlighting a single view, the medical, rather than multiple views, involving both the social and medical. Simultaneously, the medical view revealed social concerns, highlighting the patient experience related to issues of enjoyment and quality of life during his/her recovery in hospital. A design question emerges here: how can design play a role to support the ICF model at the mealtime in stroke rehabilitation? In doing so, can design help the medical to become "supra-medical"? In other words, can this mean considering design as a meaningful approach for social response? Can design help to obtain a deeper understanding of the patient experience? In this way, can a focus on the patient experience allow the exploration of opportunities to enhance the patient experience? For example, is design able to bring forth tools that will include patients and others in dialogues about experience?

This chapter begins by revealing what experience is and how to design for experiencing, which is explained through design for user experience. In exploring this context of user experience, design has shown users playing two different roles, as reactive subjects and as active participants, in the design process for the development of products. This understanding of users as active partners shows design researchers and practitioners becoming interested in designing products alongside users. Users as partners in design have highlighted this idea of users as a source to explore new ways of thinking about things that matter to them (Fulton Suri, 2003). In the context of healthcare, design "strategists" have developed a number of design models focused on the significance of people's collaboration in the design process related to the improvement of health services and patient experiences in healthcare. Collaboration has indicated the effectiveness of the integration of multiple experts such as healthcare professionals and patients. These design

models are focused on supporting medical models in order to promote well-being for those who experience health services (Cottam and Leadbeater, 2004; Murray et al., 2006).

Although design models have suggested the integration of multiple views, for example, those of both the healthcare professionals and patients, the application of this concept in relation to design research in the context of healthcare, as practiced, demonstrates that there are significant challenges to actively engage patients. Consider, for example, how some design research studies have demonstrated the involvement of the patients' representatives rather than the patients themselves (Macdonald et. al., 2010; Bowen et al., 2010a). On the other hand, medical researchers with an interest in developing models based on co-design and their application to improve health services and consequently patients' experiences in healthcare have shown that patients have been directly involved in the research process (Donetto et al., 2014). However, the application of these models reveals the significance of involving patients and healthcare professionals in co-design situations. Co-design places an emphasis on engaging multi-stakeholders in creative dialogues (Sanders and Stappers, 2008). In this line of thinking, medical research studies have used models that provided limited information on how co-design situations were conceived to engage patients in collective creativity (Tsianakas et al., 2012). In other words, they presented a lack of tools to involve patients in creative dialogues (Bowen et al., 2013; Donetto et al., 2014). However, these design and medical researchers' views are opening up opportunities for this research study to intervene. This research can bring meaning to this design expertise in order to support the quality of the design research process within the context of healthcare (Donetto et al., 2014). In the context of the mealtime in healthcare, design research has been limited and does not include the patient's voice (Macdonald et al., 2010; Macdonald and Teal, 2010; Timlin and Rysenbry, 2009). Instead, much of design research has been focused on enhancing food service provision in hospital (Macdonald and Teal, 2011) and on proposing design solutions to promote quality of eating, for example, for people affected by dementia in care homes (Timlin and Rysenbry, 2009), rather than focusing on the patient experiences. Thus, this research aims to explore how to design for the patient experience. The following investigation leads to explorations of the design of the mealtime for customer experience in order to open new ways of thinking about patients. This understanding of the customer experience has emerged to explore design considerations with a focus on promoting pleasure at the mealtime. Think, for example, how design with a focus on sensorial considerations might provide ways on how to create a more enjoyable eating experience (The Fat Duck, 2012).

Design also plays a role in restaurants, involving not only sensorial but also social considerations to evoke emotional quality (Moreno et al., 2010; Future Laboratory, 2008). Although the patient experience at the mealtime is a complex situation, how can design play a role in stroke rehabilitation, taking into consideration these sensorial and social issues and involving a different approach?

Experience and *design for experiencing* is a complex phenomenon and design in areas such as user experience, patient experience and customer experience at the mealtime has been focused on people's needs, experiences and desires in order to promote enjoyment, well-being and pleasure in their everyday lives. I will discuss how design can support the quality of patient experiences at the mealtime in stroke rehabilitation as a mean of eliciting patients' and healthcare professionals' voices. Perhaps more interesting is that design might support practices to become "socially accomplished", in other words, engaged with multiple voices. Consider, for example, that the mealtime in hospital involves planning, preparing and delivering which involves healthcare professionals' experiences, but eating requires acknowledgement of the patients' experiences. Patients are those who are acting, sensing, thinking and feeling, or in other words, living and reliving the situation. Reflecting on these issues, this research will highlight a need to obtain an understanding of the patient experience from both healthcare professionals' and patients' perspectives. In addition, this research will promote patients as a resource to explore opportunities in the design process to improve the quality of patients' experiences in health services (Bate and Robert, 2007) and so impact upon stroke rehabilitation in hospital.

3.2 Design for user experience

In the last few decades a discussion about experience, understanding experience and its relation to design has emerged with a focus on user experience. Recently this discussion has extended to encompass the relationship between design and medical practice. Who is the "user"? The term used to denote the people for whom design "serves", as has been demonstrated by Sanders (2005; 2006a). However, as Sanders (2005) notes, design is more likely to refer to the people as "users" or "end-users". The *Oxford English Dictionary* defines the term "user" as "a person who uses or operates something". In addition, the ISO 9241-210 defines user experience as a "person's perceptions and responses resulting from the use and/or anticipated use of a product, system or service". The ISO also notes that "user experience includes all the users' emotions, beliefs, preferences, perceptions,

physical and psychological responses, behaviours and accomplishments that occur before, during and after use" (ISO, 2014).

For many contemporary commentators, this view of user experience has been inspired by the philosophy of John Dewey (1980) (Folizzi and Ford, 2000) and Mikhail Bakhtin (McCarthy and Wright, 2007). In areas such as interactive systems, user experience has been described in three ways (see Figure 3.1):
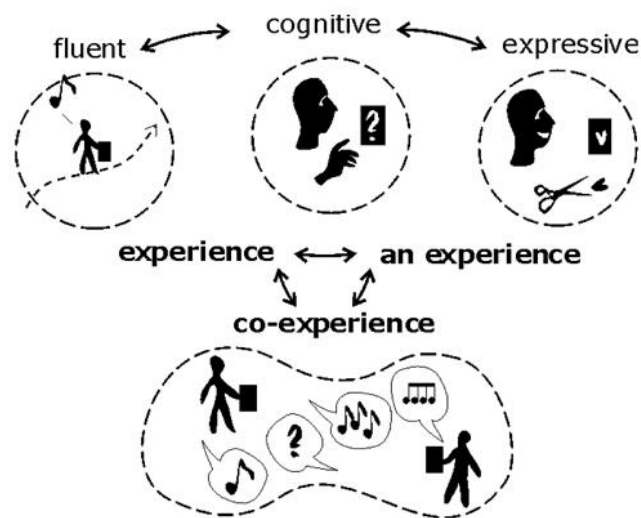
Figure 3.1 The three types of experience
(Source: Forlizzi, J. and Battarbee, K., 2004. "Understanding Experience in Interactive Systems" (2004). *Human-Computer Interaction Institute.* Paper 46. [Online] Available at: http://repository.cmu.edu/cgi/viewcontent.cgi?article=1045&context=hcii (Accessed 19 March 2014))

According to Forlizzi and Battarbee (2004, p.263)*, experience*, as a part of human subjectivity, is something that occurs continuously and happens when we interact with people, products or environment, for example, walking in a park. *An experience* is something that can be articulated and characterised by a series of product interactions and emotions. This type of experience has a beginning and an end and inspires behavioural and emotional change, for example, watching a movie. *Co-experience* is something that creates meaning and emotion in social contexts through using products, for example, playing a mobile messaging game with friends. This view shows experience as an active individual and social interaction, involving "people's acting, sensing, thinking, feeling, and meaning-making" where their perceptions and sensations are engaged through their actions (Wright et al., 2004, p.44). At the same time, attention has been paid to obtaining a theoretical understanding, not only of experience, but also how people make sense of an experience. Wright el al. discussed that an experience shows an individual emotional response. The

emotional response reveals the quality of experience. The quality of experience reveals how people make sense of an experience, which brings influences of themselves and their lifestyles (Wright et al., 2004), but also connects with the temporal living and reliving of a situation (McCarthy and Wright, 2007). As for understanding experience, attention to its components of interaction has demonstrated that experience takes place when users and products interact in a specific context of use, shaped by social and cultural factors (see Figure 3.2). The understanding of this relationship between user and product interaction has shown experience as a complex phenomenon.
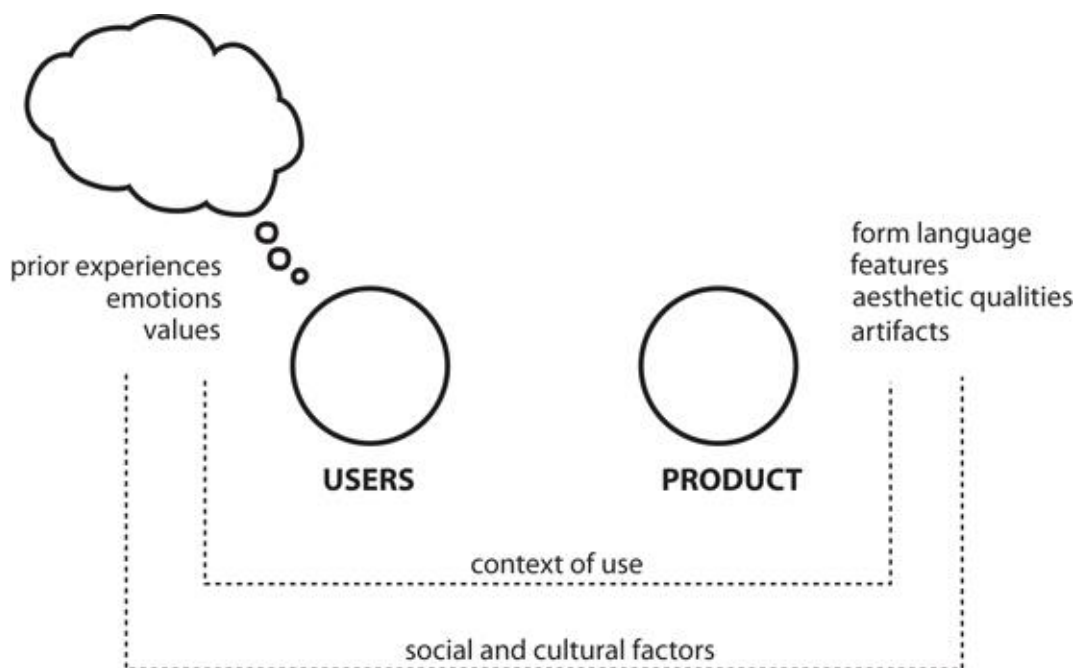
Figure 3.2 Influences on experience
(Source: Forlizzi, J. and Ford, S., 2000. The building blocks of experience: An early framework for interaction designers. In the *Proceedings of DIS 2000 (Design Interactive Systems),* 2000, pp.419-423)

According to Forlizzi and Ford (2000, p.420), *users* bring to the moment of experience "their prior experiences, emotions, feelings, values and cognitive models for hearing, seeing, touching and interpreting" and *products*, as objects, activities, services and environments (Margolin, 1997), reveal "a story of use through its form of language, its features, its aesthetic qualities, and its accessibility". The value of products has been recognised not only responding to functionality and usability, but also delivering enjoyment and pleasure. Norman (2005) wrote:

> *[…] utility and usability are important, but without fun and pleasure, joy and*
> *excitement, and yes, anxiety and anger, fear and rage, our lives would be*
> *incomplete.* (Norman, 2005, p.8)

Norman acknowledged the significance of emotions in people's decision-making and suggested three levels to design products: visceral, behavioural and reflective. The visceral level focuses on appearance aspects such as shape. The behavioural level involves pleasurable usability. The reflective level considers the rationalisation of the product in order to bring forth memories. Simultaneously, Jordan (2000) draws attention to understanding humans based on pleasure factors. This view has emerged due to the evolution of technology, which changed the paradigm of products from tools to lifestyle objects with which people have relationships, for example, when computers become a lifestyle object. In this way, Jordan proposed a discussion beyond usability to one that approaches this idea of what gives people pleasure; in other words, how products can bring pleasurable experiences to people's lives. Jordan suggests four pleasures deriving from designed products: physio-pleasure, socio-pleasure, psycho-pleasure and ideo-pleasure. The physio-pleasure is experiencing pleasure through sensory elements, for example, touch, taste and smell. The socio-pleasure is experiencing pleasure through social relationships and interactions, for example, friends, family and loved ones. The psycho-pleasure is experiencing pleasure through using the product and the emotional reaction. The ideo-pleasure is experiencing pleasure through the aesthetic and the value of the product. Although this understanding of the significance of emotions and pleasure to design products highlights views within the characteristics of users, it also opens up ways of thinking about patients, which this research study intends to investigate. These issues are also relevant for the patient's experience, in particular when sensorial and social pleasures have highlighted medical concerns at the mealtime in this context of stroke rehabilitation in hospital. The value of emotions and pleasure has addressed not only design products *for* users but also design products *with* users. In the following sections, understanding the users' roles in design becomes significant to the concerns of this research study. This exploration can highlight insights to reflect about design for the patient experience.

3.2.1   The user's role in design

According to Sanders and Dandavate (1999), design is about changing the roles of the "users" in the design process. This perception illustrates an interest in involving users as active rather than passive players. Understanding the users' roles in design can be seen, for

instance in Sander's map, developed to illustrate the landscape of design research and practice (see Figure 3.3) showing two intersecting dimensions: approach (design-led and research-led) and mindset (expert and participatory).
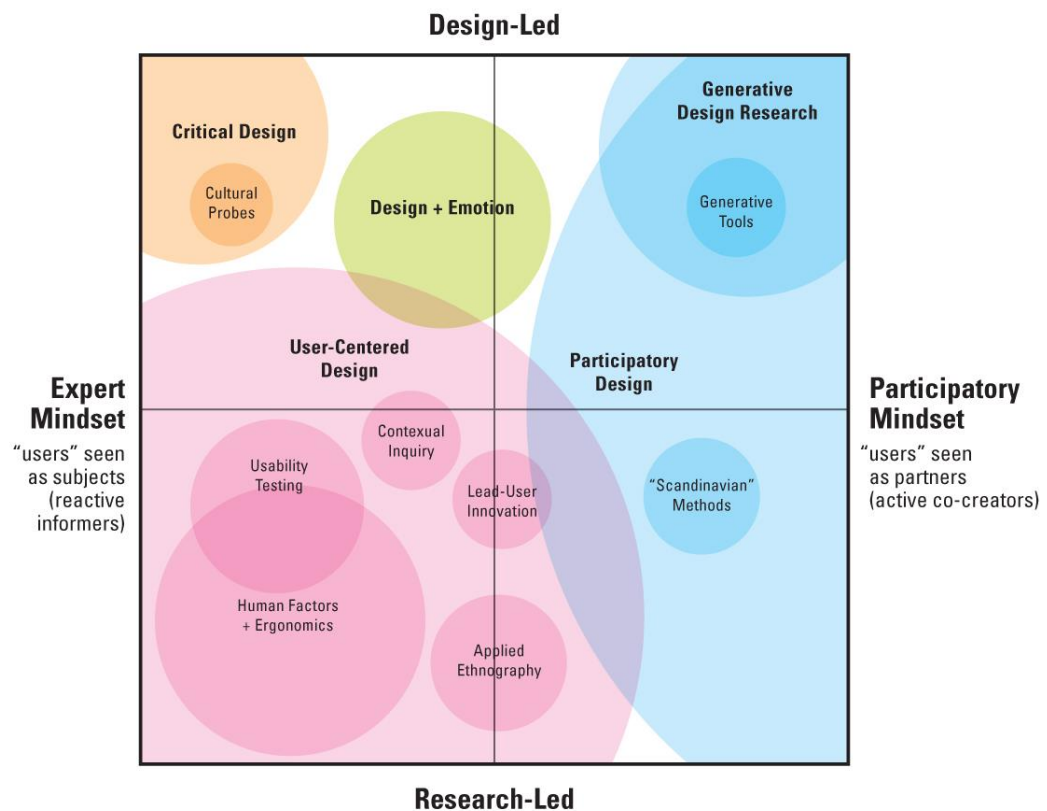
Figure 3.3 The landscape of design research and practice
(Source: Sanders, E. B.-N. (2008) An evolving map of design practice and design research. *Magazine Interactions,* 15(6), pp.13-18)

Sanders (2008) demonstrates the user's role in design through two opposing mindsets: expert and participatory. The *expert* mindset sees users as subjects who provide information to design researchers to design *for* them. Consider, for example, Desmet (2004), who has developed an instrument (PrEmo) to assess and measure users' emotional response to products. In this context, users are those who will react to the product being designed, or, act in response to a situation. However, the *participatory* mindset sees users as partners who have experience, which brings a focus on designing *with* them. For example, Sanders (2000) has developed toolkits to allow users express their thoughts, ideas and feelings to collect an understanding of concept design from their perspectives. In this context, users are those who will participate in the creativity of the product to be designed. In other words, as Sanders and Stappers (2008) pointed out, the people's role in design is shifting from a user-centred design to one of co-design with users (see Figure 3.4).
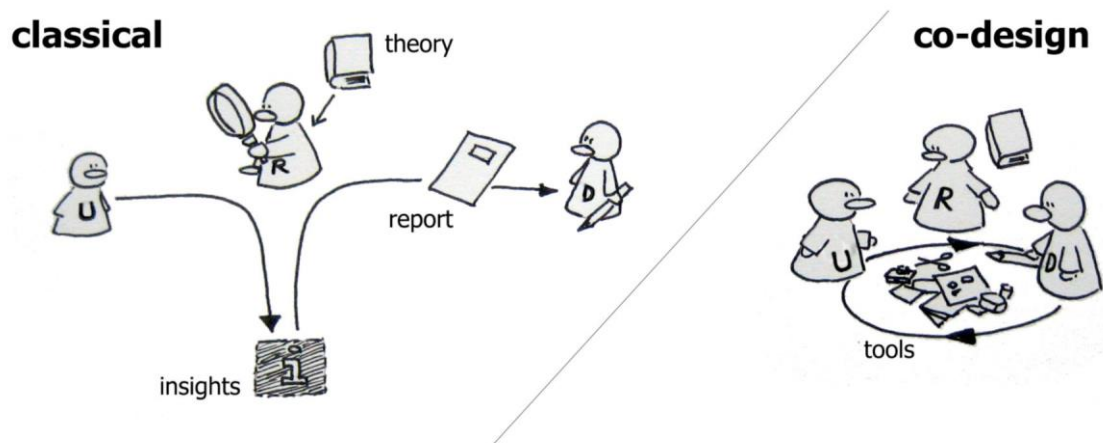
Figure 3.4 Roles of users, researchers and designers from classical to co-design
(Source: Sanders, E. B.-N. and Stappers P. J. (2008) Co-creation and the new landscapes. *Special issue of CoDesign*, 4(1), pp.5–18)

User-centred design, which Sanders and Stappers (2008) define as "classical" process, demonstrates a *passive* user "voice", one who can be observed and interviewed, as the object of the study. Here the researcher brings knowledge from theories and develops more knowledge through empirical work. In contrast, co-design emerges here as a contemporary process showing an *active* user "voice". The user is considered to be an expert in the matter under discussion due to his/her experience. This draws attention to the idea that accessing a user's experience can help to generate expertise and knowledge that can be useful to understand thinking through making "thinging" (Bjögvinsson et al., 2012). To extend this idea of thinging, Bjögvinsson et al. wrote:

> *[…] 'things' reveals a journey from the meaning of a social and political assembly, taking place at a certain time and at a certain place, to a meaning of an object, and entity of matter. (Bjögvinsson et al., 2012 , p.102)*

"Things" here is not just seen as objects but also what they suggest, following Bruno Latour's philosophy, this kind of "socio-material assembly" which deals with matters of concern. In other words, co-design seems to emphasise a network of relations between the social and material on what Latour (1999, p.174) called "a collective of humans and nonhumans". This notion of "humans and nonhumans" will be discussed in more detail in the following chapter. Although user involvement is highlighted, what can be seen here is co-design as spaces where designers, researchers, users and tools work collaboratively (Sanders, 2005; Sanders and Westerlund, 2011; Binder at al., 2011b), perhaps, in collective dialogues, linking making and creating (Sanders, 2006a). This is design as part of a process

of "dialogue", and design as a mediating process between different experts, knowledge types and competencies.

The user's experience plays an important role in generating ideas and concepts and, ultimately, in knowledge development. However, the user's role in co-design seems to change the designer's and design researcher's role. They can become "strategists" to develop a range of tools and techniques to open up collective dialogues that enable users express their emotions. In this way of acting or working, designers and design researchers have been seen as facilitators of collective creativity, but they can also be seen as mediators in presenting different interests (Binder et al., 2011b) or interpreters of people's needs and dreams (Sanders, 2005). Manzini and Rizzo (2011, p.213-214) considered that "designers can be facilitators or mediators, but also triggers. They can operate as members of co-design teams, collaborating with a well-defined group of final users, or as design activists, launching socially meaningful design initiatives". Co-design seems to play an important role in what Freire and Sangiorgi (2010) describe as "engaging the right set of actors in the right moment" (Freire and Sangiorgi, 2010, p.10). This view of involving "actors" seems to highlight intersections with the Latour's actor-network theory (Verbeek, 2005). Although this research brings a focus on patients, this understanding of the users' roles in design is opening up ways to think about how and why patients can possibly be involved in design in this context of experience.

Design for user experience has been a hot topic in a variety of areas such as designing pleasurable products and interactive systems, where approaches have been discussed from a design perspective. Consider, for example, Battarbee (2004), who provided a valuable discussion of the main approaches for user experience in her dissertation. In what follows, the explorations of design will look at in more detail within this view of users as partners.

3.2.2 Users as partners

Facing the challenges of designing pleasurable experiences, design researchers and practitioners have been interested in understanding how design can better support desirable experiences. According to Sanders (2001), designers and researchers can learn alongside users about what is desirable. Involving users at the beginning of the design process has been suggested (Sanders and Dandavate, 1999) as being useful to obtain an understanding of user's experience. This view of the user is considered to be a source to explore new ways of thinking about things that matter to them, for example, their needs and aspirations. An understanding of users' needs, dreams and motivations can provide valuable

information that can be utilised to create new products (Segal and Fulton Suri, 1997). At the same time, Fulton Suri (2003) has drawn attention to design in creating stronger emotional connections with users, in this context; customers, in particular when companies are facing the challenges of rapid advances in technology or consumer expectations, are leaning towards offering diversity in creating products. Simultaneously, Sanders (2006a, p.4) noted that "everyday people are no longer satisfied with simply being 'consumers'. They want to be 'creators' as well". Consider, for example, how changing a cover profile on Facebook can be a way of making people feel creative. These views demonstrate that the early phases of the design process, therefore, place users' views and perspectives at the centre of concept design (see Figure 3.5) because they can provide valuable insights to explore desirable experiences in the future.
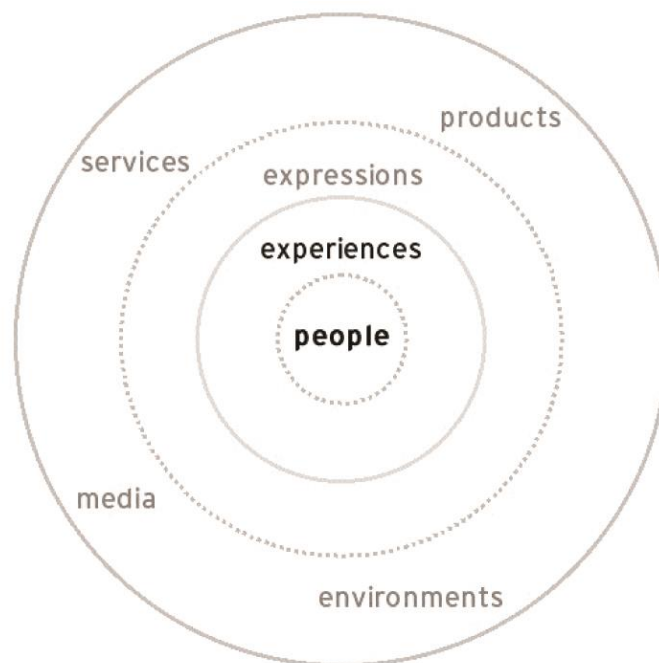
Figure 3.5 People at the centre of design
(Source: Fulton Suri (2003) The experience evolution: Developments in design practice. *The Design Journal*, 6(2), pp.39-48)

Mattelmäki (2006) emphasised a design attitude which requires respecting people's ideas, opinions and creativity to get an acess into the subjective issues. This view has discussed the significance of design in supporting empathy. Design can promote empathy through tools and/or skills to support direct contact with users to obtain insights into the users' experiences (Segal and Fulton Suri, 1997; Mattelmäki and Battarbee, 2002). Thinking about patients here, how can design support the direct participation of patients, in particular those affected by stroke? Can design tools play a role in supporting patients' disabilities to actively participate?

Sanders (2001) describes user experience as the present moment, which reveals past and future experiences (see Figure 3.6). In other words, it can be seen as the moment where design obtains an understanding from users' experiences about the past through their memories and the future through their dreams and aspirations. This is deemed to be useful because it allows the collection of a diversity of information.
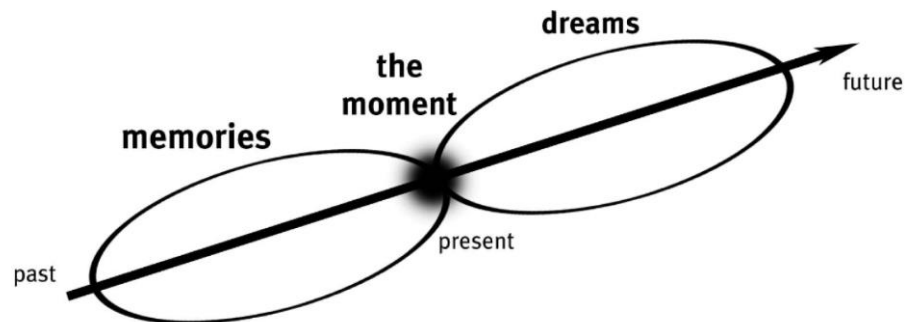
Figure 3.6 Experience as the moment between the past and the future
(Source: Sanders, E. B.-N. (2001) 'Virtuosos of the experience domain', In the *Proceedings of the 2001 IDSA Education Conference.* Boston)

This view of the temporality of experience(s) highlights attention to this design research study in obtaining an understanding of the patient experience from the present/past to the future. Thinking in the context of the mealtime, this understanding could be obtained by exploring what is currently happening at the mealtime and what would be desirable in the future. However, the context in which the experience takes place is also significant. For instance, Battarbee (2004) shows the importance of the social context in experience. Consider, for example, eating a meal alone, with someone, or with friends; surely each context will provide different experiences. The social context can change people's feelings as they are influenced by their relationships with others. This view illustrates the need to not only explore social experiences at the mealtime, but also to emphasise the role of design to support social interaction. For example, how sharing individual experiences can be influenced by the presence of others. This understanding of the relevance in establishing a direct contact with users within this idea of co-design highlights attention the need to better understand this collaborative and participative process.

3.2.3　Co-designing: A collaborative and participative process

A collaborative and participative process has demonstrated a growing emphasis on what Sanders and Stappers (2008) called "co-designing" (see Figure 3.7). This idea of co-designing as an approach to the design process has emphasised four main phases or moments: explore ideas, define concepts, develop/redefine prototypes, and implement (e.g. products or services). Why do these practitioners use these terms to describe their process rather than, say, "the double diamond"? Why is there as emphasis upon the "front end"?
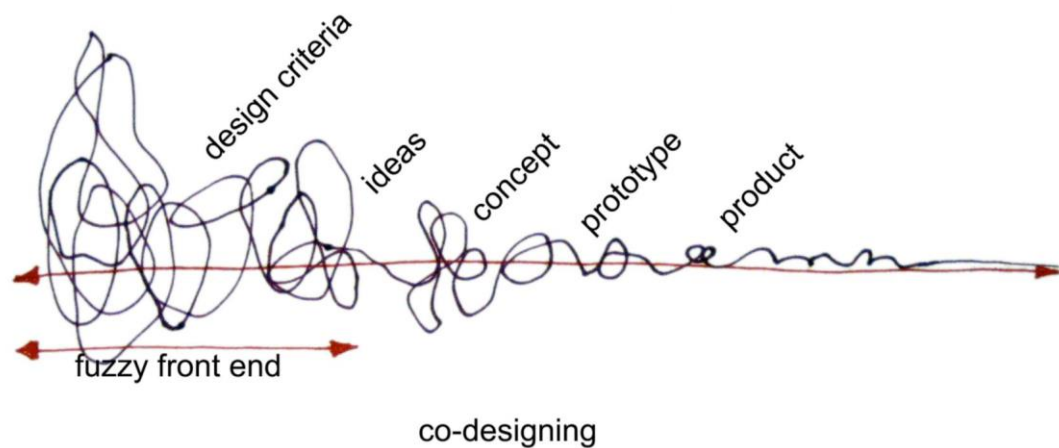
Figure 3.7 The front end of the design process
(Source: Sanders, E. B.-N. and Stappers P. J. (2008) Co-creation and the new landscapes. *Special issue of CoDesign*, 4(1), pp.5–18)

The front end has been described as the starting point of the design process which can be "fuzzy". From a business perspective, Rhea (2003, p.145) explained fuzzy as "the process of discovery what to make, deciding whom to make it for, understanding why to make it, and defining the attributes for success". In other words, this is the stage of the design process which aims to be exploratory, involving multi-stakeholders in order to develop insights to create a deep understanding of the issues. But most importantly, it can collect a variety of information about users' experiences (Sleeswijk Visser et al., 2005; Sleeswijk Visser, 2009). According to Sanders and Stappers, it can be fuzzy because "it is often not known whether the delivery of the process will be a product, a service, an interface, a building, etc." So is this about open-ended, non-goal determined exploration? Is it about reformulating the "problem" to allow for new design opportunities (experiences) to emerge? The outcome of this front-end phase of the process might be ideas, which then can be developed to create products or services (Sanders and Stappers, 2008, p.3).

Design literature on user experience can be analysed in different ways. However, this research study is about the patient experience and for the purposes of this research, the definitions and frameworks can help to understand and highlight things to be considered when looking at design for the patient experience. The following sections will focus on patient experience.

3.3 Towards design for patient experience

In the UK, the National Health Service (NHS) faces new pressures to become more focused on patient experience. They used to focus their concerns around clinical services' performance of effectiveness and safety, but now they must find complementary ways to improve quality, increase personalisation and provide choices to promote the quality of the patient experience in health services. Furthermore, the awareness of patients' experiences has imposed new demands on design practices. The patient's perspective is now considered desirable in the design process because they have knowledge of their experience in health services. An understanding of strategies for patients' involvement in research can be seen in previous research (Savory, 2010). These four strategies, as Savory notes, can have different impacts on the healthcare systems depending on the research purpose: 1) conducting research *with* rather than *on* patients can result in researchers obtaining a better understanding through a focus on ensuring that data are collected appropriately; 2) involving a wider range of stakeholders can result in obtaining a wider understanding from different perspectives about the matter in discussion; 3) adopting a patient-led approach can help to identify health priorities for change; and 4) encouraging patient participation can help to develop new levels of knowledge and consequently help patients obtaining a better understanding of the outcomes achieved (Savory, 2010, p.195). Thus, the patient is a source for exploring needs, opportunities and new ways to think and act. In the last ten years, a number of design "social" models have been described to actively consider when working on new methods for healthcare improvements (Cottam and Leadbeater, 2004; Burns et al., 2006a; Boyle and Harris, 2009; Bate and Robert 2007). These design models are considered to be significant to create conditions for involving collaboration as a way to drive innovation in healthcare. In seeking collaboration, models focus on co-creation, co-production, and experience-based co-design.

Cottam and Leadbeater (2004) define co-creation as an approach which seeks to combine different experts and expertise to think and do things collaboratively. However, co-creation can be an act of collective creativity where people share ideas together (Sanders and

Stappers, 2008). Cottam and Leadbeater has drawn attention to the growth in chronic diseases, which demands co-creation models in order to bring those who are involved and have experience to redesign health services. In other words, co-creation is based on this view of responding to the promotion of well-being and living well for those who experience health services. At the same time, Murray et al. (2006) write:

> *The growth in chronic conditions and the limitations of the current model of healthcare in preventing and treating them, leads, in the end, as conditions deteriorate, to a growing demand for acute care. The acute care of chronic conditions is one of the primary factors in the pressure on NHS resources.* (Murray et al., 2006, p.5)

According to Murray et al., chronic diseases are connected to how people live their lives and emerging models in healthcare need to be more diverse and personalised to shape individual needs and preferences. In other words, it places demands on design to support healthcare models to offer ways that promote people's quality of life. In this way, Murray et al. also suggested that attention should be paid to the patient's role, which needs to become active rather than passive. This view has also highlighted co-creation as an approach, which sees patients as contributors to the conception, design, production and management of health services. The design perspectives continue within this view of transformation design. Burns et al. (2006a) define transformation design as that based on user-centred design principles. This view draws attention to the complex social and economic problems, which require action and participation, engaging multi-stakeholders to define roles and tasks. In other words, this perspective is "opening up design process to the people who were to use its results" (Burns et al., 2006a, p.10). This highlights the significance of looking at such problems from the perspectives of both the individual and the group, and the patients and the professional. What seems to be emphasised in this understanding of *transformation* is that design is fulfilling the role of connecting patients' and healthcare professionals' views. By connecting these patients and healthcare professionals' views in the design process, these voices can inform design teams on how to change things for better. But also, the design process will allow patients and healthcare professionals to obtain insights into how things can work differently by engaging them in the discussion. The role of the design researcher or practitioner has been seen as facilitating the collaborative process. Sangiorgi (2010) illustrates the attention to *service design*, as a distinct practice, in this context of transformation. According to Sangiorgi, designers need to become reflexive in their work in order to address power and control

issues in design activities. This view suggests introducing new skills and tools in design practices to reflect on processes, mapping multiple perspectives and/or exploring collaborative interpretations and evaluation of design situations. In this way, reflexivity could help to better understand designers' roles within transformational processes. In these social and economic concerns appears co-production. Co-production has emerged to allow people to share ideas and contribute with their experiences in ways that can strengthen services and make them more creative and effective. This is changing people's roles in public services. People who use services, such as patients, are considered to be "vital ingredients" to provide effective services. Co-production is based on the idea that an equal and reciprocal relationship between people, shifting the balance of power, responsibility and resources from professional to individual, is a way to reinvigorate *the core economy* in public services (Boyle and Harris, 2009). Simultaneously, Bunt and Harris (2009, p.11) highlight the idea that "the majority of spending still takes place in acute hospitals where models of care have been designed to treat acute illness". According to Bunt and Harris, 15 million people are currently living with a long-term health condition in the UK. The cost of caring for long-term illness has been estimated at £69 billion per year, much of which goes on hospital-based care based within the current model of service delivery.

A patient-centred redesign has emerged as a possible approach capable of generating sustainable savings and improved outcomes. Alternative models, involving patients, can allow patients to share their experiences to then improve their health outcomes and their experience of the service (Bunt and Harris, 2009). At the same time, Murray et al. (2010) have drawn attention to this notion of social innovation. Murray et al. defined social innovation as "new ideas (products, services and models) that simultaneously meet social needs and create new social relationships and collaboration" (Murray et al., 2010, p.3). In this line of thinking, Manzini and Rizzo (2011) have discussed that integrated participatory design initiatives can contribute to social innovation. In this way, the Department of Health (2005, p.3) placed an emphasis on involving a "Patient-led NHS" as an approach where the health services work *with* patients in order to support their health needs. Creating a Patient-led NHS aims at addressing "more choice, more personalised care, real empowerment of people to improve their health". This is a move towards a service that works with rather than for patients in order to support their health needs (Department of Health, 2005, p.3). Simultaneously, the significance of the patient experience has become a focus for the NHS. Consider, for example, that the former NHS Institute for Innovation and Improvement, in collaboration with medical researchers, has developed the experience-based co-design

(EBCD) model to respond to the quality of the patient experience in healthcare. Bate and Robert (2007) write:

> *[…] in a context where people are obviously not there for pleasure or enjoyment but for essential, sometimes life or death, clinical reasons. The experience design movement says it is no longer sufficient to seek to meet users' expectations but to exceed them in situations like these.* (Bate and Robert, 2007, p.2)

According to Bate and Robert, design needs to respond to the patient experience. However, is it about experience or expectations? The political context of service reform is obvious here – but it cannot seek to meet "users' expectations", but rather, patients' expectations. EBCD has been considered as a move towards bringing about health service improvements (Bevan et al., 2007). In this way, Bate and Robert (2007) have emphasised the significance of direct patient participation in the design process, as they can bring knowledge of their experience that can be useful to redesign future experiences. By applying co-design, patients and healthcare professionals will be involved in "collective creativity" through the whole design process and this is important to generate ideas and create a deep understanding of emerging issues (Sanders and Stappers, 2008). In this perspective, *thinkpublic* (a London-based social design agency) use co-design to enable involving frontline staff and citizens together in order to understand the lived experiences, ideas and skills of those who use, run and deliver services (Thinkpublic, 2014). They believe that "co-design has a crucial part to play in the future of healthcare and services". People who use and deliver services are the experts and they have ideas to help find opportunities to make things better in the future (Szebeko and Tan, 2010, p.580).

This understanding of design for patient experience shows that people are becoming empowered and actively involved in their demand for creative ways of living (Sanders, 2006a). This demonstrates a move towards expert networks involving "team-work and multi-skilling" (Kimbell, 2011). In the context of healthcare, the importance of the patient's voice is emerging, in particular, the voice of the patient's experience in health services. Perhaps acknowledging that patients possess different kinds of knowledge and promoting an equal partnership between healthcare professionals and patients can enable all of them to participate and "not just those who are already more able, articulate and socially advantaged" (Boyle and Harris, 2009). The value of the multi-stakeholders' participation in the design process highlights that attention is placed on looking at the patient experience, in this instance at the mealtime and in the context of stroke in

rehabilitation. A shared view emphasises that design, as a social agent, has a role to support healthcare. In other words, it seems to suggest that a social model of design practice would highlight a social agenda (Margolin and Margolin, 2002) to address a combination of the medical and social approaches, as described in the context of the International Classification of Functioning (ICF) model. These views demand that design creates social networks to design *with* people in order to explore opportunities that help promote their quality of life in healthcare. But perhaps more interesting is this idea of empowering through a collaborative and participative process which establishes a balance of power between professionals' and individuals' voices. The balance of power can be recognising the value of giving democratic voice for both patients and healthcare professionals. These views illustrate that design is moving its focus from products and services towards experiences. As discussed earlier, experience is a complex phenomenon. What seems to be emerging in this understanding is; *what is the patient experience?* and *how can patients be involved to help design for experiencing?* Think, for example, how patients are not only users or consumers, they are those who receive care and treatment and/or are living with a health condition in their everyday lives (INVOLVE, 2012). In what follows, investigations will present how design research as it is practiced is engaging patients (those who are receiving treatment and care and/or are living a health condition) and healthcare professionals (those who work day-to-day with patients) in the design process. As demonstrated in Chapter 2, healthcare professionals and patients can be seen as the experts of healthcare experiences. Hence, investigations will look further into how design research as it is practiced has identified these experts in the design process to discuss issues within healthcare, but most importantly, with special attention to design research as it relates to the patients' mealtimes.

3.3.1   The current situation in design research as practiced in healthcare

Reviewing the literature and websites regarding design research as it is currently practiced in the context of healthcare reveals that many such studies tend to involve patients' representatives, rather than patients themselves in this "co-designing" process. Several examples are presented in Table 3.1. As discussed earlier, the way in which design research is practiced can determine the value placed on delivering a service. However, engaging patients has been identified as a significant element of promoting the improvement of health services, in particular, to deliver better patient experiences in the future (Bate and Robert, 2007). Moreover, some literature suggests the importance of design research to make direct contact with the real experts because they can bring a

valuable contribution to the design development through their experiences (Sanders, 2001; Krippendorff, 2006).

Table 3.1 Examples of design research as practiced in healthcare context.

Cottam and Leadbeater, 2004	A design team, at the Design Council, used co-creation methods (e.g., interview, observations, workshops) in developing a new service to support people living healthier. **Direct participation:** residents, workers, local stakeholders
	A design team, at the Design Council, used co-creation methods (e.g., interview, observations, prototyping ideas) in developing a new service to support people managing diabetes. **Direct participation:** patients, frontline staff
Tsianakas et al., 2012	A medical research team, used experience-based co-design methods (e.g., interviews, observations, co-design working groups) in which they identified ways to improve patient experience in breast and lung cancer services. **Direct participation:** patients and staff
Golden et al., 2011	A research team, at the University of Toronto's Rotman School of Management, used methods (e.g., observations, interviews, workshop) in which they built understanding of patients' needs and identified ways to improve the patient experience. **Direct participation:** patients, caregivers, oncologists, pharmacists, nurses, researchers, administrators
Bowen et al., 2010a	A design research team, used experience-based design methods (e.g., interviews, workshops) in which they identified ways to improve outpatient services for older people. **Direct participation:** volunteers
Macdonald et al., 2010	A design research team, in the mappmal project, used co-design methods (e.g., workshops) in developing a new prototype food service to address malnutrition for older patients in hospital. **Direct participation:** food producers, caterers, frontline ward staff, dieticians, physicians, speech and language therapists, occupational therapists, carers, older people's representatives

Looking at the table above, the RED team at the Design Council, considered to be pioneers in co-creation models for healthcare, conducted two health-related case studies: one to promote services to motivate people to live healthier; and another to provide services for people to managing their diabetes effectively (Cottam and Leadbeater, 2004; Burns and Winhall, 2006; Vanstone and Winhall, 2006), both of which have been evaluated and discussed by design researchers (Freire and Sangiorgi, 2010). Although both of these studies applied a collaborative process to generate ideas with people for whom the design is going to serve, as Freire and Sangiorgi (2010) note, they operate outside of the NHS system.

A number of the medical teams have used the *Experience-Based Co-design* (EBCD) model around the world for healthcare service improvement (Donetto et al., 2014). Looking at the table, an example is a case study with a focus on improving patient experiences in breast and lung cancer services which was carried out, considering the direct participation of patients and staff in the research process to be relevant to ensure that the outcomes of the process delivered what patients need (Tsianakas et al., 2012). In this study, patients and staff were involved as active partners to identify "touchpoints" or "improvement priorities" for breast and lung cancer services. However, there is little indication or discussion of what kind of tools and techniques were used in this study to involve these patients in co-designing. For example, Tsianakas et al. described:

> *Patients and a variety of medical, allied health professional and administrative staff volunteered to join specific 'co-design working groups' to design and implement improvements to services [...] these groups were facilitated by service improvement leads and ground rules were established from the outset, ensuring all participants had equal voices.* (Tsianakas et al., 2012, p.2641)

Although it shows a focus on promoting equal voices, the illustration of these co-design activities does not clearly reveal how "collective creativity" was involved. If we go back to co-designing with users, as Sanders and Stappers (2008) illustrated, these co-design activities are spaces, involving people with different roles and tools working together. Now, consider, for example, how those patients and healthcare professionals were participating and what kinds of tools were used to open up creative dialogues. The involvement of the designers is also unknown. Recently, evaluations of EBCD models also emphasise this view of having limited tools (Bowen et al., 2013) and this is problematic because it might not contribute for idea generation. However, as expressed earlier,

designers can bring valuable skills to develop tools and techniques to open up collective dialogues to enable people to express their views and emotions or share ideas and aspirations. In the context of healthcare, design in creating tools and techniques has been suggested as a significant vehicle for innovative moves in healthcare (Cottam and Leadbeater, 2004; Burns et al., 2006a). Innovative moves are new ideas, which can be valuable to find directions on how to enhance health services in the future (Cottam and Leadbeater, 2004). According to Burns et al. (2006a), designers can make problems and ideas visible. In creating visual maps they can illustrate complex information. But also, they can quickly sketch ideas to communicate with others. The significance of EBCD has been reported by a large number of international studies that used this model in the context of healthcare in the last 10 years (Donetto et al., 2014), noting that using EBCD required making adaptations. Respondents to the survey in Donetto et al.'s study reported that the co-design methods need to evolve in order to work *with* patients. Although some respondents have revealed a need to do adaptations to the EBCD approach; for example, using tools originally from service design. The kind of tools they used has not been discussed. In this report, Donetto et al. (2014) make an invitation for designers. They write:

> *[…] to design practitioners to share their thoughts on what needs to be borne in mind when using design expertise in the healthcare sector, what their particular form of expertise brings to well-established quality improvement processes in large and complex healthcare organisations, and the nature of the critical thinking needed to increase the impact of co-design approaches in this setting.* (Donetto et al., 2014, p.50)

Although this view apparently shows an interest on how design "thinking" can benefit co-design approaches in this context of healthcare, design researchers have suggested the application of service design skills and tools in this context of healthcare (Carr et al., 2009). In this view, design could make the process more explicit, visible and shared, supporting practices and people to think in different ways. This research study can also contribute within this debate by exploring how design can promote the quality of the patient experience in the context of stroke.

Another study, as we can see in Table 3.1, focused on improving patient experiences. Golden et al. (2011) considered that a patient-centred approach is significant to the redesign of cancer services in hospital. In this study, Golden et al. began to understand

patients and what matters most to them in order to identify ways to improve their experiences. This was a study where the researchers had initially contacted patients and staff to create a holistic picture of patients' lives in this context of chemotherapy treatment in hospital. This initial contact helped them to build patient personas as a tool that described the varied needs of patients. However, the development of ideas to create the ideal patient experience for the future involved a diversity of professionals but did not include the patients. Involving patients in what they called "ideation session" seems also emerge issues here. For instance, Golden et al. revealed:

> *Oncologists, pharmacists, nurses, researchers and administrators were in attendance; were it not for scheduling challenges, patients would have been present also.* (Golden et al., 2011, p.38)

This view demonstrates that planning activities to involve patients can be a challenge. Donetto et al. (2014) also found that studies involving EBCD faced challenges related to time in organising activities with patients and staff, especially when studies are carried out by only one person.

In addition, a design research team has applied the EBCD model for "Better Outpatient Services for Older People". Patients participated indirectly, rather than directly, in the design process by volunteers (Bowen et al., 2010b; Bowen et al., 2010a). For example, the authors reported:

> *We provided a training session to the volunteers from SCCC on informal interview skills and how to use audio recorders. Subsequently the volunteers were able to interview their clients and carers who had experience of using hospital outpatient services, in their own homes. The volunteers attended the project sessions on behalf of their clients and represented their stories.* (Bowen et al., 2010a, p.2)

The direct involvement of patients in design research revealed other challenges related to the patients' conditions. Consider, for example, Bowen et al. (2010a), who observed that "some older people rely upon patient and public transport services, and some clearly find it difficult to attend at all given their circumstances and condition". Time issues were also addressed in this study.

In reviewing design research studies into the improvements of the mealtime for patients, a design research team, using co-design approaches, also highlighted the difficulty of involving patients in the design process. Macdonald et al. (2010) reported:

Due to ethical and practical considerations, it was not possible to interview the type of patients selected for this study, namely those who had experienced stroke, dementia, or hip fracture. (Macdonald et al., 2010, p.3)

What seems to be highlighted here is the importance of ethics in order to get patients involved in design research. This understanding of research as practiced seems to be highlighting two views: design and medical researchers. Design researchers recognise the importance of involving the experts in the design process, but patients' voices tended to be illustrated by those called "volunteers" and "representatives" (Bowen et al., 2010a; Macdonald et al., 2010). However, design researchers seem to face challenges in bringing forth the patients' voices due to a range of issues, such as time, ethical considerations and/or patients' conditions. At the same time, medical researchers acknowledge the significance of design to support improvements in healthcare, but they have been focused mainly on models of "thinking like a designer" (Bevan et al., 2007, p.140) instead of involving designers who have particular well-developed kinds of skills and expertise, as providing tools to support dialogues to the generation of ideas. However, medical research demonstrated direct participation of patients throughout the research process, but provided little indication of how they engaged patients in collective creativity. An understanding of patients' ideas can be relevant to highlight desirable ways to improve services, considering that patients are "the real virtuosos of the experience" (Sanders, 2001) in this context of healthcare.

All of the views discussed here have demonstrated an interest and concern with the patient involvement. Although these views highlight participatory processes, they show patients participating in the design process in different ways and playing different roles. What these views seem to divulge here is a need to think on how to involve direct participation of patients in design research. Fundamentally, acknowledging the value of involving "the real virtuosos" (Sanders, 2001) of healthcare experiences both patients and healthcare professionals who have experiences, views and opinions. Consider, for example, that supporting identifiable users has emerged to be a relevant element within the design process in order to change products or services that better support users' interests in the future (Binder et al., 2011a). Furthermore, the research study in this thesis aims to bring

improvements for the patients' experiences at the mealtime in stroke rehabilitation. This review illustrates that a limited number of studies have focused on the context of stroke, for example, studies conducted in healthcare using the EBCD model have been undertaken in a range of clinical services but these have not included stroke units (Donetto et al., 2014). In addition, the EBCD model apparently seems to be limited in providing tools to engage patients and healthcare professionals in collective creativity. As a result, it tends to influence "quick" solutions rather than open up new ways of thinking (Bowen et al., 2013). Can a participatory co-design approach bring a different understanding in this context of stroke? As discussed earlier, there has been little research carried out in the context of the mealtime in healthcare by exploring the patient's voice. However, as we have seen, the patient's voice must be involved in design research. Thus, the mealtime as a day-to-day experience requires further investigation in order to understand what should be taken in consideration to design the mealtime for people experience. In doing so, it can open up new ways of thinking about the patient experience which is missing. In the following section, explorations will place a focus on looking at how design has been playing a role at the mealtime for the customer experience. The patient experience in stroke rehabilitation in hospital is different from the customer experience, however, adopting this perspective can allow a vantage point for reflecting about the experiences of patients.

3.4 The design of the mealtime as a customer experience

The appreciation of food and the design of the mealtime has long been the concern of restaurateurs, chefs and designers who have been exploring ways to provide a more hedonic experience for their customers. This way of thinking of the mealtime demonstrates a possible role for design practices focused on promoting pleasure. Consider, for example, Heston Blumenthal (a Michelin Star chef and owner of the restaurant *The Fat Duck*), who considers sensorial aspects, including sound, smell, touch, taste and sight as well as the senses of memory, nostalgia and wonder, to enhance the appreciation of the food (see Figure 3.8). Fundamentally, he emphasises sensorial aspects in order to create a more enjoyable and memorable eating experience for his customers. Although patients present a complex situation at the mealtime, as discussed in Chapter 2, how can these sensorial considerations be addressed by understanding that patients will require a different approach? In this idea of *the sensory*, Riva (2000) considered that the shape and colour of food are attributes that stimulate the senses in anticipation of the taste. This can be seen as proposing ways of visually presenting food to influence food choices, but also as the

application of "food design" (Guixé, 2010). Taking forward this idea of food design, the International Food Design Society on its website has indicated "food design" as a new discipline that plays an important role in creating solutions related to food and eating.

Figure 3.8 "Music Generates Taste of Sour, Bitter, Sweet and Salty"
(Source: Molecularrecipes.com [Online image]. Available at: http://www.molecularrecipes.com/molecular-gastronomy/taste-music/ (Accessed: 5 April 2014))

According to Bayley (1999, p.34), "there is always a direct link between the food we eat and the place we eat it". Think, for example, how the interior of a restaurant can reveal the type of food served. This view draws attention to the influence of design on people's perceptions and sensations. At the same time, Alsop (1999) observed that a combination of components such as food and tableware can evoke a sense of conviviality while eating. The act of eating has been a matter of interest for designers. Here design plays a role in restaurants. How can design play a role in stroke rehabilitation with more detailed nuance? Vogelzang (2008) demonstrates a variety of design concepts related to eating. One example was Vogelzang's project, *Sharing Dinner*, which presented an extended tablecloth with special openings that invited customers to put their hands and heads through to keep

their clothes covered in order to create the idea of equality and community while eating (see Figure 3.9) (Vogelzang, 2008, pp.74-79).

Figure 3.9 Sharing dinner
(Source: Good [Online image]. Available at: http://magazine.good.is/articles/video-marije-vogelzang-designs-marshmallow-clouds (Accessed: 5 April 2014))

This way of understanding "eating" seems to be highlighting design interventions that promote social and sensorial qualities to evoke emotional quality. According to Moreno et al. (2010), commercial spaces such as restaurants, cafés and bars are spaces that promote socialisation and can inspire people's everyday lives. Socialisation, the *Encyclopedia Britannica* says, "represents the whole process of learning throughout the life course and is a central influence on the behaviour, beliefs, and actions of adults as well as of children". What Latour sees in this view of socialisation is this relation of "actor" and "network", or in other words, the interaction between social and material (Ehn, 2008) in everyday life. This shows that people live and relive social experiences in their lives. Design practices seem to play a significant role in promoting a sense of socialisation at the mealtime for customer experience. Therefore, design can play a role in this idea of "socialisation". But also, it can explore how to promote socialisation at the mealtime in stroke rehabilitation in hospital.

According to Desmet and Shifferstein (2008), people might only eat what they expect is going to provide them with a pleasant emotional impact. At the same time, Future Laboratory (2008) sought to demonstrate that the design of the interior of a restaurant can provide an emotional and aesthetic response to lifestyles. Design related to food might become significant in people's lives (Future Laboratory, 2008). From the perspective of "eating out", Moreno et al. (2010) observed that the appreciation of food influences the design of eating environments to be more sophisticated and delightful in their presentations. The design of environment, according to Worthington and Vlegels (2009), must consider elements such as colour, materials, light, objects and scale in order to create an atmosphere which can be romantic, intimate, cosy, warm and harmonious, as appropriate. According to Worthington and Vlegels (2009), these are important elements that influence experiences of feeling safe or enriched. Investigations with a focus on eating out found that people might experience pleasure and satisfaction (Warde and Martens, 1998). Here pleasure was associated with the experience of being in more relaxed and convivial situations, such as being a guest in other people's homes. What this highlights here is design in playing a role in delivering outcomes rather than social engagement, involving the customers' voices in the creativity. However, design for customer experience is centred on providing sensorial, social and emotional influences in order to provide a more enjoyable experience, when it is a purchased experience in a restaurant. Perhaps more interesting, however, is the idea that a more convivial design can make the experience of eating become more pleasant. These suggestions within a customer experience framework are pertinent to the issues and concerns of this research. As discussed in Chapter 2, the mealtime for patient experience is revealed as having a need to address more sensorial, social and emotional considerations as part of its role within post-stroke rehabilitation.

In this research study, two interviews were conducted with restaurateurs in order to obtain insights into the current understanding of designing the mealtime for a customer experience (see Appendix A). The aim of these interviews was to complement the information described in the literature so that the description would resemble the current state of practice. But also, it could provide insights for reflecting on design for the patient experience and for issues or approaches that might not have been considered or found in the "healthcare" literature. In the following section, the discussion will highlight issues that this research study considered to be significant for further investigation in design.

3.5 Opportunities for designing social engagement

The design models, as demonstrated in Section 3.3, pointed out the need to involve multiple views as a source to explore ways of thinking and opportunities in order to respond to the promotion of well-being for those who experience health services. Although design approaches emphasised attention as to the significance of the patients' and healthcare professionals' involvement in the design process, design researchers have demonstrated indirect patient involvement in the design process. Consider, for example, how the studies outlined in section 3.3.1 communicated patients' views via patients' representatives. However, people who undergo, participate in and experience health services, such as patients and healthcare professionals, can be seen as "vital ingredients" to share their ideas and contribute with their experiences. At the same time, the patients' and healthcare professionals' views are desired to bring a balance of power between professional and individual (Boyle and Harris, 2009). Fundamentally, the NHS Institute of Health and Research have considered that patients offer unique and invaluable insights and their views make studies more effective and credible (INVOLVE, 2012). Therefore, what design can bring here is a focus on the relationship between the direct involvement of patients' and healthcare professionals' to offer, perhaps, the actual rather than representative voice of patients and healthcare professionals. More interesting is that by directly eliciting patients' and healthcare professionals' voices, design can demonstrate a democratic voice of the mealtime. But also, it can support this social view that is missing in the ICF model (see Figure 3.10).
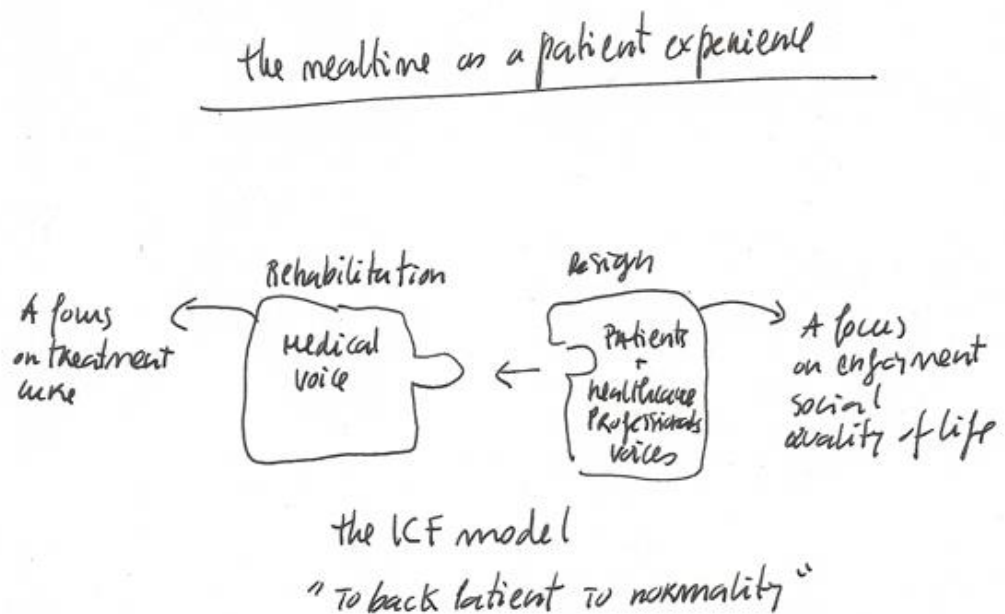
Figure 3.10 Design bringing patients' and healthcare professionals' voices to support the ICF model.

Thinking in terms of patients' and healthcare professionals' experiences, Sleeswijk Visser (2009) reported that understanding experiences can be complex and that a design focus on collecting a variety of information about people's experiences can help to obtain a contextual view of the situation. For example, Sanders (2001) suggests that accessing people's experiences through design research practices should involve a variety of methods to collect information from the past, present and future. Although it highlights an interesting way of understanding people's experiences, this study was focused on users. What this research study proposes is an understanding of patients that considers patients' and healthcare professionals' experiences to be fundamental in this context of the mealtime. However, designing the mealtime draws attention to experiential considerations such as the social and sensorial. In this way, design can explore and provide a diversity of information about the patient experience that can help to explore opportunities to promote the quality of the patient experience and consequently the improvement of the mealtime in hospital.

The discussion of design within this literature review of designing for user, patient and, ultimately, customer, in the specific context of the mealtime, has been valuable for this research because it was aimed at examining how design might act as a social agent in the context of healthcare and as an interventionist agent at the mealtime. The review of

literature has also been valuable for this research because it was aimed at identifying specific issues; in particular, how design research as it is practiced incorporates people as the "virtuosos" (Sanders, 2001) of any particular practice or experience, such as patients and healthcare professionals, in the design process. The involvement of patients demonstrates opportunities for this research to intervene. As mentioned earlier, design can bring a focus to elicit patients' voices directly.

The literature review identified three key elements that were found to be directly related to the purpose of this research. First, the literature asserted the significance of a design perspective for experiencing that is focused on the user. By exploring design for the user, the research has indicated evidence of the user as a partner in design. Design *with* users must be considered to be a means of exploring new ways of thinking about designed artefacts, interactions and services that matter to them and which they value. Secondly, views related to the improvements of health services and patient experience showed a focus on multi-stakeholders, such as patients and healthcare professionals. Although design models highlighted collaboration, for example, the review revealed models related to co-creation, co-production and experience-based co-design, and the application of these models indicated the indirect involvement of patients in design research practices, particularly those affected by stroke. In other words, design research practices tended to demonstrate patients through their representatives. However, the patient involvement "voice" in research does exist in health field work (Dickson et al., 2011). In addition, the co-production models indicated the significance of involving collaboration from the level of the professional and the individual in order to promote a balanced view, or, an equal participation. This way of thinking revealed a move toward the involvement of design within social and economic concerns in public services. Thirdly, this review found that views for designing the mealtime focused on the customer. In exploring customer experiences of eating or dining, it highlighted that experiential considerations such as social and sensorial qualities might induce more pleasurable experiences during the mealtime. Although stroke patients present a different and more complex situation at the mealtime, for example, patients often cannot eat a diversity of food and/or speak, but design can play a role here. By exploring experiential aspects of the mealtime, promoting quality of life highlighted reflections on how design can support stroke rehabilitation, when considering the mealtime as an integral component of the rehabilitation process with an aim to put patients back to the "normality" of life.

Experience and *design for experience* is a complex phenomenon and design in areas such as user experience, patient experience and customer experience at the mealtime has previously been focused on people's needs, experiences and desires in order to promote enjoyment, well-being and pleasure in their everyday lives. However, as discussed in Chapter 2, this research has a role in supporting the ICF model. In doing so, it hinges upon collaboration. Collaboration is not only professional but also individual to obtain a valuable perspective of the situation. Consider, for example, the mealtime where different roles and experiences are connected, such as those who plan and deliver and those who live and relive. Hence, central to this discussion is how design approaches can elicit the patients' and healthcare professionals' voices, and how such voices can highlight opportunities to promote the quality of the patient experience at the mealtime in stroke rehabilitation in hospital. However, this idea of "voice" requires design attention, in particular when patients present a number of difficulties such as verbally communicating. How can this research allow us to explore voices as a possibility of giving voice and as a participation of voice? In the following investigation, the discussion will place a focus on how better to involve the direct participation of patients and healthcare professionals in design. Ultimately, this thesis aims to explore how investigations focused on the direct participation of stroke patients and healthcare professionals centred upon the mealtime experience can generate knowledge which can be used in order to support future experiences.

3.6 Summary

This chapter began by discussing experience as a complex phenomenon and locating that discussion within the context of user experience in design practices, thereby revealing users as participants in the design process and their contribution as central to the development of products and services. Here design identifies users as a source of knowledge and a means to explore opportunities to develop new products that better respond to their needs and desires. It also revealed that design in the context of healthcare has suggested design models to incorporate collaboration in the design process. Design strategists considered collaboration as a way to drive improvements in health services. In exploring *co-creation* models, as distinct from *collaboration*, it indicated the involvement of multiple stakeholders "voices" in the design process to respond to the promotion of well-being in health services. Within this idea of collaborative participation, co-production models indicated the relevance of involving the experiences of professional and patient "voices" to provide an empowered perspective of the situation. Experience-based co-

design models revealed that patients' involvement in the research process is significant due to their experiences. Patients were seen as partners with whom designers and medical professionals could identify and explore opportunities to improve the quality of the patient experience in health services. In examining design research as it is practiced, this chapter demonstrated that design research applied collaborative models but presented the indirect involvement of patients in the design process. Patients' voices were considered through their representatives. The focus at the mealtime demonstrated design practices in promoting pleasurable customer experiences. Promoting pleasure indicates experiential considerations such as the social and sensorial. This indicated that design practices from a business perspective are centred on providing customer satisfaction. To conclude, this chapter has discussed the value of this review and has addressed the issues that are required to be explored in this research. In the following chapter, I will present the methodological approach adopted in this study with the aim of allowing voices to become "orchestrated".

4

Methodology

4.1 Introduction

Central to this research is the focus on exploring "desirable futures" and on delivering these to those who will go on to experience them (Krippendorff, 2006). Previously, in Chapters 2 and 3 of this thesis, I began with quite open-ended questions concerning how design research can improve the quality of the mealtime for the experience of patients undergoing stroke rehabilitation. In Chapter 2, an exploration of the context of stroke rehabilitation revealed that the mealtime is approached largely from a singular view: the medical. I identified a need to integrate a multiple view, involving both the social and the medical. In Chapter 3, design research within healthcare was revealed to emphasise a social model of design practices (Margolin and Margolin, 2002), but I found two things: differences between the patients' voices (virtuosos of experience) as representatives; and participatory democracy. As I have argued, design for the enhancement of the patient experience is not designing with "users", but rather, with patients and healthcare professionals, "the real virtuosos" (Sanders, 2001) of healthcare experiences. Hence, both chapters have addressed the research questions with the intention of inquiring how design can potentially and desirably involve the direct participation of both the patient and the healthcare professional in the design research. The intention has been not only to inquire how this particular direct participation could contribute to integrate a more social model at the mealtime but also to generate information based on patients' and healthcare professionals' expectations, which is useful to inform design research into the improvements of the mealtime for patient experience. Hence, a participatory design research methodology illustrates how it would be possible to conduct research through direct participation. Fundamentally, this chapter suggests how to construct the design research path to address the issues in order to deliver the design purposes.

This chapter, therefore, begins by situating the research approach within a participatory design context. As I identified in Chapter 3, participation plays an important role in exploring and understanding human experience. In adopting participatory design research as a methodological approach, it emphasises a language inspired by the philosophy of

Bruno Latour. Participatory design discusses the idea of design as both a socialised and materialised space in what Latour (1999, p.174) called "a collective of humans and nonhumans". Fundamentally, this is an approach that involves "socio-material *design things*" as a form of organising and structuring a research project (Bjögvinsson et al., 2012, p.105). Think, for example, of design activities, involving multi-stakeholders, objectives, time, space, sketches and other materials. I see this notion of design, socialised and materialised, as being important to involve patients and healthcare professionals in an exploration of the mealtime situation. This connection between human and non-humans is useful to design the change of something for the better (Binder et al., 2011a). This is an approach that suggests "infrastructuring". Infrastructuring is necessary to design in time and space (Ehn 2008). Time and space are issues relevant to the concerns of this research. Think, for example, of the mealtime, as an everyday experience; it looks at patients and healthcare professionals in a specific space (hospital) and time (temporarily recovering from stroke effects). But perhaps more interesting is that a form of design research is searching within the present "to proceed into a desirable future" (Krippendorff, 2006, p.29).

Furthermore, I identified a methodological framework which emphasises that design for experiencing is collecting a diversity of information about people in order to understand different levels of knowledge about experience (Sleeswijk Visser et al., 2005). This framework inspired this research which views design for patient experience as taking an approach to actively involve patients and healthcare professionals in order to understand patient experience at the mealtime. The direct involvement of patients and professionals might become important to acknowledge as forms of expertise in design dialogues, which are seen as social accomplishments (Kimbell, 2012).

Although this relationship between social and material is a valuable approach, I will demonstrate that structuring a design research process to engage patients (those who are receiving treatment care or living with a health condition) and healthcare professionals (those who work day-to-day with patients) draws attention to design methods to better support and accommodate patients' needs. But most importantly, the purpose of adopting this method is to encourage patients and healthcare professionals in this idea of collective creativity. As such, I will demonstrate how an approach focused on connecting patients, healthcare professionals, tools and techniques, and space might reveal a different level of knowledge about experience with an emphasis on the mealtime in healthcare. Most importantly, I will emphasise a focus, not only on issues of establishing equal voice, but

also, how voices of the virtuosos who have disabilities such, as verbal communication, can be voiced and can participate with their voices through design.

Although participatory design is a well-established field of research, I suggest that participatory design as a methodology can gain from adapting a number of methods to better engage and accommodate patients and healthcare professionals, in particular those who have experience in stroke rehabilitation in hospital. Further, I will demonstrate how this research intends to demonstrate how desirable worlds come together. The chapter ends by discussing how the patients' and healthcare professionals' voices are important to uphold in order to generate insights (findings) that can be used as the basis for concepts and proposals to promote the quality of the patient experience at the mealtime in hospital.

4.2   Research approach

As my research focus was to address the possibility of making improvements to the quality of the mealtime experience for patients undergoing stroke rehabilitation, I had to find the most appropriate methods to promote active participation and also to collect meaningful data to explore design possibilities for positive change. Therefore, this research is twofold: it entails collecting data; not only about what is happening (present), but also about how things could be different (future). As I have argued, design for enhancing the mealtime experience must design specifically with patients and healthcare professionals because they add different experiences and roles at the mealtime. With patients and healthcare professionals I want to be more specific about what Sanders (2001) called "the real virtuosos" instead of referring to them as as users, traditionally, a term more centred around the field of Human Computer Interaction to highlight those who use or operate with a system. In this view, participative activities play an important role in collecting human perspectives or experiences. Therefore, the most appropriate research methods for this particular research are those derived from participatory design, as one of the basic principles of participatory design is to conduct research by involving the direct participation of those who the design is serving (Sanders, 2006b). This involves looking at people with a specific role, knowledge and experience. By involving patients and healthcare professionals, each having different experiences, in the design research, I can acknowledge their roles and value them (Ehn and Badham, 2002; Bjögvinsson, 2007; Sleeswijk Visser et al., 2005; Sanders, 2001; Sanders 2006b; Sanders and Stappers, 2008).

As I demonstrated in Chapter 2, the mealtime involves specific roles: those who plan, treat and deliver, and those who recover, receive and experience. However, receiving and

experiencing the mealtime while recovering from stroke seems not be an enjoyable experience for patients (Ekberg et al., 2002; Perry and McLaren, 2003; Carlsson et al., 2004). Although medical research draws attention to sensorial, social and emotional issues of the patient experience at the mealtime, it tends to address suggestions to more of a physical type of support (e.g. care assistance and food supplements). What it highlights here is a need to explore these sensorial, social and emotional concerns along with patients and healthcare professionals in order to understand how to stimulate patients' interest and enjoyment in eating (Caterall, 1999; Vogelzang, 2008; Desmet and Shifferstein, 2008; Moreno et al., 2010). Hence, I advocate that eliciting the patients' and healthcare professionals' voices are concerns of this research. Design research with a focus on improving the current situation highlights the concept of collective creativity with an aim of generating new ideas (Sanders and Dandavate, 1999; Sanders, 2001; Sanders, 2006b; Sanders and Stappers, 2008). Collective creativity, as Sanders (2001) pointed out, is creating opportunities for people (those who have experience) to express themselves, and involve their needs, feelings, dreams and aspirations. What Sanders notes is that collective creativity can be "powerful". Powerful, as I see it here, is the importance of understanding what people expect for their future. By understanding what people expect for their future, design might play an important role in discovering and delivering these expectations. This can be a way to promote more valuable experiences in the future. Within healthcare, Bate and Robert (2006, p.308) have discussed "what is the point of a great process and a terrible experience?" What I see relevant to consider here is how value-driven design research can deliver constructive experiences.

4.3 Participatory design

Participative design has been described as a "proliferating family of design practices that hosts many design agendas" (Brandt et al., 2013, p.145). The Scandinavian countries have presented its values within the social and rational idea of democracy which advocates that those affected by design changes should have a say in design for the future (Ehn and Badham, 2002; Ehn 2008). What participative design highlights here is the relevance of expressing voices through design. Initially focused on work on the design of computer systems, this has been a movement that highlights the idea of shifting the balance of power in decision-making, perhaps linking this view that design based on establishing equal partnership between professional and individual can strengthen design for change (Boyle and Harris, 2009). As I mentioned in previous chapters, this research is also concerned with the balance of power within "voices" in this context of stroke rehabilitation,

especially at the mealtime in hospital. Establishing an equal participation of voices from the patients and healthcare professionals, the virtuosos of experience, seems to be fundamental to the orchestration of this design research. Rather than merely designing for "decision-making", Bate and Robert (2007, p.30) took on challenges to also design for "experience-making", a concept that I see as being significant for the focus of this research study. In other words, it advocates design alongside all experts to gain a practical understanding of their needs as well as identify priorities for change. Thus, this research study considers the idea of design in developing strategies that allow people participation to be significant, and consequently, will legitimise their participation (Binder et al. 2011a; Bjögvinsson et al. 2012). By eliciting the patients' and healthcare professionals' voices, I might be able to legitimise their participation in this research.

Another important gain of this approach is participation to generate tacit knowledge (Sanders and Dandavate, 1999; Sanders, 2001; Sleeswijk Visser et al., 2005). Tacit knowledge, as Sanders and Dandavate (1999) note, is personal knowledge, involving emotions such as feelings and dreams. According to them, design can play an important role in creating tools that enable people to express their emotions. This can be the way to access tacit knowledge. What seems to emerge here is that providing opportunities for people to express what they think, feel and dream about something might allow us to obtain an explicit understanding of what they expect for their future experiences.

This generation of tacit knowledge highlights design practices to involve collective creativity. Collective creativity brings about a paradigm shift away from the individual towards networked, co-creative approaches of making, which involve the active participation of people, described through open-ended generative processes (Sanders, 2001; Sanders and Stappers 2008; Armstrong and Stojmirovic, 2011). This is an attitude which acknowledges people's knowledge and expertise. Hence, design research with an aim to improve or change 'things' should involve the everyday people, who have experience in doing or using these 'things', to understand and use these 'things' from the experiencer's point of view. This strategy, in turn, can help to bring about desirable futures for those people.

4.3.1 Socio-material assemblies, design games and infrastructuring

When design considers the future, it does not only place a focus on people because it is seen as an assembly of things (human and non-human), a setting that demands design in infrastructuring. Within the subject of participation, Ehn (2008), inspired by the

philosophy of Bruno Latour, points out that participatory design is an approach of "the kind of socio-material assemblies" as design things, involving a focus on the human (e.g. designers, users and stakeholders) but also the non-human (e.g. objects and artefacts). What seems to be highlighted here is not only the importance of acknowledging the voices of people but also the role of artefacts, tools, the interactions and relationships between the people (human actors) and these non-human actors in design. This view opens up ways to think about this research study. For example, how can artefacts and/or tools play a role in eliciting voices while at the same time supporting the participation of voices? In fact, as Bjögvinsson et al. (2012, p.105) note, the origin of participatory design as "socio-material *design things*" derives from the philosophy of Bruno Latour (1999), who views human interaction as "sociotechnical". According to Latour, the sociotechnical is a collective of human and nonhumans:

> *We are never limited to social ties. We are never faced only with objects […] we belong in the crossover […] the articulation, the possibility of mediating between mediators.* (Latour, 1999, p, 214)

In this view of mediators, McCarthy and Wright (2007, p.109) provide an example. They write: "the mobile phone can be seen as a tool that mediates community practices such as social chat"; perhaps their view connects this idea of physical manifestation of a social assembly; mobile phones are mediators of conversations using things people can touch. Within this perspective, "things" are both socialised and materialised as assemblies. These assemblies are characterised by "public spaces" where common social objectives are established to solve political decisions. In this idea of making things public, participatory design suggests that we constructively deal with heterogeneity and controversy rather than resolve conflict (Bjögvinsson et al., 2012). Following this view, the mealtime is a public space, engaging people with different roles, perspectives and with their interactions with the non-human actors. Think, for example, in stroke rehabilitation, how it involves a diversity of healthcare professionals with different roles and patients with different disabilities. Providing spaces to open up dialogues, where these different perspectives of the mealtime are elicited, can be significant to suggest future directions and is a concept that must be addressed in this research study.

Initial participatory design conceptualisations have followed the theories of Wittgenstein; "the language-game" philosophy. For example, Bjögvinsson (2007) draws upon this concept, which views that the language and meaning-making in participation is defined by

practical issues. In other words, language is part of an activity "game", involving participants demonstrating in practice their "experience". Here, games reveal the concept of rules, which guide an activity within a particular purpose (Brandt, 2006). Within this view of "language-game", Ehn (2008) suggested seeing design as participative "design games" which assume participation is playing and doing. In other words, as an approach which entangles a diversity of design games where the design researcher's role becomes one of organising these design situations as "arenas" (Bjögvinsson et al., 2010). In this perspective, design as games are to be played in order to achieve a purpose. The concept of design game, as Ehn defines, involves "participation, communication, community, language and artefacts". These views show that people share experiences through rules, but also, through rules of artefacts. In doing so, they give form to things. In this line of thinking, design brings a focus on creating forms of alignments with both human and non-human participants (Ehn 2008). In other words, it shows a concern for how design can organise social and material situations around matters of concerns. Think, for example, how non-human participants, as Binder et al. (2011a) show, are objects of design, which evolve, but fundamentally, how they support people's participation in the design games and provide a playful and sociable experience for them. Involving patients and healthcare professionals in a more convivial experience can encourage their participation to think about things differently. Objects of design (e.g., workshops) can also be seen as boundary objects, those which generate insights and possibly suggest future directions for ongoing design games (Ehn 2008).

Furthermore, this view of design games places attention on infrastructuring as moving towards ongoing envisioning design, involving time and space (Binder et al., 2011a; Bjögvinsson et al., 2012). This can be seen as a continuous exploratory design process, where initial infrastructures can support following infrastructures. By reflecting on the meta-design approach, Ehn (2008, p.96) suggested seeing "every use situation as a potential design situation". According to him, "there is design during a project (at project time), but there is also design in use (at use time)". In other words, infrastructuring involves design after design. This research is looking at patients and healthcare professionals in a specific space (hospital) and time (temporary recovery from stroke effects). Fundamentally, it intends to create what Sanders (2001) calls "the scaffolds" for patients and healthcare professionals to express their experiences and ideas. This research also aims to constructively conceive design activities to put participation in action, as a public space, to think and reflect about the patient experience at the mealtime, starting

from the present and looking forward to a desirable future. Infrastructuring here might illustrate a design path, involving the binding of design situations at different times to proceed into a design purpose of changing things for the better.

4.4 A framework for participatory design research

Design researchers create proposals for changing products, services and spaces in order to deliver "desirable futures" (Krippendorff, 2006). Participatory design also, as I will demonstrate, proposes design practices in order to reach the desirable change in question, with the focus on how things could be different. From this perspective, the purpose of participatory design research might be to gain a better understanding of what happens in the present to posit a statement in order to explore alternative possibilities for the future. For example, ethnographic studies can be valuable as starting points in design research on the one hand (Laurel, 2003; Sanders, 2002), and workshops and design laboratories as a vehicle for collaboration and exploration on the other (Binder, 2007; Bødker and Buur, 2002). Hence, I see the design research not only as a question of designing games but also on how these design games can support the participative and creative dialogues in order to support and inspire changes. In addressing change, Binder (2007) highlights attention to see design research becoming more like an open agenda for new opportunities. In this line of thinking, I have to involve patients and healthcare professionals, tools and artefacts to make this happen. Fundamentally, I need to understand what design methods, tools and techniques can better stimulate and support patients' and healthcare professionals' participation and creativity in order to move to "desirable futures".

According to Sanders et al. (2010, p.195), "every project is unique". Following this view, what I need to consider as important is the way of organising "the proliferation of tools and techniques and methods" to involve patients and healthcare professionals in designing. What they propose is a framework to help in organising the tools and techniques to carry out participatory design research. Organising tools in participatory design, as Sanders et al. (2010) note, illustrates three dimensions: i) techniques of form; ii) purpose; and iii) context, of the research:

> Form: describes the kind of action that is taking place between the participants in an activity, and is described as making, telling and/or enacting.

> Purpose: describes why the tools and techniques are being used and is described along four dimensions:

1) for probing participants,

2) for priming participants in order to immerse them in the domain of interest,

3) to get a better understanding of their current experience or,

4) the generation of ideas or design concepts for the future, for instance by creating and exploring future scenarios.

Context: describes where and how the tools and techniques are used and is described along these four dimensions:

1) group size and composition,

2) face-to-face vs. on-line,

3) venue,

4) as well as stakeholder relationships.

(Sanders et al., 2010, p.196)

These dimensions of the practice show participatory design research shaped in a particular context, which places special emphasis on what Sanders et al. (2010) define in five key concepts:

Tools: the material components that are used in PD activities.

Toolkit: a collection of tools that are used in combination to serve a specific purpose.

Technique: technique describes how the tools and toolkits are put into action. For example, many different techniques can be used with a deck of image cards. They can be sorted, categorized, prioritized, used to make a collage, tell a story and/or used to spark conversations.

Method: a method is a combination of tools, toolkits, techniques and/or games that are strategically put together to address defined goals within the research plan.

Approach: the approach describes the overall mindset with which the research plan is to be conducted. (Sanders et al., 2010, p.196)

These concepts highlight design practices, using tools and techniques to engage people (making, telling and or enacting), with the aim to achieve a specific design purpose. This

framework leads to considerations of strategically assembling a combination of tools and techniques, when planning participatory design research, to address defined questions within the research. Moreover, using a framework seems to emphasise the notion of "infrastructuring" (Ehn, 2008). Rather than thinking of design research to involve a variety of phases (e.g., analysis, design, construction and implementation), it suggests "thinging", to see the "socio-material" orchestrated, or in other words "the performative 'staging' of it" (Bjögvinsson et al., 2012, p.104; Binder et al., 2011). As discussed in the previous chapter, "thinging" brings forth this idea of a journey involving social and material arrangements to deal with matters of concerns in time and place. This is a perspective with a focus on the process of design in time and space. In other words, this is planning, putting participation in action, and temporary experiencing.

Another motive for using such a framework is that it might allow me to plan the research at different times (present and future). This also allows me to access patients' temporary experiences and consequently obtain a diversity of information based on "what people say, do and make" (Sanders, 2001). In collecting a diversity of information, I might also obtain the generating of different levels of knowledge (Sleeswijk Visser et al., 2005) (see Figure 4.1).
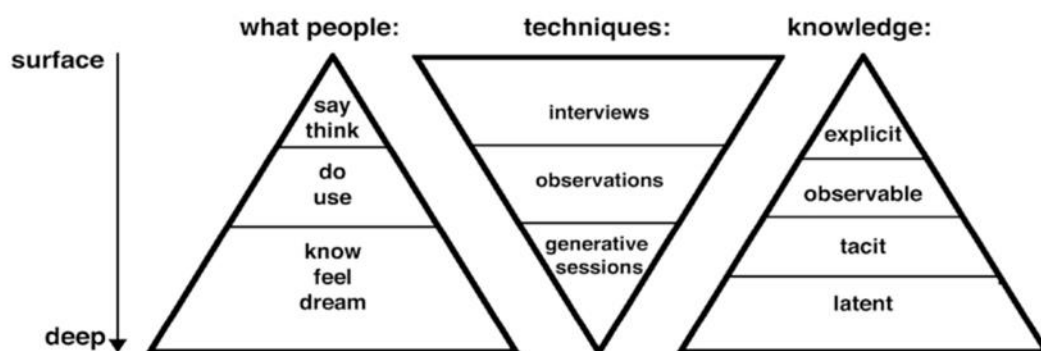
Figure 4.1 Different levels of knowledge about experience are accessed by different techniques (Source: Adapted from Sleeswijk Visser F., Stappers J. P. and Sanders E., 2005. Contextmapping: experiences from practice. *International Journal of CoCreation in Design and the Arts*, Vol.1, No, 2, pp1-30)

Figure 4.1 illustrates a framework in the context of user experience, which shows how design researchers access user experience, fundamentally, how they plan to engage people with different techniques to demonstrate different types of knowledge and how different knowledge allows them to understand user experience and consequently create a map of a particular context. By adapting this framework to the context of patient experience, I might be able to access patient experience. Collecting a diversity of information, as Sanders (2001, p.5) notes, is valuable to the design research. According to Sanders, "each research

phase can be informed by the previous phase". Research, involving different phases, is about linking one design situation after another design situation. From this perspective, I can build this research to understand the patient's mealtime experience, creating temporary design situations. Think, for example, how searching the present to deliver valuable paths can proceed with investigations into "desirable futures" (Krippendorff, 2006), or perhaps, how moving from explicit to latent knowledge can open up new avenues for knowing.

What this entails for this research is the need to emphasise an "infrastructuring" approach which pays attention to what tools and techniques are more appropriate to engage patients and healthcare professionals in temporary experiences, but also, how design, as a socialised and materialised space, can better elicit the patients' and healthcare professionals' voices. Therefore, infrastructuring fits in this view of eliciting multi-voicedness through a process of inquiry.

The importance of planning this design research needs to be emphasised through three approaches (see Figure 4.2). The first is an applied ethnography approach, in which I aim to engage healthcare professionals in dialogues as well as observe their work practices to gain a better understanding of the present situation at the patients' mealtime. In the second, a patient experience approach is employed, whereby I aim to engage patients in dialogues to gain an understanding of their current experiences at the mealtime; and in the third, a participatory workshop approach in which I intend to involve patients and healthcare professionals in two separate co-design dialogues to explore future possibilities. In what follows I will lay out in more detail what this means, reiterating the importance of connecting tools, techniques and people to open up the possibility for patients' participation in the design research process, in particular those affected by stroke.
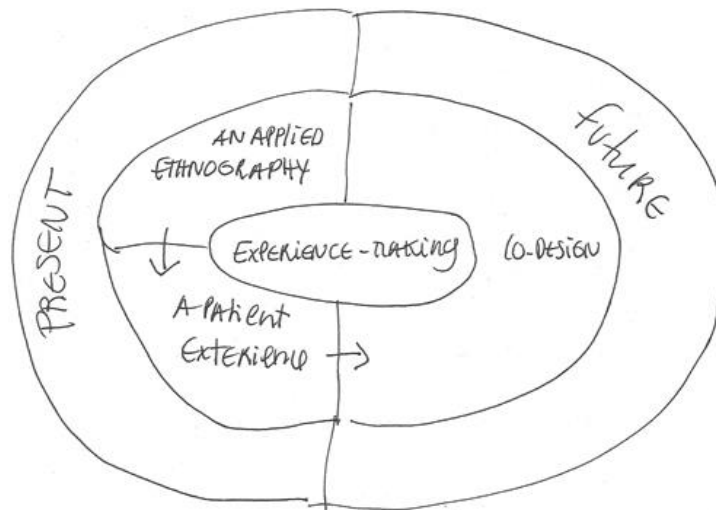
Figure 4.2 Design research through three approaches

4.5 Methods

4.5.1   An applied ethnography to investigate the existing situation

Understanding the existing situation will begin by inviting the healthcare professionals to talk about their work experiences while at the same time observing their work practices. Participatory design research advocates a strong emphasis on integrating ethnographic approaches at the beginning of the research (Binder et al., 2011a). Sanders (2002) suggests the use of ethnographic approaches to understand people's daily activities from multiple perspectives. According to Sanders, these multiple perspectives, listening to what people say while at the same time looking at what people do and use, can allow us to obtain a more comprehensive understanding of these activities. This understanding relies on combining interviews with observation methods.

Adopting such conceptualisation, the talking-watching, in the form of socio-material infrastructuring, is fundamental for effective investigation of existing experiences. By conducting observations, as Crouch and Pearce (2012) point out, I am able to collect detailed descriptions of what happens before, during and after an event. This might be useful to understand the patient experience at the present time, but also in the context of the mealtime, as a temporary patient experience in hospital. Sanders (2002) points out that notebooks, stills cameras and video cameras are useful tools to record events. In fact, as I will show in the next chapter, the video methods can be an issue within healthcare because people can feel uncomfortable with the idea of being later observed, in particular when the activity involves patients. According to Crouch and Pearce (2012), semi-structured

interviews are an important way to capture individual experiences and perspectives in narrative forms. Additionally, they suggested that interview transcripts could be useful tools to guide the dialogue (Crouch and Pearce, 2012). According to Sanders (2002), audio-recorders and notebooks can also be useful tools to record and take notes of the conversations.

From this view, an applied ethnography, as a starting point in this research, will enable me to provide a detailed description of the existing mealtime activity, which can be visually represented in the form of a storyboard (Martin and Hanington 2012). Storyboards, according to Martin and Hanington (2012), provide a visual narrative to communicate a sequence of stages, or in other words, the people's interactions, within their context and experience. A design situation created with an aim to deliver a storyboard might be useful to demonstrate what happens at the mealtime. Moreover, the use of a storyboard of the mealtime can be valuable to explore patient experiences with patients. I will argue that understanding patient experience might involve providing the current mealtime scenario. Building a scenario, as Truong et al. (2006) note, is not only to describe the details of people's interactions in a specific context, but also their emotions and motivations when experiencing the service. In what follows I will explain in more detail how to accomplish this aim.

4.5.2 A patient-experience approach to explore the current mealtime

Exploring mealtime experiences draws attention to adapting participatory design methods to accommodate the patients' needs in order to explore research questions. Participatory design has shown an increasing trend towards the use of probes as a means of exploring experiences. As Brandt et al. (2013, p.158) illustrate, researchers are "transforming questionnaires into delicately designed instruments for data collection that both expose the design agenda of the researchers and invite ambiguous and emotional responses from the informants". Probes are kits, which contain physical exercises or tasks with specific requests, for example, inviting people to record pictures using a disposable camera (Gaver et al., 1999). Moreover, Mattelmäki (2005) demonstrates that probes can be used in an interview (see Figure 4.3).

Figure 4.3 Using probes during an interview with a nurse
(Source: Mattelmäki , T. (2005). 'Applying probes-from inspirational notes to collaborative insights', *CoDesign: International Journal of CoCreation in Design and the Arts*, 1(2), pp.83-102)

In figure 4.3, Mattelmäki (2005, p.90) reported, "a nurse is explaining and interpreting the probes to the design team in an interview". What it seems to highlight here is that design probes can bring out voices in different "open-ended" ways. Using probes can promote a more dynamic interview, involving verbal and visual components. But perhaps more interesting is that involving visual components might stimulate participants to explain and clarify issues to the researcher. This seems to be useful for researchers in order to collect valuable information about the participants' views and experiences. What Mattelmäki (2006) points out, is that using probes can facilitate the participation of "users" in different situations. However, as I have been arguing, this research needs to support and facilitate the multi-stakeholders' participation, in particular, patients affected by stroke.

Practices with probes have presented design challenges within healthcare. Applying probes in the hospital setting, as Jääsko and Mattelmäki (2003) note, can be a challenge. They report: "hospital administrators were not sure how self-documenting in hospitals would affect the nurses' ability to concentrate on the care of their patients" (Jääsko and Mattelmäki, 2003, p 129). Although this previous work shows that probes might be useful for designers and researchers in order to collect valuable information about participants, this study demonstrates the conflicting issues of using probes within healthcare. Think, for example, how using probes with patients after stroke can discourage rather than encourage their participation due to the required physical effort needed to perform the requested tasks.

As I demonstrated previously in Chapter 2, the impact of stroke reveals that patients experience a number of difficulties in performing daily activities with a strong emphasis on the physical. Instead of using probes, I needed to select methods to support and engage the patients' participation in the dialogues. Semi-structured interviews, as I discussed earlier, are an important way to capture individual experiences (Crouch and Pearce, 2012). Hence,

conducting interviews with patients allowed me to create open dialogues in order to collect individual perspectives and stories without the need for demanding physical performance.

Additionally, Vertelney and Curtis (1990) point out that storyboards can be useful when they are used to develop scenarios (Vertelney and Curtis, 1990). From this perspective, by using a storyboard I can collect detailed descriptions of the current patients' mealtime experiences based on their emotional responses.

From this view, a patient-experience approach, as the second design activity of this research, involving a combination of methods to accommodate the patients' needs, seems to be a significant way to support and facilitate their participation. Adopting this approach perhaps highlights the idea that using a variety of methods in various combinations might support the participation of multi-voices, and especially those of patients.

Hence, I aimed to conduct interviews combined with tools, such as a storyboard, and techniques, to collect detailed individual information in order to provide a visual narrative of the current mealtime scenario for patient experience. Constructing scenarios, according to Carroll (1999), evokes reflections in the context of design. Additionally, this method allowed me to demonstrate a situation from multiple perspectives, involving the patients' and healthcare professionals' actions and experiences (Carroll, 1999). Most importantly, however, they can help to define "what happens next?" (Vertelney and Curtis, 1990, p.16) in order to change future situations (Koskinen et al., 2011).

4.5.3   Participatory workshops to explore design possibilities for the future

One way of exploring alternative possibilities for the future is to invite healthcare professionals and patients to participate in "the design collaboratorium" (Bødker and Buur, 2002), "co-design space" (Sanders and Westerlund, 2011) and "design laboratory" (Binder, 2007; Binder and Brandt, 2008; Binder et al., 2011b). These are concepts that suggest collaborative situations to explore new possibilities. The design collaboratorium, as Bødker and Buur (2002) pointed out, is at the same time a space and a process where tools and techniques are "orchestrated" to allow a number of participants' "voices" to collaborate and contribute to a productive outcome. A co-design space, as Sanders et al. (2011) note, is a socialised and materialised experience to explore, create and suggest future possibilities about the issue in discussion. According to Binder (2007, p.3), the design laboratory becomes "an opportunity for the partners involved to try out what could be accomplished in a collaboration spanning across organizational and community

boundaries". What it highlights here is the idea of the laboratory, which becomes these encounters, involving the social and material, as dialogues, to collaboratively envision new possibilities (Binder et al., 2011b). In other words, design collaboratorium, co-design spaces and or laboratories are participatory workshops used as a vehicle to explore design for change in desirable ways. However, participatory workshops to engage patients, as I argued earlier, require that attention is paid to adapting participatory design methods to better accommodate their needs.

Participatory workshops have been shown to be central to involve collaborative inquiries into "what is" and "what could be". Brandt (2006) points out that the way of formatting participative dialogues is through "design games", a process that assumes creating what Ehn (2008) calls "socio-material" activities with the aim of generating knowledge. According to Brandt (2006), this notion of a design game is about designing practices to elicit a dialogue within a specific purpose. Fundamentally, this is planning the performative design situation of "design-by-doing" and "design-by-playing" (Ehn 2008; Binder et al., 2011a; Bjögvinsson et al., 2012). Participatory workshops' "design games" within this idea of doing and or playing are considered to help in creating with the participants a common language, involving this familiar notion of practice as learning while doing or playing. But most importantly, it supports "creative moves in the shared design language games" (Binder et al., 2011a, p.164). Think, for example, in workshops to involve patients, how the designing of games needs to drive reflections on how better design games can accommodate the patients' needs in order to encourage and stimulate their participation.

Design games have been suggested to be an effective tool to facilitate participatory design (Brandt, 2006). From this perspective, structuring design activities through play, involving game pieces, game boards and rules for playing, can encourage people to express their thoughts meaningfully. These games are aimed at exploring design possibilities instead of putting an emphasis on people competing to win the game. In fact, as Brandt notes, these games aim to inspire and stimulate people's imaginations, which can create opportunities for participants to step outside of their usual habits to bring forth that which is unknown (Brandt, 2006). In adopting this idea of the design game, I can create workshops to involve both patients and healthcare professionals in a playfulness experience to explore alternative possibilities for the future patients' experiences at the mealtimes. Most importantly, however, a design game approach might evoke a sense of community as well

as a sense of being part of something important for the patients' and healthcare professionals' future experiences.

Furthermore, according to Brandt (2006), a "design game" is a tool to represent what participants are creating while playing. Think, for example, of a game where participants are placing cards on a game board. This act of placing a card can stimulate a collective meaningful discussion but also emphasises a common understanding of the issue.

Moreover, Brandt (2006) places attention on scenario-oriented design games, following Schön's (1983) views of constructing scenarios as a design move toward the restructuring of the existing situation. According to Carroll (1999), scenarios help to make design activities more accessible to the great variety of expertise as well as facilitating and supporting communication (Martin and Hanington, 2012), all elements that can contribute to design. Playing exploratory scenario games allows for the generating and exploring of ideas (Brandt, 2006). From this view of generating ideas, Sanders (2000) directs me towards generative tools. According to her, a landscape of visual and verbal components can evoke and provoke thoughts, feelings and ideas, but they also can encourage people to express tacit and latent needs (Brandt et al., 2013). Encouraging patients and healthcare professionals to express their tacit and latent needs can be valuable to understand what they expect, as a scenario, for their future mealtime experiences. Visual components, as Sanders (2000) notes, results in a design language created through artefacts, which assumes a variety of forms such as maps, collages and stories. I see the idea of using verbal and visual components as significant to conceive design games in this research. However, generative tools require different tools. In other words, this research demands that adaptations are made to these tools to make them appropriate within this context of social engagement, one which includes patients.

Design as a practice places a focus on physical embodiment in making or doing things. This focus can be on participants in performing tasks such as mapping, collaging and or modelling. As I mentioned earlier, for patients to perform physical tasks requires particular kinds of support due to the effects of their condition to enable and stimulate their participation. Hence I intend to conceive design games while acknowledging connectedness among tools, techniques and patients in order to accommodate their needs but, most importantly, to encourage and stimulate their participation to express their views about future ways of experiencing.

4.6 An illustrative path in participatory design research

Design research, as Krippendorff (2006, p.29) notes, needs to demonstrate "realistic paths from the present toward desirable futures and propose them to those who can bring a design to fruition". A realistic path, as Krippendorff points out, is design in presenting a transparent path, demonstrating how "stakeholders" were invited to participate and contribute to the design concerns of their worlds. Fundamentally, participatory design is about acknowledging the benefit of those who have experience in living and will come to live in these new future worlds. In this view, design concerns are centred on clearly demonstrating the paths to follow to move into a desirable future world, which calls for the gathering of insights among its expertise.

As I discussed earlier, this research aims precisely to posit a statement about the present in order to move towards exploring desirable future experiences. The path here is demonstrating how patients and healthcare professionals will be invited to participate but also involved in this research in order to proceed into a desirable world.

Participatory design research aims at involving people in design spaces, both socialised and materialised, in order to explore opportunities of the desirability. Additionally, it aims at generating new knowledge that is useful for other design researchers and designers on how the social-material space can be created to explore questions, delivering a purpose to "change something for the better".

This research considers patients and healthcare professionals to be the main experts in the mealtime experience in stroke rehabilitation. These experts have different roles at the mealtime; therefore, they can express a diversity of information in the socio-material spaces to support the design purposes for change. The National Institute for Health Research reports the importance of involving patients and healthcare professionals in what they call "the experience of someone who is using the service", not only to give them a "voice" but, most importantly, to provide opportunities for their knowledge and experience to influence the research to inform more efficient directions for their future experiences. For instance, they argue:

> *Patients [...] always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.* (INVOLVE, 2012, p.8)

The involvement of patients and healthcare professionals in this research study shares this line of thinking. By engaging patients and healthcare professionals in a variety of dialogues, I truly believe that they can provide new insights about the matters of concern in this research. But also, they can contribute to making this research not only credible, but also valuable and useful in the context of stroke rehabilitation. In doing so, this research highlights the view of a semantic turn for design as a paradigm shift which sees designs as proposals for artefacts, involving working within a network of stakeholders (Krippendorff, 2006). Extending the meaning of artefacts, as Krippendorff explained, can help to communicate with stakeholders and by sharing it through the multi-stakeholders, this can, in turn, help to share information. This perspective aspires to validate semantic claims, as Krippendorff (2006) points out, by demonstrating how representative these experts are and how incompatible concepts are resolved. Although I agree with Krippendorff, in that design research needs to demonstrate clearly these forms of expertise and that exposing patients' and healthcare professionals' experiences can contribute to the proposed design, I am reluctant to view this research as a tool to resolve incompatibilities. I cannot see the experts as distinct but instead view them as being connected on the matter discussed in this research. These connections must demonstrate their ways of arguing within the issues of concern in this research. As I will demonstrate in Chapter 5, this does not mean that the discourse is structured by rules, but demands that they discuss things in certain ways.

4.7   Analysing and interpreting the information collected

Analysing and interpreting the information collected within this research must demonstrate its generated insights through the debate in the context of design for patient experience. This is also, as I will demonstrate in Chapter 5, a process of organising the diversity of the information collected in such a way as to generate and contribute to new knowledge. In other words, this knowledge can highlight professionals' and individual's expectations for future experiences at the mealtime in stroke rehabilitation in hospital.

Participatory workshops, as Sleeswijk Visser et al. (2005) note, can produce a diversity of information in the form of artefacts, which people use to express their experiences and perspectives. They follow an approach of Grounded Theory to analyse information collected from participatory workshops. According to them, it can help to enable the discovery of potential indicators of a phenomenon during the analysis. However, the purpose of this research is to provide an opportunity to find voices and to recognise forms of expertise and experiences. In this way, the patients' and healthcare professionals' voices

can deliver a significant perspective for this particular design research. Hence, I do see the advantage of what Green and Thorogood (2004, p.184) indicated as a Framework Analysis approach, which is more prudent to preserve the integrity of the study participants' accounts rather than "fracture the information in order to open up avenues for analysis".

A Framework Analysis, as I will demonstrate in more detail in the next chapter, will be the focus of my analytical approach. The National Centre for Social Research suggests the use of a Framework Analysis approach to enable researchers to provide a more transparent and rigorous process of organising the information collected. This method is based on the idea of using a thematic framework to help in classifying and summarising the raw information. In other words, it will allow me to develop an analytical method to demonstrate the conceptual and analytical process. This analytical process, as I will describe in Chapter 5, presents different levels of analysis through distinct phases to obtain an overview of the information and, consequently, to make sense of the information in each phase (Ritchie and Lewis, 2003; Green and Thorogood 2004).

The context of design for user experience is a concept defined in participatory design research, a concept on which Sleeswijk Visser et al. (2005, p.3) note; "the way in which a product is used depends on its use and on a variety of factors in the environment". This is about investigating users' experiences in order to obtain a better understanding of their ideas, opinions, desires and aspirations to propose desirable futures (Mattelmäki, 2006; Dandavate et al., 1996; Sanders, 2001; Krippendorff, 2006). Knowledge about design for user experience shows, as I discussed in section 4.4, that design research practices use a diversity of methods to access different levels of understanding of the user experience (Sanders et al., 2010; Sleeswijk Visser et al., 2005). The knowledge gained through these different methods, as Sleeswijk Visser et al. (2005) point out, provides the point of departure on which to build an understanding of user experience, based on the present to move into a possible future, which can be useful to inform the design process into the development of new products or services.

The context of this research is design for patient experience with an aim to bring an understanding of the patient and healthcare professional experience which I see as relevant to illuminate ways on how design can improve the patient's experience at the mealtime in stroke rehabilitation in hospital. As Krippendorff (2006) states, to research experience requires the recognition of the "experts" of the matter in discussion, those who are very well informed and willing to act in support of the design development. My hope is that

making these connections and articulations will allow me to generate and make a new contribution to knowledge.

4.8 Summary

In summary, I have situated the research approach for this study within participatory design, which has emphasised the notion of design as being both socialised and materialised, aiming to design within time and space (see Figure 4.4). I have described how participatory design as a research method can be used to explore current experiences and to design for the enhancement of experience has previously drawn upon an infrastructuring approach to create temporary experiences. This has highlighted an approach to think about participation in a performative design situation. Here a framework has been discussed which allows design research practices to strategically plan a combination of patients, healthcare professionals, tools and techniques to address the research questions in discussion. This has also revealed that using multiple methods to collect data consequently creates different kinds of data for analysis and synthesis from which to derive knowledge. Lastly, in this chapter, I have also discussed the value of illustrating a transparent path that demonstrates how patients and healthcare professionals will be actively involved in the research. In relation to the design research delivery, the value of the results depends on to what extent the research has involved patients and healthcare professionals in temporary design situations and which elements participants have taken into account and how these results are connected to the concerns of the design research. The following chapter will present the study design conducted in collaborative research with the Stroke Rehabilitation Unit. In other words, it will show a rehearsal of my standpoint outlined in this chapter where I will discuss what I have done and why I did things the way I have done.
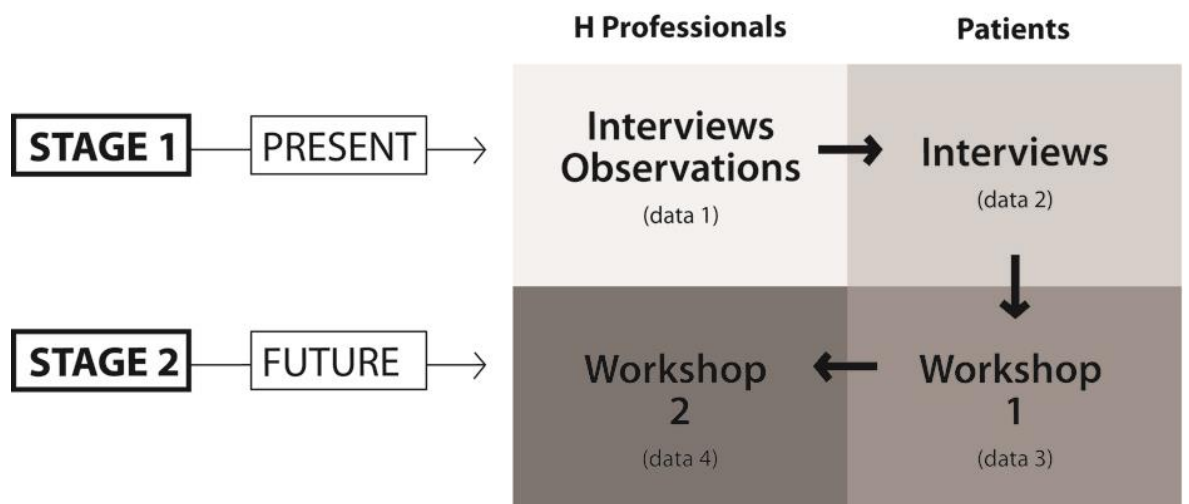
Figure 4.4 Methodology overview

5

Study design: Collaborative research with the Stroke Rehabilitation Unit

5.1 Introduction

The design research presented in this thesis entailed the collaboration of the Stroke Rehabilitation Unit. As I argued in Chapter 4, design for the enhancement of the mealtime experience is a matter of discussion with patients and healthcare professionals who are "experts" in the existing experiences. By bringing together different voices, positions and practices, I highlight contested experiences at the mealtime. This idea of "contested" voices can be seen as demonstrating different viewpoints (who speaks and with what knowledge and authority). Hence, this chapter discusses how the study design was conducted and conceived in the stroke rehabilitation unit context. The first part of this chapter reports on design challenges to conduct design research, involving healthcare organisations as collaborators. The second part illustrates practices of design research to conceive design situations to engage patients and healthcare professionals to investigate the mealtime experiences.

In the first part I describe my reasoning for involving patients and healthcare professionals within the healthcare organisation in this study to allow them to see the value of their collaborative participation. This involvement draws attention to the expertise required at the mealtime in stroke rehabilitation practices. However, I also emphasise the importance of observing an ethics application process which entails the approval of the Health Research Authority as an approach to legitimate participation. Most importantly, this is a mandatory process and unless one obtains ethical approval, work of this nature would not be permitted. Further, I describe how the study participants, patients and healthcare professionals are purposefully selected to the proposed study, a process which was completed by acknowledging that they are the real experts. I also describe how these experts, as a form of expertise and experience within the stroke rehabilitation unit, were invited to participate in the study. I point out that this research builds and attributes meaning to the practices of design research to engage healthcare organisations as collaborators with particular consideration for stroke rehabilitation care.

In the second part I describe how conducting participative design research with patients and healthcare professionals requires a relationship between predetermination of goals for data collection and dynamic aspects. I also report on how these goals were prepared for in each phase. Therefore, this is something that includes co-design processes which become complex and articulated (Manzini and Rizzo, 2011). Further, I show how applying a conceptual framework as the focus within the design research process allowed me to explore a diversity of insights about the mealtime experience. I will begin my arguments with a discussion on how adapting participatory design methods and developing a connectedness through design games (Brandt, 2006) can better involve patients and healthcare professionals but also, how it can also potentially reveal a different level of knowledge. I also describe how the data collected were analysed to illuminate the participants' voices, and also how I infrastructure each research phase by using the insights generated by the previous phase (Sanders, 2001). Finally, I illustrate how this research study is therefore a process of collecting a diversity of information as a way to generate "rich" insights about patient experience at the mealtimes.

5.2 Conducting the study

5.2.1 Study overview

In conducting this research study, I intended to begin with an understanding of the present in order to provide what Sanders (2001) calls "the scaffolds" to explore the future. The research study ran between December 2010 and December 2012 and had the collaboration of the Stroke Rehabilitation Unit in Scotland. The study aim was to explore the patients' mealtime experiences. Here I will focus on the design research process at work in assembling the participants. The assemblage of the participants included patients, healthcare professionals, tools and techniques, as I will demonstrate later.

The outcome of this research, as argued in Chapter 4, is a process, revealing spaces of interaction among participants. This process can not only be seen as a way to generate a variety of spaces to open up different ways of thinking and reflecting about mealtime experiences, but also as a platform to stand back from and explore patients' and healthcare professionals' experiences.

Hence, this study was conceived to progress through three phases of research exploration (see Figure 5.1). Such an approach involved the application of different techniques to collect different kinds of knowledge.
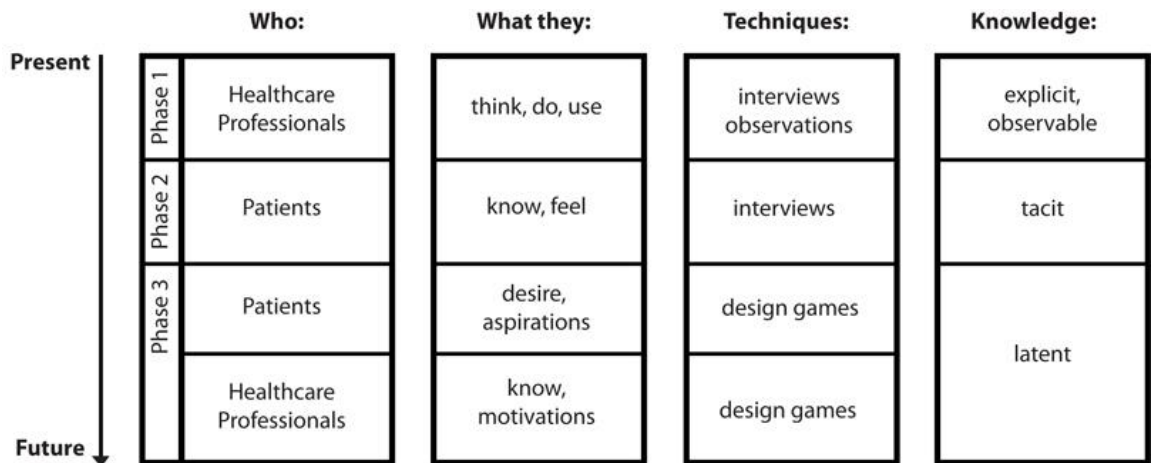
Figure 5.1 A framework to explore different levels of knowledge by involving participants in temporary experiences from the present to the future
(Source: Adapted from Sleeswijk Visser F., Stappers J. P. and Sanders E., 2005. Contextmapping: experiences from practice. *International Journal of CoCreation in Design and the Arts*, Vol.1, No, 2, pp1-30)

As I demonstrated previously in Chapter 4, participatory design research has contemplated the combination of methods relevant to generate valuable information in the context of user experience (Sleeswijk Visser et al., 2005). Here I intended to adapt this framework to the context of design for patient experience. Adapting it was not only to demonstrate what participants will do, but most importantly, identify who is going to do what. I also aimed to reveal different kinds of knowledge through different voices. For example, by placing a focus on healthcare professionals' voices to achieve explicit and observable knowledge and by placing a focus on patients' voices to achieve tacit knowledge, we can bring forth a deeper level of information instead of just surface information about the present.

In the first phase of the study (Phase 1), running between December 2010 and January 2011, I conducted an applied ethnography approach to begin the research. As I discussed in Chapter 4, this understanding relies on combining interviews and observations simultaneously in order to understand the existing situation from multiple perspectives (Sanders 2002). However, this design research process started from the standpoint that collecting a detailed description of what happens in the present situation would provide the foundation on which to build a storyboard of the mealtime, which I could then use to explore the patients' temporary experiences. This method reflects that the aim of intertwining interviews with observations was to enhance the quality of the storyboard. A further, more complementary approach for this research was to ensure the collection of a diversity of information while maintaining the achievement of explicit and observable knowledge as an outcome of this research process.

In the second phase of the study (Phase 2), running during the month of October 2012, I adopted a patient-experience approach to the data collection. In Chapter 4, I argued for the adaptation of participatory research methods, especially when considering how to better accommodate the patients' needs. This is, as will be demonstrated, also fundamental to my understanding of the practices of participatory design research within healthcare. The attempt here is to adapt these sources of inspiration (Mattelmäki, 2005; 2006) to understand the patients' experiences. At this point, the aim of the design research process was to collect a detailed description of what patients experienced at the mealtime in order to build a scenario. Constructing the current mealtime scenario allowed me to envision the structuring of a research process to explore the future (Vertelney and Curtis, 1990; Koskinen et al., 2011). Interviews, combining tools and techniques, were aimed at collecting detailed information from the patients to connect with initial information gathered from the healthcare professionals. In this way, I was not only building a scenario, but also accessing a diversity of information while benefiting from the achievement of tacit knowledge as an outcome of this research process. Tacit knowledge embodies what is being voiced and articulated. In other words, it is relevant here because it allowed me to obtain a better understanding of the patients' knowledge, revealing his/her perspective, and revealing their perceived feelings (Sanders and Dandavate, 1999; Sanders, 2001).

Afterwards, as explorations proceeded, I conducted the third phase of the study (Phase 3), running between November and December 2012, employing a participatory workshop approach. As I discussed in Chapter 4, this method relies on designing games (Brandt 2006) to be played in groups (Ehn 2008). In paying close attention to how to better engage patients, this was a design research process aimed at understanding the patients' and healthcare professionals' expectations for the future. A new scenario concept was thus provided from which I could draw design strategies for the improvements of the mealtime within stroke rehabilitation. Hence, I conducted two separate workshops as games. In the first I explored the patients' ideas for the future by evoking their desires and aspirations. In the second I explored the healthcare professionals' ideas for redesigning the future by provoking their motivations. This strategy reflects that the aim of exploring both patients and healthcare professionals' ideas was to ensure that the research process delivered what they all expect for their future (Krippendorff, 2006). The outcome of such a research process was to achieve latent knowledge. As I mentioned in the previous chapter, encouraging patients and healthcare professionals to express their latent needs can be

valuable to understand what they expect, as a scenario, for their future mealtime experiences.

I initially intended to develop this research study within a healthcare setting in both Scotland and Portugal, where I also established collaboration with a rehabilitation centre to conduct initial explorations at the mealtime (see Appendix B). However, collaborative design research within healthcare can be challenging in itself and there were high material constraints due to the heavy demands on my time spent gaining permission to take part in the research process within the National Health Service (NHS). Therefore, developing a study in both countries became an issue of time and did not fit within the schedule allowed for a PhD study. Also, the study within the single site had sufficient scope and access to patients and staff to test my approach and to ensure the integrity of my study. In what follows, I will demonstrate the design research practices necessary to establish collaborative research within healthcare.

5.2.2 Study within the National Health Service ethical approval system

In this study, I will demonstrate the importance of making design proposals in order to make sense of design research so as to invite and ultimately inspire health organisations to engage and collaborate with it. Perhaps more interesting is how this research, as a collaborative approach, demonstrates a meaningful relationship between design and healthcare communities. Think, for example, about design research for doing things in appropriate ways; this, in turn, will establish a respectable appreciation by doing these things. When the study intentions envisioned the value of the patients' and healthcare professionals' participation to change the mealtime experiences for the better in stroke rehabilitation, it drew attention to ethical, practical and potentially political issues in the research process (Krippendorff 2006). According to Krippendorff, these are significant issues "to bring a design to fruition" but also to assure that research increases its reliability (Krippendorff, 2006, p.75).

In applying for ethical approval, I developed two research proposals in two stages (see Figure 5.2). The first stage involved a proposal to obtain permission to conduct the first phase of this research. Here I met with the Manager for the Managed Clinical Network team (hereafter I will use the term "Stroke Manager") at the stroke rehabilitation unit in hospital to present the study aims. The second stage involved writing a proposal to obtain permission to conduct the second and third phases of this research. I also began to present the study aims to the Glasgow School of Art (GSA) Research Ethics Committee where I

was advised to develop an ethics application via the Integrated Research Application System (IRAS) to obtain the permission of the Health Research Authority (see Appendix C) to conduct the research.
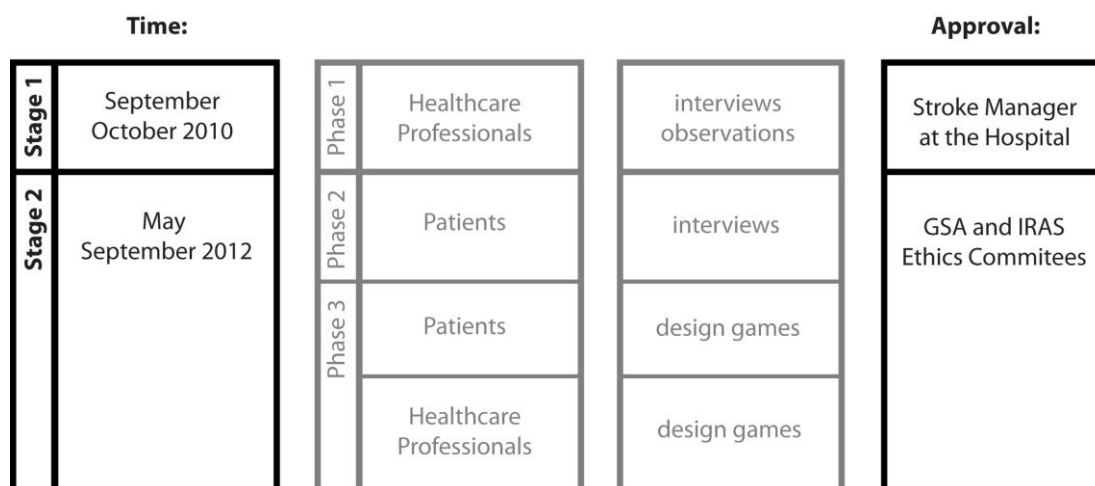
Figure 5.2 The study within the National Health Service for ethical approval.

The first study proposal to be approved, running between September and October 2010, planned to conduct a set of interviews with healthcare professionals and with myself also observing the mealtime workplaces in hospital. The proposal described the intended action plans to conduct the study in giving voice to the healthcare professionals. For example, I described my intention to obtain a consent form from the healthcare professionals to ensure adherence to ethical issues of anonymity and confidentiality of the information reported through this study. Thus, this design research took place not only in a performative situation but also in an administrative process within an ethical and humanitarian process whose interests were to safeguard individuals involved in research.

The second study proposal to be approved, running between May and September 2012, planned a set of interviews with patients and also to develop two separate workshops; the first with patients, and the second with healthcare professionals. The proposal described the intended actions plans to conduct each study. As part of the approval process, I was required to complete three NHS forms (see Appendix D), involving an ethics application via IRAS. Here I provided a more detailed description of the study aims, methods and hypotheses in order to secure the Health Research Authority approval by the Research Ethics Committee (REC) and NHS Lanarkshire Research and Development (R&D).

The design challenge was, however, not only a question of making design proposals, but also to navigate in the NHS system. Completing an ethical application via IRAS was not a question of completing forms, but of understanding a medical language, possibly by following the governance requirements of community care research in the UK. I had to understand this language in order to make constructive proposals that made sense to the healthcare community. In other words, the ethics application procedures revealed a design process facing the challenges of language games in participation (Binder et al., 2011a). Understanding the medical language was not only a question of discussing issues with my supervisors but of following advice from the GSA research ethics coordinator, a researcher colleague in the field of healthcare and the Stroke Manager. Prior to the ethics application, I also presented the study at an NHS Lanarkshire (R&D) meeting in order to receive their feedback and advice. This is a design practice that shows what multi-stakeholders means in this research and how giving patients and healthcare professionals a voice requires that design participates in a specific language game; the medical one (Binder et al., 2011a; Ehn, 2008). In doing so, I became familiar with this medical "game" by doing things as a form of inquiry.

So far, I have discussed the study within the ethical approval system, involving practical but also political issues in developing and presenting study proposals. But perhaps more interesting is that these design proposals were making sense of and potentially motivating the healthcare community to support and collaborate with design research. In other words, it shows design research in developing strategies that allow people's participation, and consequently, legitimises their participation (Binder et al., 2011a; Bjögvinsson et al., 2012). In this situation, what Krippendorff (2006, p.74) says is that "the more stakeholders have a hand in a design, the more likely will it come to be". Fundamentally, this perspective underlines the discussion in the previous chapter about infrastructuring, alignment, rules and ordering that sees design research as a process which has to be organised and managed. Involving stakeholders shows relevance in design research. What seems to be significant here is to identify in more detail the stakeholders involved in this research. In what follows I will discuss who the stakeholders are in this research study.

5.2.3   Selecting participants

By exploring mealtime experiences I intended to engage the experts of the mealtime; the healthcare professionals and the patients. Involving the healthcare professionals and the patients was a means to recognise different roles, such as who plans and treats and who

receives and experiences. The healthcare professionals, as I will demonstrate in Chapter 6, comprise characteristics to provide healthcare. Fundamentally, they bring not only experiences of work practices in stroke rehabilitation but also different responsibilities to the patient experience at the mealtime as a whole. From a different view, the patients, as I will show in Chapter 7, receive post-stroke rehabilitation in hospital. Receiving temporary rehabilitation in hospital demonstrates not only that patients with specific health conditions have eating difficulties, but that the individual nature of the condition generates personal perspectives and experiences of the mealtime. As I discussed in Chapter 4, this research was concerned with how illustrative the experts are to demonstrate these forms of expertise and experiences (Krippendorff, 2006). From this perspective, by highlighting expertise and experiences, I intended to demonstrate a research study with a focus on qualitative rather than quantitative representations. In other words, the basis of selection was on the key characteristics of the specific population being studied (Ritchie and Lewis 2003). The following diagrams demonstrate how the patient and healthcare professional participants were selected following the study criteria for inclusion and exclusion.

Inclusion | Exclusion

Inclusion	Exclusion
Clinical diagnosis of stroke	Severe visual or cognitive problems precluding participation study
Post-acute stroke rehabilitation in hospital	Involved in another research study
Of either gender	
Age > 25 years	
Have English as a first language	
Had swallowing difficulty in acute rehabilitation	
Had care assistance during mealtimes in acute rehabilitation	
Able to understand and follow simple instructions	
Able to give informed consent when assisted to do so with suitable communication aids if required	

Figure 5.3 The inclusion and exclusion criteria when selecting the patients as participants.

I envisioned that inviting a minimum of six patients should be a large enough sample to capture the types of sources of information that the study needed, which were their experiences and ideas. The patients included in this study were day patients who went home after treatment in hospital. They had a clinical diagnosis of stroke. They experienced the mealtime element of stroke rehabilitation in their stay in hospital for a certain period of time. Each patient involved in this study presented different stroke-related impacts at the mealtimes when they were in hospital, as described in Chapter 7. Involving a diversity of patients in this study was an appropriate way to generate rich and diverse insights about

human experience. Patients in this study represented both genders with varying ages, but none was less than 25 years.

Inclusion | Exclusion

Inclusion	Exclusion
Clinical rehabilitation professionals	Involved in another research study
Have English as a first language	
Have involvement with stroke rehabilitation at mealtime	
Have represented a specific role at mealtimes	
A nurse	
A speech therapist	
An occupational therapist	
A dietitian	

Figure 5.4 The inclusion and exclusion criteria when selecting the healthcare professionals as participants.

I imagined that involving the four healthcare professionals, those who represent the multidisciplinary team involved with stroke care – a nurse, a speech therapist, an occupational therapist and a dietician – should be enough to capture the types of sources of information which the study needed, which were their experiences and ideas. Healthcare professionals included those who were working specifically in clinical rehabilitation practices, in particular those who were engaged in regular contact at the mealtime. Each healthcare professional in this study had a specific role to conduct at the mealtime, as described in Chapter 6. What I envisage here is a view of the mealtime as "granularity", revealing different parts or "grains" as a form of experience.

5.2.4   Inviting participants

Inviting patients and healthcare professionals was achieved through the support of the Stroke Manager, who represented the "gate-keeper" to meeting participants (see Figure 5.5). This diagram shows research developments taking place through the collaboration of those who know others (Krippendorff, 2006). Here, inviting participants involved a set of meetings. Before I met healthcare professionals and patients, I met with the Stroke Manager. Hence, meeting the Stroke Manager was carried out in the first instance. Let me now demonstrate how healthcare professionals and patients were therefore invited to participate in the study.
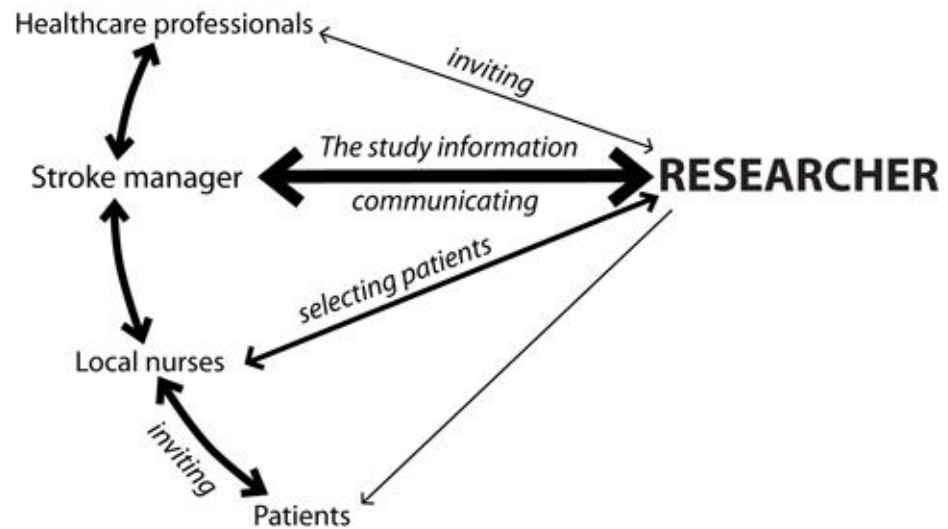
Figure 5.5 Inviting participants within a set of meetings.

The healthcare professionals

As already mentioned, the first meeting was with the Stroke Manager. Here we discussed the study where I revealed the criteria for healthcare professionals' participation (see Figure 5.6). After we met, she, on my behalf, discussed the study first-hand with healthcare professionals and collected their informed decision on whether they were to participate or not. Afterwards, I was informed who the potential participants were. The second meeting was with healthcare professionals in the hospital. Here we clarified issues about the study, as I discussed earlier as Phase 1, and defined a schedule to begin the interviews. This was arranged and agreed with each healthcare professional who wished to participate. Then we met to develop the study. Later, we met to clarify issues about the study, as discussed earlier as Phase 2, and a schedule for me to conduct a workshop was arranged and agreed with all healthcare professionals who wished to participate. These meetings were significant because they allowed me to personally express to the healthcare professionals how I considered their participation to be invaluable to this research. These meetings took place over the period of seven months. Healthcare professionals tend to have busy schedules and it is often difficult to find time to meet with them, but I still think that these meetings were fundamental to the concerns of this research.
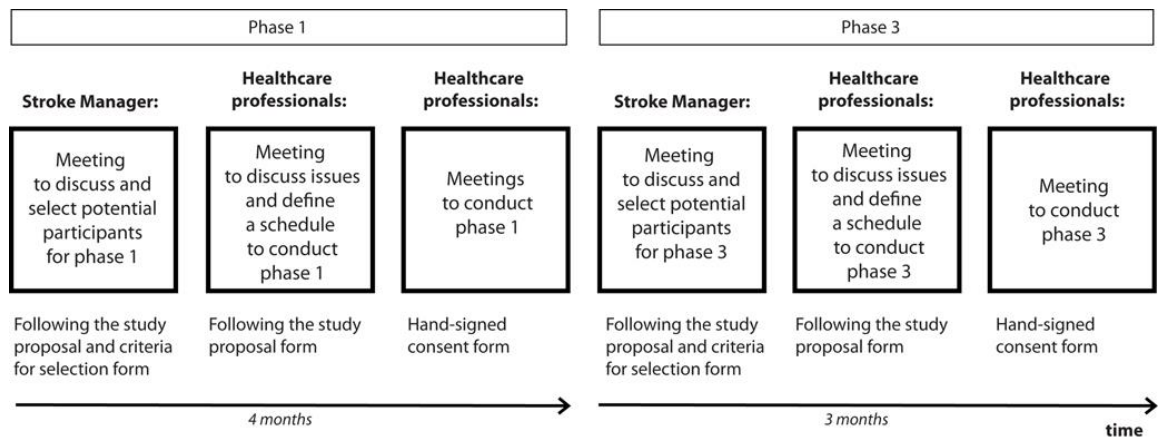
Figure 5.6 Healthcare professionals' invitation process.

The patients

In inviting the patients (see Figure 5.7) I was involved in a different way. The first meeting was with the Stroke Manager. At this time we discussed the involvement of patients in the study and I revealed the criteria for their participation, as mentioned earlier. After we met, she, on my behalf, discussed the study first-hand with the local nurses at the stroke rehabilitation unit in hospital. Local nurses were those who support patients in their own homes after discharge from hospital. Afterwards, I was informed to contact the local nurses. The second meeting took place with the local nurses in the hospital. Here I clarified issues, as discussed in the outline of Phases 2 and 3, and discussed the study criteria for the eligibility of patients to take part in the research, as I discussed previously in section 5.2.3. Before I met the patients, the local nurses discussed the study first-hand with the patients and their relatives on my behalf and collected their informed decision on whether to participate or not. Afterwards, the local nurses contacted me to meet them in the hospital. The third meeting with the local nurses was to let me know who the potential participants were. Here we arranged a schedule to conduct the study with the patients. The fourth meeting was with patients in their own homes before I began the interviews. At those visits, I clarified what they would be expected to contribute to the study and responded to any issues they may have had. I asked if they were happy to continue and made sure that they were relaxed and comfortable. Patients post-stroke tend to feel tired; therefore, the importance of making them feel comfortable was essential. At the end of each interview I invited each patient interviewed to participate in a workshop.
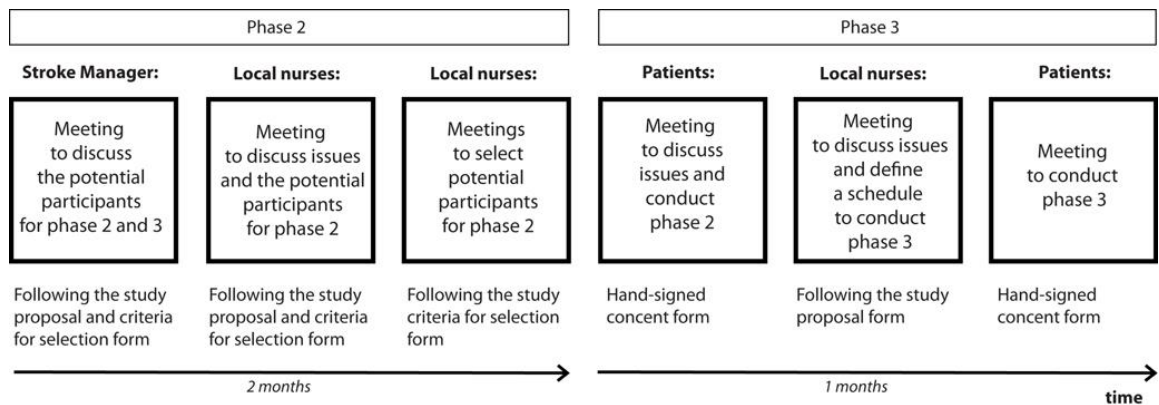
Figure 5.7 Patients' invitation process.

Inviting patients to participate in the workshop was challenging, with one patient in particular. When I was discussing the study with his patient and his family, I wished to video-record the workshop. At this point, the relatives demonstrated their concerns with allowing the patient to participate in this way. Here I mentioned my total understanding about their concerns. Fundamentally, I explained in more detail the process of ensuring the confidentiality of each patient. I also added that my intention to video-record the workshop was solely for the purpose of study analysis rather than to report the video-recorded data. However, I still felt the need to invite the relatives to attend to the workshop in order to demonstrate to them the great value of patients' participation in the study. The local nurse, who attended to the interview, also said that she would attend the workshop to support patients if needed. I perceived that inviting patients' relatives would make sense in this research. But most importantly, I understood that the collaboration of the local nurses assured trust, which in turn might stimulate the patients' relatives to feel more comfortable in letting the patient participate. Although some relatives attended the workshop, as discussed in Chapter 8, they did not participate in the dialogue.

These meetings took place over a period of three months, but inviting patients could not be realised in any other way. The local nurses know their patients and their advice and input in the recruitment process was invaluable. Furthermore, participation of those who really matter might enhance the acceptability of the design research proposals (Krippendorff, 2006). I will now discuss how I conducted this study in order to bring patients and healthcare professionals' participation in the design research process by looking further into how I designed the research process to involve these participants.

5.3 Designing the study

5.3.1 Phase 1: Exploring the existing mealtime situation with healthcare professionals

Initial explorations began by obtaining an understanding of the mealtime from the healthcare professionals' perspectives through their experiences of their work practices, for example, planning, preparing and delivering the patients' meals in their day-to-day activities at the stroke rehabilitation unit in hospital. In fact, as I will show in Chapter 6, these explorations would acknowledge that it is the research process that generated insights as a starting point in this research (Sanders, 2002; Binder et al., 2011a). As I mentioned earlier, this was a research process that involved intertwining interviews with observations (see Figure 5.8). By saying that interviews intertwined with observations, I mean that through the interview process observations were conducted in order to understand and clarify issues. With such an approach, I was collecting a diversity of information. This process can be seen as dialogues providing information to enhance the quality of the storyboard, rather than thinking of it simply as a process of listening while at the same time watching (Sanders 2002). It was a more sequential process, which used communication to understand things and then observing these things in order to clarify things in practice. Here I will demonstrate two designed spaces of interaction among participants when interviews and observations were conducted. With interviews, I attempted to open up a dialogue with healthcare professionals in order to understand the mealtime. With observations, I aimed to participate, as a visitor, in the context of the mealtime practice in order to add information for my early understanding with healthcare professionals. In what follows I will lay out in more detail how these two spaces of interaction were designed, with the important point of building a storyboard of the mealtime.

Figure 5.8 Intertwining interviews with observations.

Interviews

Let me now explain the designed space of interviewing used at the time. Using semi-structured interviews I could capture the individual experiences and perspectives (Crouch

and Pearce, 2012) of the participants while thinking, for example, of the mealtime in stroke rehabilitation. This method has been understood to involve a multidisciplinary approach, as I demonstrated in Chapter 2, but this could also be understood to encompass a specific role as it does in work practices. But perhaps more interesting is the experiences of these different roles at the mealtime. Here interviews were spaces to open up individual dialogues to bring forth different experiences such as those of a nurse, a speech therapist, an occupational therapist and a dietician. This form of dialogue was created within a topic guide, as a communication tool (see Appendix E). Designing the topic guide emerged as being an effective way to dynamically support the dialogue to stimulate healthcare professionals to explain and clarify issues, revealing verbal and visual components (see Figure 5.9). In this way I envisioned that I could collect valuable information. Verbal components were a set of open-ended questions to explore different issues of stroke: impacts, pathway and mealtime. In exploring some of these issues, I combined both verbal and visual components. Here the form of dialogue was to introduce a topic guide to open up different ways for healthcare professionals to express their experiences, but a topic guide for recording experiences in words and pictures. For example, I explored mealtime aspects such as the texture-modified food, prompting a question while at the same time showing a graphic which illustrated the scale of the texture-modified food (see Figure 5.10). The possibilities to explore issues through this graphic were envisioned in a variety of ways such as what type of food might patients eat and how patients' likes and dislikes about food are take into account, to collect and bring forth a diversity of information.
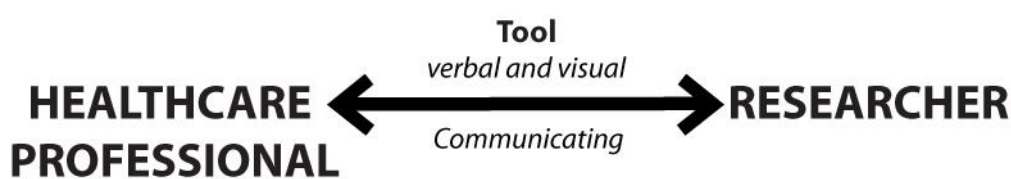
Figure 5.9 The topic guide acting as a communication tool when interviews were conducted with healthcare professionals.

Is this how you see the texture of food for patients with stroke? If not, how would you explain this?
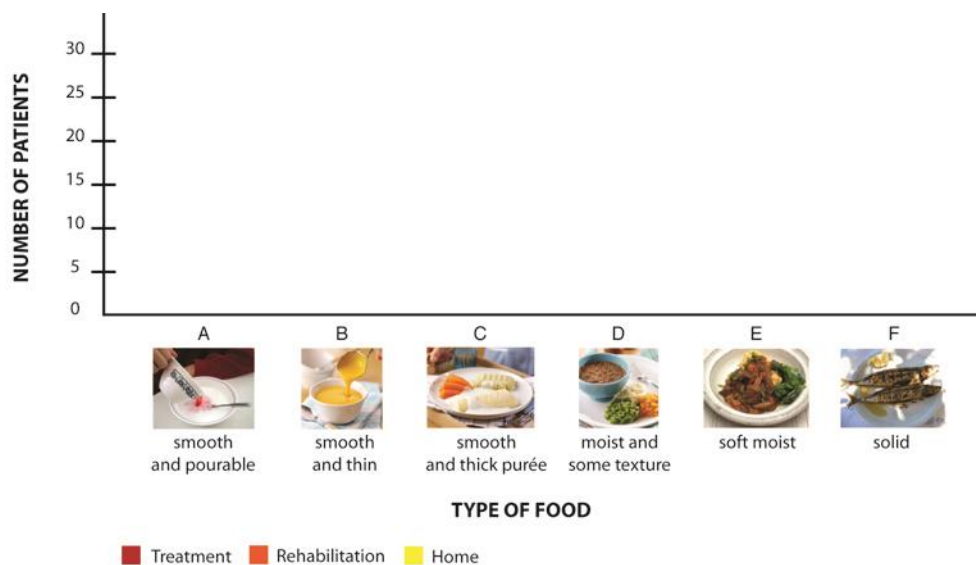
Figure 5.10 Combining verbal and visual components when interviews were conducted with healthcare professionals.

This form of dialogue, involving verbal and visual components, created a variety of possibilities to discuss issues in certain ways and across different ways. In this situation, I was potentially providing opportunities to clarify issues from my initial understanding through the stroke contextual review, as I demonstrated in Chapter 2.

Furthermore, this process explored how this topic guide, as an object of design, was designed to be used and how these visual and verbal components were conceived to be experienced in the space of interaction. For example, it included a set of graphics and prompt questions (see Figure 5.11). Typically, this process involved me prompting the questions and placing the pictures on the table, as a form of inviting healthcare professionals to express their views. Here sketches and notes were taken with healthcare professionals as a public thing to be clarified through our conversation. More specifically, the process was creating a dynamic conversation to enable active expression through pictures and questions. Our dialogue was audio-recorded.

Figure 5.11 Tools used to support communication and collect information when interviews were conducted with healthcare professionals.

Observations

Rather than thinking of myself engaged as a participant, for example, I could take part in the actual work practices at the mealtime such as preparing meals for the patients, I intended to be a visitor "participant" to capture what was going on at the time and place. Hence, observations were a focus only on my experiences when observing healthcare practices. I considered the idea of observing, providing the opportunity to access different but also complementary information to add to my collection from interviews with healthcare professionals. In fact, this method can be seen as an attempt to ensure a collection of detailed information. For example, after I interviewed the nurse I observed the central kitchen in the hospital, which allowed me to better understand the meals that were prepared and delivered every day for patients. This allowed possibilities to explore and to clarify issues discussed during the interview with the nurse that were envisioned into ways such as observing the appearance of the texture-modified food, for adding information. This also allowed the opportunity to explore these "observations" in the following interviews when I spoke with the dietician and so on. In doing this, I was able to relate to the collected information.

Before starting the observations, I discussed my intended plans first-hand with healthcare professionals in order to obtain their permission. The purpose of this meeting was to ensure that the study was appropriate. Here observations were performed during the mealtime service, during the preparing and delivering of food, in different places and times in the hospital. Most importantly, I looked at the stroke patients' mealtimes.

Hence, observations took place in the central kitchen at the time of preparing meals and in the ward at the time of delivering and receiving meals at lunchtime. Observations were envisioned to be reflective situations about things that were happening at the time. In doing so, I was sketching, writing, and, at some points, taking photographs (see Figure 5.12). This observation process was designed to use a notebook and a digital camera, as collectors' tools (see Figure 5.13). For example, during my observations in the ward setting, looking at the healthcare professionals' experiences in plating and delivering the patients' meals, I used the notebook to illustrate this temporal experience in this context. A digital camera had a specific purpose, collecting food appearance and the products used to prepare food rather than capturing human actions and/or interactions in their work experiences.

Figure 5.12 A diagram of the form of observation through a notebook and a digital camera when observations were conducted in the kitchen and the ward environment in hospital.

Figure 5.13 Tools used to collect visual information when observations were performed at the mealtime workplaces.

With such conceptualisation, the watching-illustrating, in a more active involvement and expression, I envisioned providing generative insights of the existing situation. By conducting observations in these ways, I imagined that I would be able to illustrate what happened before, during and after the mealtime (Crouch and Pearce, 2012), as I will demonstrate in Chapter 6.

Furthermore, with the idea of participating as a visitor, I paid special attention to my role in the study. For example, I was guided by a cook, when observing the kitchen, who showed me how food was prepared day-to-day. Naturally, issues emerged; I asked the cook to show and explain things to me in order to clarify my understanding. In the ward context, I was by myself. The corridors were important places to perform observations; this was the point of arrival and departure of the patients' meals. Corridors allowed me to watch patients waiting, receiving and eating in their rooms. A stranger sharing the same place could potentially create discomfort for them (Perry and McLaren, 2003), but perhaps more importantly was that by observing from outside their rooms I could more naturally capture their experiences.

5.3.2 Phase 2: Exploring the patients' experiences

In Phase 1, I aimed to obtain an understanding of the mealtime from the healthcare professionals' experiences. As the investigations proceeded, I intended to gain a better understanding of the patients' experiences at the mealtimes when they were temporarily recovering from their stroke at the stroke rehabilitation unit in hospital. As I argued in Chapter 4, it was acknowledged that this is a research process that brings forth both the patients' and the professionals' experiences as the way to build an understanding of the current mealtime scenario (Carroll, 1999). Here I will demonstrate a design research

process focused on exploring the patients' experiences in order to capture their emotions and motivations when experiencing the mealtime (Truong et al., 2006). This design situation involved interviews, combining tools and techniques (see Figure 5.14). By saying that interviews combined tools and techniques, I mean that the interview was conducted to provide a space of interaction in which to collect the patients' stories of their mealtime experiences. With such an approach, I envisioned collecting detailed and individual information rather than thinking of it as a design situation that required physical embodiment to perform tasks such as self-documenting thoughts (Mattelmäki, 2006). It was more like storytelling to engage, encourage and support patients to tell what the experience was like. First, however, I will provide a note on the techniques and tools used in the research process to build the scenario of the current mealtime.
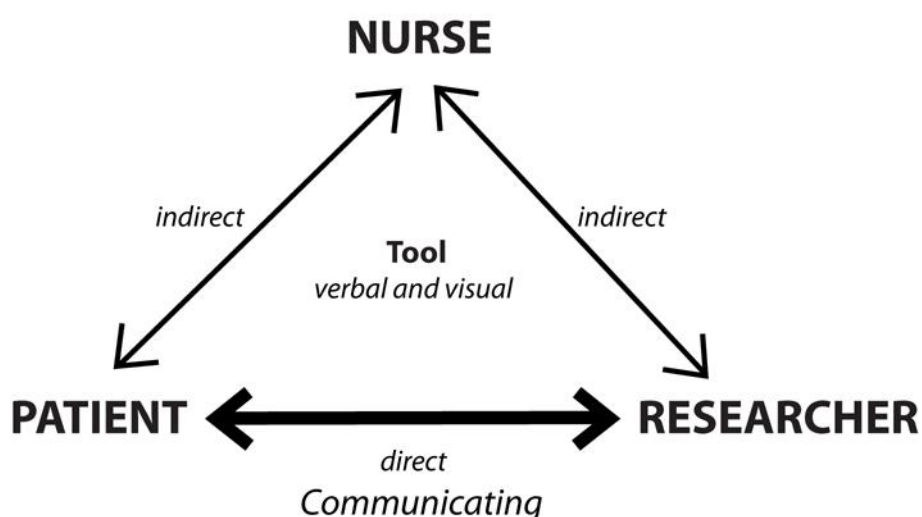
Figure 5.14 Interviews combining a tool and a technique.

Interviews

In designing the study, I paid special attention to the conception of tools to support and encourage the patients' participation. To explore the patients' experiences I used semi-structured interviews to capture personal stories (Crouch and Pearce, 2012). This method allowed me to think of the mealtime as an event in sequential order, which I have understood as connecting a diversity of experience aspects, as I will demonstrate in Chapter 7. More specifically is the experiences of these personal views of living the mealtime. Here, using interviews involved combining a tool and a technique to create individual dialogues to bring personal experiences. Hence, I created a topic guide as a communication tool (see Appendix F).

This topic guide, revealing verbal and visual components, emerged to support the dialogue with patients. Verbal components were a set of open-ended questions to explore different experiential aspects: sensorial, physical, social and emotional response. Visual components were a set of pictures to explore different mealtime stages: before, during and after. As I discussed in Chapter 4, I structured each research phase informed by the previous phase (Sanders, 2001). Using the mealtime storyboard, generated in Phase 1, I envisaged that it could be useful to explore experiences in a sequence of mealtime stages (Martin and Hanington 2012).

The mealtime storyboard

Here I paid special attention to the visual narrative in order to support patients' understanding and invite them into a dialogue. Therefore, I represented the three mealtime experience stages that I will refer in to in this thesis (see Figure 5.15).

> *Before* – when the patient is waiting for his/her food.

> *During* – when the patient is receiving food and eating.

> *After* – when the patient has finished his/her food.
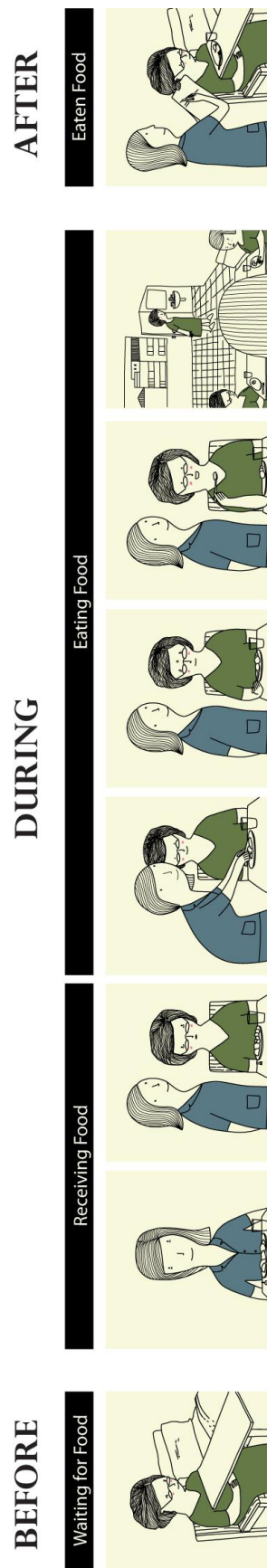
Figure 5.15 The mealtime stages acting as a visual component when interviews were conducted with patients.

A combination of verbal and visual components was conceived as a form of dialogue to open up ways of allowing patients to express their experiences. In this way, I imagined that I could collect detailed descriptions for each mealtime stage. For example, I explored the stage before the meal arrived using a picture and simultaneously prompting a question (see Figure 5.16).

Is this similar to the ward environment you were in, in hospital? If not, how would you describe this?

Figure 5.16 **Combining verbal and visual components to open up a dialogue when interviews were conducted with patients.**

Prompt questions were created through a conceptual framework (see Figure 5.17). In creating a framework, I conceived that this could be useful (Sanders et al., 2010) to explore experience aspects at the mealtimes. The possibilities to explore experiential aspects through prompt questions could possibly help in the collection of a variety of information. The collection of different information is valuable (Sanders, 2001; Sleeswijk Visser et al., 2005) and could enable to gain better understanding of the patient experience at the mealtime.

The conceptual framework

The concepts that I used to describe the application of the framework have come from my early understanding of design for user experience and of the mealtime for customer experience, as I demonstrated in Chapter 3. Therefore, I considered four inter-related key concepts at the mealtime as a patient experience that I will refer to in this thesis. They are:

Sensorial – the sights, smells and sounds that are perceived.

Physical – describes how patients, space and objects interact with one another. For example, physical aspects can be experienced with healthcare professionals delivering meals. They can be cutting and feeding to help a patient eat.

Social – describes the sociability with which the patient is involved. For example, social aspects can be experienced with patients talking with others.

Emotional – the thoughts that come into the patient's mind when experiencing.
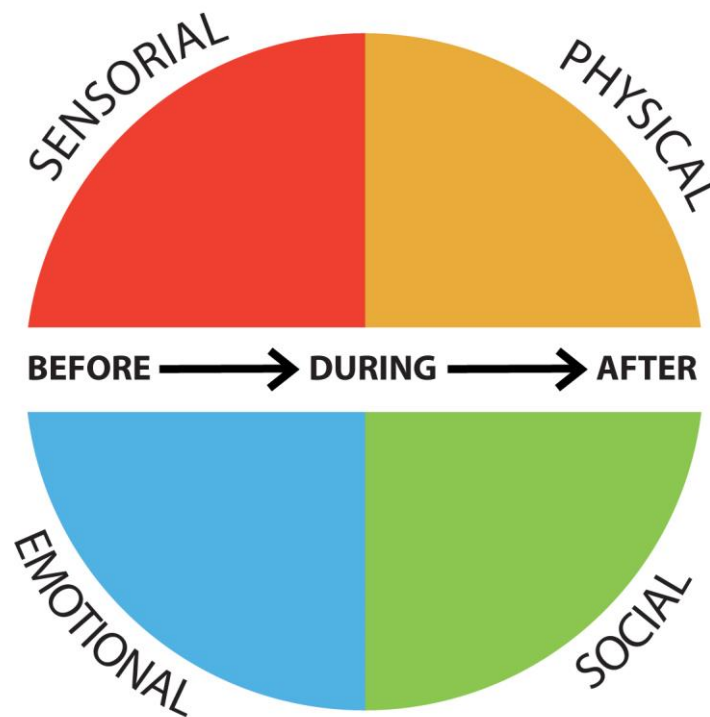
Figure 5.17 The conceptual framework acting as a verbal component for verbal prompting when interviews were conducted with patients.

This diagram illustrates a conceptual framework in the context of patient experience at the mealtime, which shows sensorial, physical, social and emotional as key concepts involved throughout the mealtime stages. In other words, it shows a conceptualisation of the four inter-related key concepts with the mealtime storyboard. Here, I was concerned with the best techniques to apply to put the topic guide into action. In a meeting with the local nurses of the stroke rehabilitation unit, when they revealed who the participants were, we

discussed the idea of creating opportunities during the dialogue to verbalise and clarify issues. As I will demonstrate in Chapter 7, stroke patients can present a range of challenges, not only physically, but also that their ability to speak and understand can be affected to different degrees. The aim of involving a nurse in this dialogue was for a specific role: assistance in helping patients' verbalising. Verbalising is an important component because it gives a voice to the patient's experience. This voice is historical (e.g. "I had a stroke") and professional. Nurses, as I already mentioned, know their patients. The idea of the process linked with artefacts makes this happen. In this way, I was potentially facilitating patients' participation while also providing opportunities to enhance the quality of the collection of stories.

One limitation of this form of dialogue as conceptualised here could be the identifiable nurse. The design research process was laid out to create the opportunity for patients to express their views. By involving a healthcare professional I envisioned that it could inhibit the patients to being open with their views. The patients were still being involved in rehabilitation care where trust becomes expected. Does this mean that the idea of designing tools to better involve patients' participation and the envisioning of techniques to support their participation can limit their voices?

Using this topic guide, an object of design, I envisioned how these visual and verbal components were made to be experienced throughout the dialogue. For example, it included a set of pictures and prompt questions (see Figure 5.18). Naturally, this involved me prompting the questions and placing the pictures on the table as a form of inviting patients to express their views. Here the pictures were made public to patients to be clarified through our conversation. More specifically, it was creating a dynamic conversation through pictures and questions. Furthermore, the nurse was often verbalising what patient and/or I said in order to clarify what was said from me to the patient and vice versa. Our dialogue was also audio-recorded.

Figure 5.18 Tools used to support communication and collect information when interviews were conducted with patients.

5.3.3 Phase 3: Exploring future possibilities with patients and healthcare professionals

In the previous Phases, 1 and 2, I intended to build up a picture of the current mealtime scenario, including both the healthcare professionals' and the patients' experiences. Constructing the current mealtime scenario helped to infrastructure investigations in order to explore alternatives for the future situation (Vertelney and Curtis, 1990; Koskinen et al., 2011). As I argued in Chapter 4, this is a design research process, which begins by investigating the present in order to move forward to explore a desirable future. Hence, in

Phase 3, I aimed to conduct explorations to obtain an understanding of the mealtime from the healthcare professionals' and the patients' expectations for their future experiences. Here I will demonstrate how the two elements of the study are connected (see Figure 5.19). In the first part, bringing forth a research process was focused on exploring the patients' ideas in order to capture their desires and aspirations. By evoking the patients' desires and aspirations, I intended to collect their ideas of what would be the ideal experience. The second was a research process focused on provoking the healthcare professionals' motivations and knowledge to collect their ideas of how the new mealtime experience should be redesigned.

Both design research situations involved participatory workshops, as design games. Hence, the participatory workshops were based on this idea of design by involving playing as a way to encourage people to express their ideas (Brandt, 2006). With such an approach, I was possibly involving the patients and the healthcare professionals in "playfulness experiences" (Binder et al., 2011a), rather than thinking of it as a design situation, which requires physical embodiment in making artefacts to evoke ideas (Sanders and Westerlund, 2011; Binder et al., 2011b). Fundamentally, a more convivial experience might become valuable to support and accommodate the patients' needs, but might also encourage their participation. This research involving a process of connecting was more a space of interaction to engage in dialogues, using the idea of playing to open up new ways of thinking and reflecting about the mealtime experience. This process can be seen as "the kind of socio-material assemblies" (Ehn, 2008) that comprise game pieces and game boards. In what follows I will explain in more detail how these two workshops were designed with the important point of collecting ideas and then using these ideas to generate creative moves to build a new mealtime scenario concept.
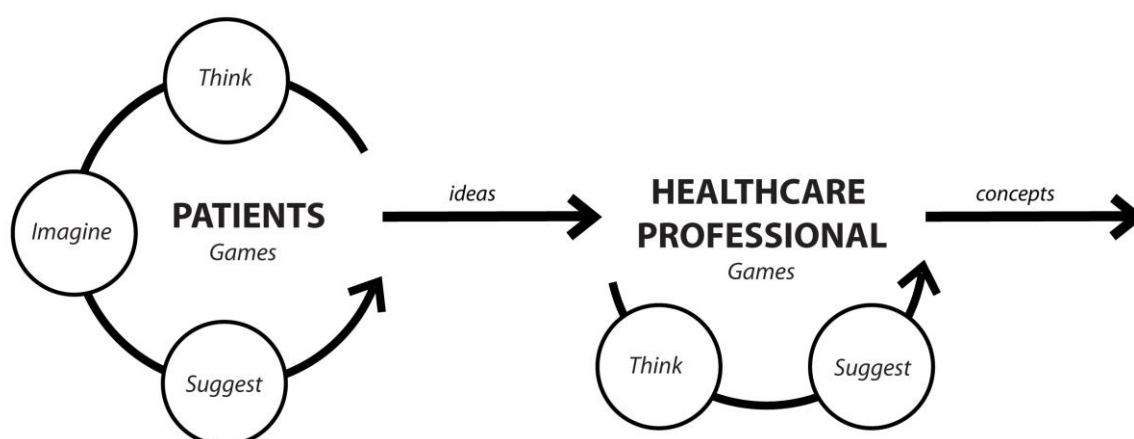
Figure 5.19 Connecting design games: the design research process used to explore the future.

5.3.3.1 The workshop with patients

The workshop with patients entailed tools and techniques to connect thinking, imagining and suggesting (see Figure 5.20). This can be seen as a research process that allowed continuing exploration of the patients' ideas within three design games. To explore the patients' ideas I could use playful strategies to stimulate their imagination (Brandt, 2006). Playful strategies could provide "keys to unlock the door to the unconscious and to release the visual and verbal poetry of collective creativity" (Gooding, 1995, p.10). Thinking, for example, of the mealtime as an event involving three sequential stages (before, during and after) and four inter-related experience aspects (sensorial, physical, social and emotional), which I have understood as significant issues for designing, as I will demonstrate in Chapter 7. This could, however, also be understood in different circumstances, such as when recovering from stroke in hospital. But perhaps more interesting is the experiences of these different circumstances at the mealtime. Here the workshop was a "public space" (Bjögvinsson et al., 2012). By saying that the workshop was a public space, I mean that through the dialogue with a group of patients the workshop was conceptualised to constructively deal with their individual views and ideas. Patients who are temporarily recovering from stroke in hospital, as discussed in Chapter 2, experience different health conditions and circumstances. Think, for example, of two patients, one who is paralysed on one side of the body and one who still cannot speak and who has swallowing difficulties. Both experience the mealtime in different ways. Providing a "public" space in which to open a dialogue to elicit these different experiences was considered relevant to suggest directions into the desirable futures.
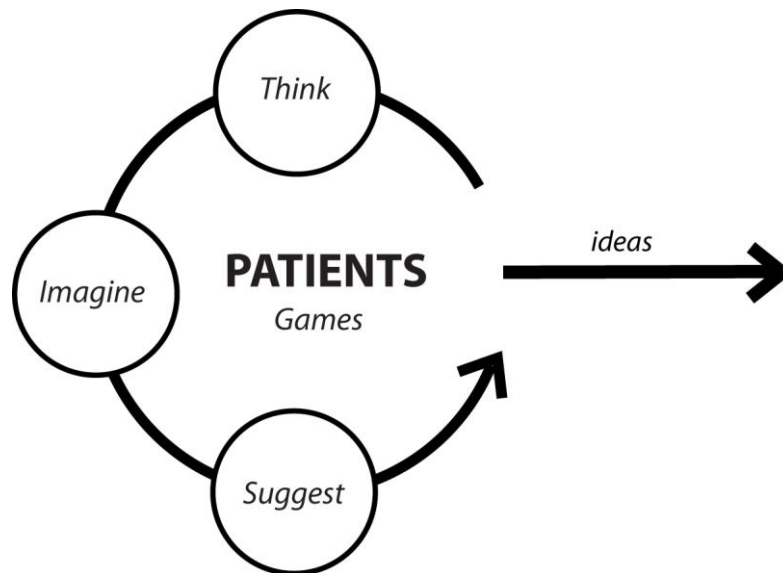
Figure 5.20 A workshop with patients acting in a game that connects thinking, imagining and suggesting to explore ideas.

The aim in designing this workshop was also to conceive design games that encourage and stimulate but also support and facilitate the diversity of patients' needs. The form of dialogue was by playing games, as a space of interaction that connects tools, techniques and people (see Figure 5.21).
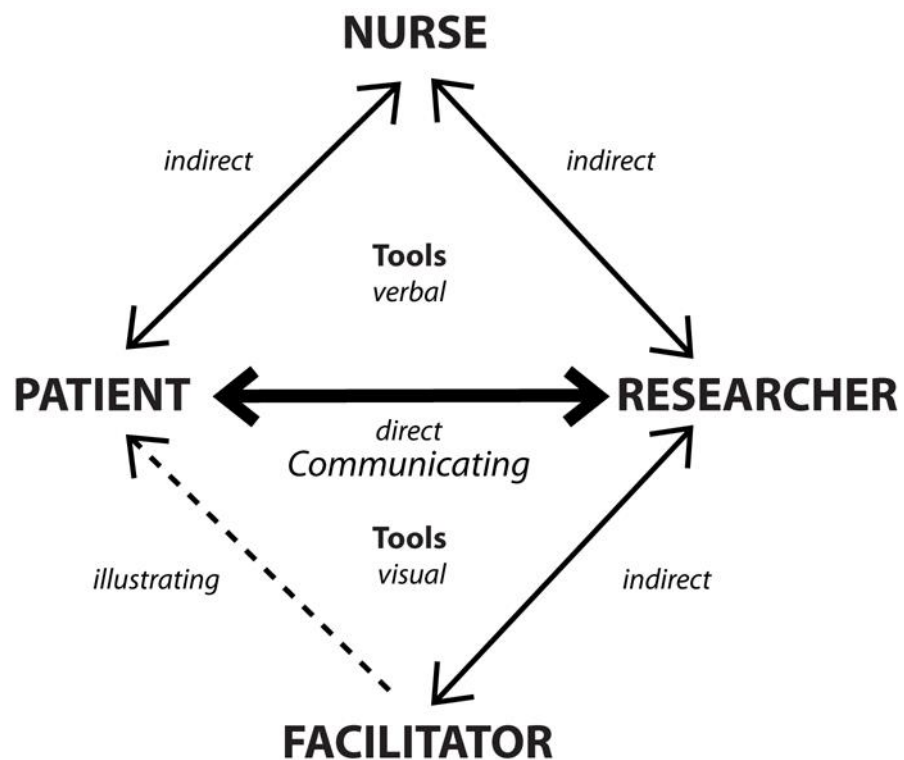
Figure 5.21 The form of dialogue as connecting tools, techniques and people in the workshop with patients.

The aim of designing games emerged to evoke the patients' thoughts, but the attempt at playing games creates an active and supportive dialogue for patients, revealing both verbal and visual components. To capture the verbal components, I created a set of prompt questions, as game pieces. Here I also used the conceptual framework (see Figure 5.17) to explore different types of information about experiences such as sensorial, physical, social and emotional. Using the conceptual framework, I created theme colour-cards. The purpose of the cards was to invite patients to select a colour in order to open up a dialogue around a predetermined theme. Opening a dialogue through a theme, I envisioned putting patients' thinking and expressing of their thoughts and ideas about the mealtime experience in different ways, as I will demonstrate in more detail in Chapter 8. What I envisioned here was the possibility to obtain an understanding of the important elements to deliver desirable future patient experiences at the mealtime as an outcome of the games. For example, I explored the patients' desires and imaginations by playing the Magical game. Here I was inviting patients to choose a theme colour-card. Selecting, for example, "sensorial", I prompted a question to evoke patients' thoughts (see Figure 5.22).

The possibilities to explore ideas through this question were envisioned in a variety of ways, such as the smells, sound and the visual appearance. In this way, I might potentially provide a collection of different types of information. For example, by playing the Magical game I envisioned that I could possibly gain a better understanding of the mealtime as an enjoyable experience.

How would you imagine the magical mealtime experience to be sensorial?

Figure 5.22 Material components to open up a verbal dialogue when patients were playing the theme colour-cards in the workshop.

In this form of dialogue, as illustrated in Figure 5.21, I was also concerned with how the patients' ideas could be visually represented without inviting them to perform physical tasks. Visual components were a set of tools, as game-boards, to collect information in the form of maps and stories (see Figure 5.23). In illustrating these game boards I aimed to engage two facilitators. Involving two facilitators in this space of interaction had a specific role: illustrating the patients' ideas. The two facilitators were design students at the Glasgow School of Art with experience in facilitating workshops but with relevant skills in drawing. I imagined that drawing could be useful to visualise participants' thoughts and ideas. In this way, I was potentially facilitating patients' participation but also providing opportunities to collect their voices; perhaps, in visualising ideas, I might create a possibility to open a dialogue for discussion. This can also be seen as providing patients with a sense of being part of something important to bring about change in future experiences.
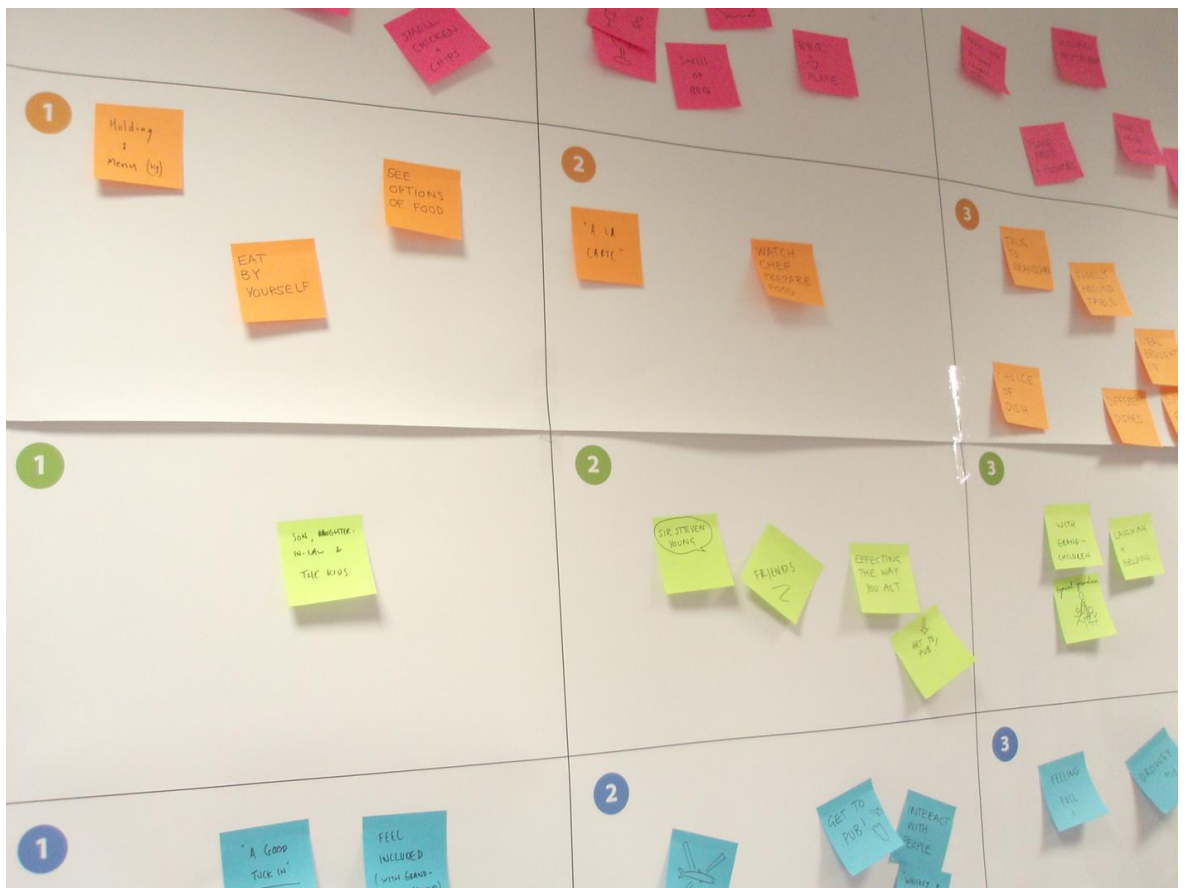
Figure 5.23 Tools used to illustrate stories when patients were playing the Magical game in the workshop.

Once again, in involving patients in design activities such as a workshop, I was concerned with the best techniques to put the games into action. As I mentioned previously, in Phase 2, when meeting the local nurses, we discussed the idea of creating opportunities during the dialogue to verbalise and clarify issues in the workshop, but most importantly, to support patients' needs if required. Nurses can be relevant collaborators to support eventual health circumstances, as I will demonstrate in Chapter 8.

Using design games, I conceived of how game pieces and game boards were made to be experienced in a form of dialogue. For example, the process included a set of tools (see Figure 5.24). From the figure, we can see that tools were four theme colour-cards as game pieces, a game board to place the colour-cards at the table and a number of player pieces. Typically, this process took the form of me explaining the roles of the games to be played, inviting patients to play, and placing the cards on the game board on the table and or wall. This involved me actively interacting with game pieces. Furthermore, the nurses sometimes verbalised what some patients (or I) were verbalising in order to clarify what was said. Two facilitators illustrated the patients' ideas on post-its and placed them on the game boards on the wall. The dialogue was video and audio-recorded. The issue of the placement of a video camera was discussed prior to this workshop in order to provide a comfortable experience for patients participating in this research.

Figure 5.24 Tools used to conduct the workshop with patients.

Designing this workshop required time considerations. Here I will demonstrate how I planned each activity, as a game, in time, in order to potentially create a calm and comfortable experience for patients (see Table 5.1). In fact, the workshop took place over two hours and 45 minutes. The planned length of time was considered to be sufficient as it was envisioned that it would allow ample time to provide opportunities to explore a diversity of issues without tiring the patients.

Table 5.1 Timetable used to conduct the workshop with patients.

Time	Action	Checklist
5 min	Introduction	Explaining the set of activities, the goals and how they are experts in this matter
10 min	Exercise 1: playing the *What if?* game	Showing the current mealtime scenario in hospital, explaining the inter-related experience aspects at the mealtime and prompting the question *What if…*it was made by your favourite chef?
10 min	Patients' voices	
5 min	Discussion	Exploring the patients' voices
5 min	Exercise 2: playing the Magical game	Inviting patients to play the Magical game and explaining the instructions
40 min	Patients' voices	
5 min	Reflection	Summarising the patients' stories, expressing how their stories are valuable to explore the next activity
15 min	Break	
5 min	Summary	Showing visually what patients have done in the first part
5 min	Exercise 3: playing the Map game	Inviting patients to play the Map game and explaining the instructions
40 min	Patients' voices	
10 min	Discussion	Exploring the patients' voices
10 min	Conclusion	Summarising the day and thanking all patients for their invaluable contribution

Games

Let me now explain the idea of the designed games used in this workshop (see Figure 5.25). The idea of structuring the workshop through three games was to open up three different ways of thinking. The first was focused on stimulating the patients' reflections

about designing, with a focus to the mealtime experience. Here I adapted the idea of "*what if?*", as a game. Rather than introducing drama techniques (Brandt and Grunnet 2000), I created a question as a source of inspiration to trigger patients to reflect about design. In other words, I aimed to ask patients to think from a chef's perspective. As I discussed in Chapter 3, the design of the mealtime has become a concern of chefs and restaurateurs who have been exploring ways to provide the more hedonic experience for their customers. Here I envisioned patients' reflections while playing "*What if the mealtime experience was created by Jamie Oliver? How would he create it for the patient?*" By providing a prompt question, as a game piece, I intended to invite patients to change their position of expertise. In providing opportunities to think about things from a different perspective, I envisioned this as a way of inspiring patients to express ideas.

The second game was aimed at evoking patients' desires and aspirations. Hence, in creating the Magical game I aimed to invite patients to imagine. Here I used "magical" in the sense of exploring what is unknown, "secret" (Gooding, 1995). The aim of this game was to achieve, as an outcome, a better understanding of what the most delightful and enjoyable experiences are like.

The third game was focused on encouraging patients to think about what can be done to improve the mealtime experience for patients in stroke rehabilitation in hospital. In exploring this idea of what can be done, I created the Map game to invite patients to suggest ideas of what should be done. Here I used the current mealtime scenario and the outcome of the research process in Phase 2, to map the patients' ideas. The game, through a scenario, was mapping the ideas throughout the mealtime stages (before, during and after), as I will demonstrate in Chapter 8. Using a scenario to structure a game might highlight directions to restructure the existing situation (Brandt, 2006).

Figure 5.25 "Thinking, Feeling and Suggesting" framework that I used when conceptualising design games for the workshop with patients.

Pilot workshop

Prior to the workshop with patients, I conducted a pilot workshop with a group of colleagues at the Glasgow School of Art in order to evaluate the designed games in action. Here I paid special attention to how these design games were made explicit for the participants in order to reduce the risk of me projecting assumptions on the participants. This process also allowed the evaluation of design by playing in order to understand how tools, techniques and people were connected. The aim was to achieve, as an outcome, that playing the game elicits the participants' voices and, furthermore, to explore how the participants' voices were visually represented as public things to be opened up for discussion.

This pilot of evaluating these games in practice highlighted some points that required more consideration. Playing *What if?*, I began by presenting the current mealtime scenario in hospital in a PowerPoint format, as we can see in Chapter 8. Here I gave printouts of the presentation to the participants (see Figure 5.26).
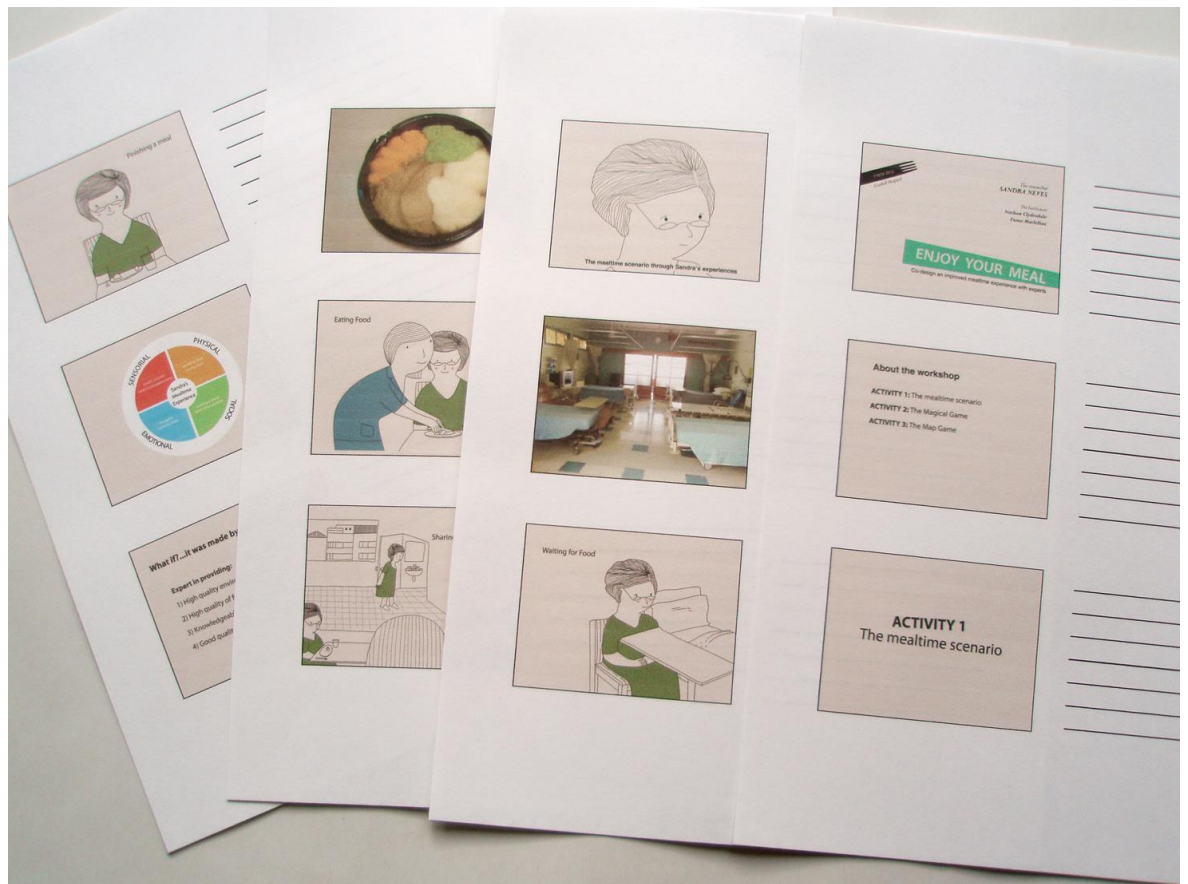
Figure 5.26 Printouts used when playing the *What if?* game in the pilot workshop

Although I aimed to give out printouts to support our communication, I found them to be distracting. For example, participants were constantly trying to follow the presentation on the printouts rather than on the screen. Here my reflections revealed attention to the need to bring a more focused presentation when using this method with patients. This demonstrated that there might be a benefit to using only a tool such as the PowerPoint. Calling the fictional patient character "Mary" in this mealtime scenario brought unexpected associations. For example, participants expressed that Mary was a name associated with a charity. A less charity-associated name for the patient fictional character needed to be considered to ensure the possibility of less emotional issues associated with the fictional character when used with patients. When I introduced the four inter-related experience aspects (sensorial, physical, social and emotional), the physical aspect required attention. For example, participants became a little confused in understanding the physical related to interactions. The key concepts need to become explicit when used with patients. For example, I might need to provide some examples of situations such as those related to physical interactions are healthcare professionals in cutting food for patients. Starting a dialogue, I invited participants to wear a paper hat when playing the *What if?* game (see Figure 5.27).

Figure 5.27 Chef's hats used when playing *What if?* game in the pilot workshop.

The idea of using a hat was conceived as a stimulation of being in a different role such as a chef. I found that through our dialogue, some participants were often trying to fit their hats to their imaginary role. However, I have discussed in this thesis that performing physical tasks are an issue when involving patients. Therefore, I considered that this method might not be appropriate with these particular patients. What this issue highlights here is the design attention for the kind of "socio-material" performance, especially to involve patients. Furthermore, I also prompted the following question: "*What if it was made by Jamie Oliver?*" As I mentioned earlier, I intended to bring a source of inspiration to explore ideas. Although Jamie Oliver is a TV chef and owner of a range of restaurants in the UK, I found that some participants were interested in expressing their ideas by discussing other chefs, revealing different ones to be their favourites. Here my reflections drove my attention to restructure this prompt question in a different way: "*What if it was made by your favourite chef?*" By prompting the question in this way, I might possibly provide the opportunity for patients to have a choice.

In playing the Map game, I was inviting participants to suggest ideas to change the current mealtime experience for the better. In suggesting ideas, I invited participants to look at a game board (see Figure 5.28). This game board was strategically designed to map ideas in

three mealtime stages (before, during and after). While we were playing, I found participants to be somewhat confused. For example, they were asking me and/or looking at the printouts that I initially gave to them to find a picture as point of reference of what currently happens in each stage. Strategies to allow the envisioning of each mealtime stage needed to be considered to facilitate communication when used with patients. More specifically, it might be better to develop a game board to ensure the envisioning of the current mealtime in each stage.
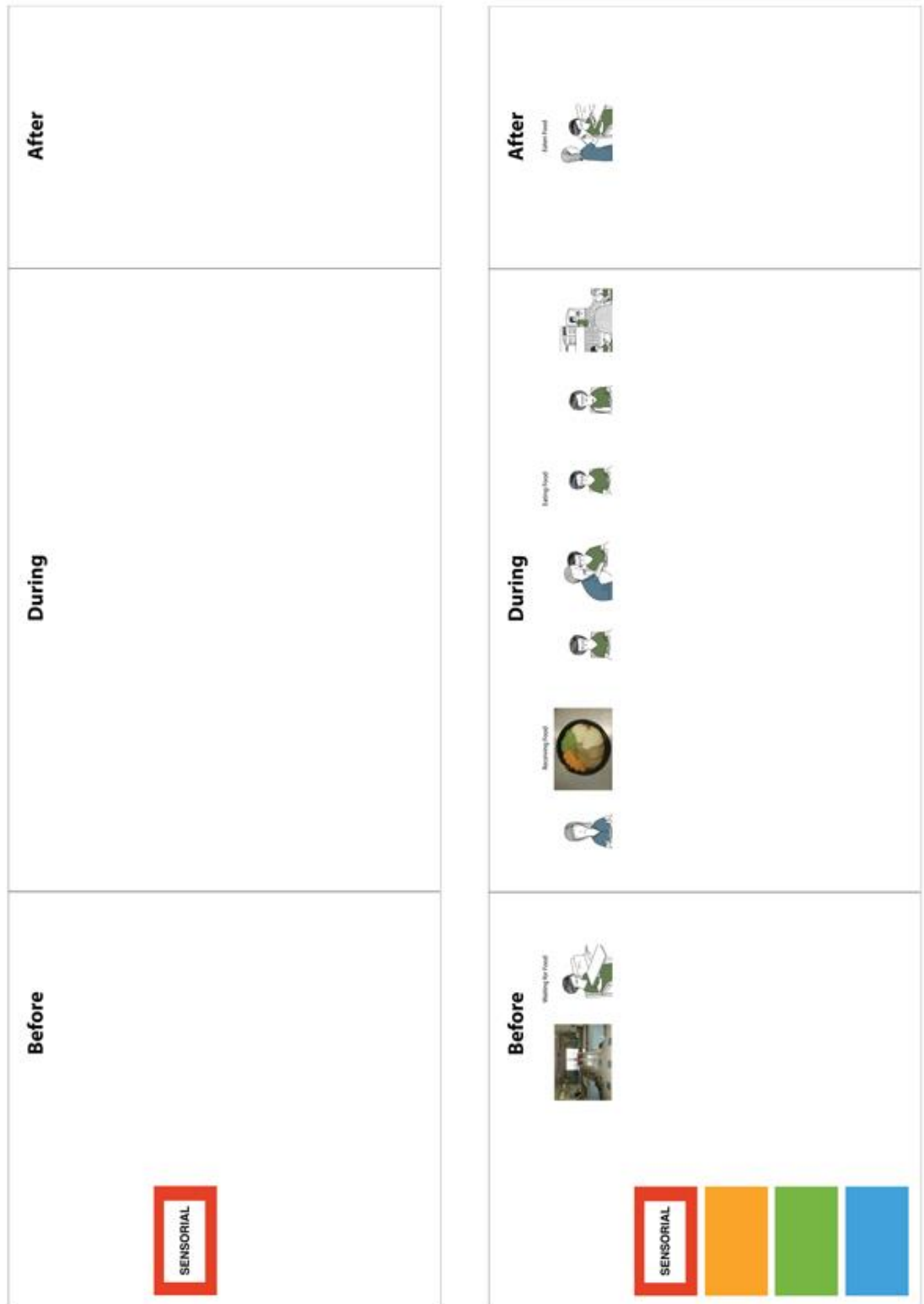
Figure 5.28 **The game board on the left was used when playing the Map game in the pilot workshop. The game board on the right was modified to use when playing with patients.**

The pilot workshop was significant to see how things work in practice. This was a strategy used to refine design before use. In other words, it can be seen as a way of reflecting on practice to understand the dynamic situation (Schön, 1983). More specifically, the aim of the pilot is "to understand what happens in order to find ways of looking forward" (Crouch and Pearce, 2012, p.47).

5.3.3.2 The workshop with healthcare professionals

In the previous workshop with patients, I discussed a research process to obtain an understanding of the patients' ideas to restructure the existing mealtime experience scenario. A workshop with healthcare professionals was aimed at gaining an understanding of their ideas to redesign a new mealtime scenario. As I mentioned earlier, it is a research process that acknowledges both the patients' and the professionals' ideas as a way to demonstrate their expectations for future experiences (Krippendorff, 2006). Here I will describe a workshop focused on provoking the healthcare professionals' motivations and knowledge in order to explore their ideas. The aim of this strategy was to conceive a space of interaction that entails tools and techniques to connect thinking and suggesting (see Figure 5.29), but it can also be seen as a research process to continue exploring ideas within two games. I structured games based on the patients' ideas, the outcome of the previous workshop, as I will demonstrate in Chapter 8. The ideas were those suggested to change the patient experience for before, during and after the meal. These ideas were relevant to understand how to proceed into the designing for patient experience at the mealtime. The patients' ideas were valuable to define the patient experiences, and different levels of experience (anticipation, encounter and reflection). Hence conceptualising a desirable patient experience would consider the redesign of the elements of experience for different levels of experience. This workshop was also conceived as a public space to open up a dialogue with a group of healthcare professionals such as a nurse, a speech therapist and an occupational therapist and a dietician.

Figure 5.29 The workshop with healthcare professionals acting as a game that connects thinking and suggesting to explore ideas.

The aim of creating games was to encourage and stimulate healthcare professionals to express their thoughts. Hence the form of dialogue was conceived as a space of interaction that connects tools, techniques and people (see Figure 5.30).
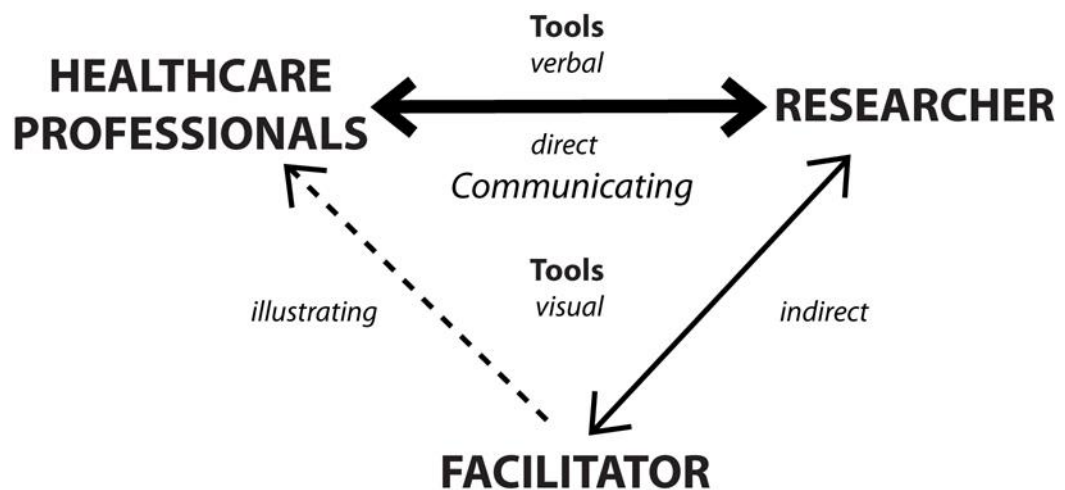
Figure 5.30 The form of dialogue as connecting tools, technique and people in the workshop with healthcare professionals.

Here games emerged from the ideas of patients to provoke thoughts and consequently the generation of further ideas. The aim was to create a dynamic dialogue, revealing verbal and visual components. Verbal components were a set of prompt questions, as game pieces. I intended to create prompt question cards as a way to introduce the patients' ideas collected in the previous workshop. This process involved inviting the healthcare professionals to think of what can be done to provide these ideas. As I argued in Chapter 4, it can be seen as a research process that connects both the patients' and healthcare professionals' views on the matter in discussion. But perhaps more interesting is a design research process that legitimises the patient's voice. The aim of creating games based on

the patients' ideas was to ensure their expectation through the redesigning process, for example, playing the Roller Coaster game was a way of prompting the patients' ideas. The purpose of prompting the patients' ideas, as questions, was to provoke healthcare professionals' thoughts. To generate ideas, for example, for before, when patients are waiting for food, I prompted five questions in order to generate ideas (see Figure 5.31). The possibilities to generate ideas through these prompt questions were also envisioned as a method of opening up ways of exploring experiential aspects (sensorial, physical, social and emotional).
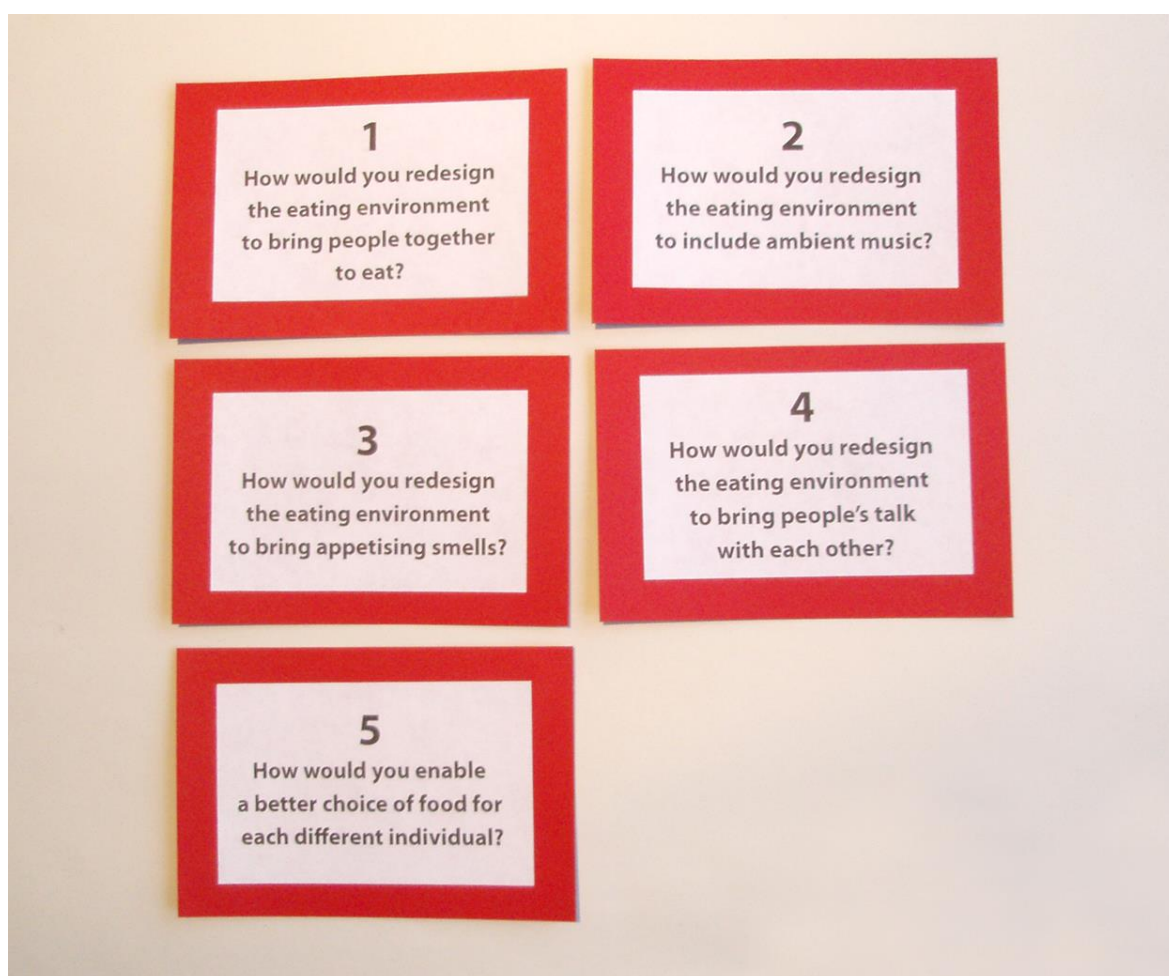
Figure 5.31 Material components to open up a verbal dialogue when healthcare professionals were playing the Roller Coaster game in the workshop.

In this form of dialogue, as illustrated in Figure 5.30, I was also interested in illustrating the healthcare professionals' ideas. Visual components were a set of tools, as game boards, to collect information in the form of maps (see Figure 5.32). In illustrating these game boards I intended also to engage a facilitator. As I mentioned earlier in the previous workshop with patients, involving a facilitator in this space of interaction was for a specific role: illustrating the healthcare professionals' ideas. The facilitator was a PhD student at

the Glasgow School of Art with experience and skills in facilitating design workshops. In this way, I was potentially creating opportunities to collect information in a variety of ways. In illustrating healthcare professionals' ideas, I was creating a dialogue opened up for discussion.

Figure 5.32 Tools used to illustrate ideas when healthcare professionals were playing the Roller Coaster game in the workshop.

In exploring the healthcare professionals' ideas, I was concerned with the best techniques and tools to put the games in action in order to support their creativity. A question of generating ideas in this workshop was not only a question of stimulating, but of looking for creative moves possible by playing the mealtime experience in unforeseen ways.

Hence, design games included a set of tools (see figure 5.33). From the figure, we can see that tools were ten questions in colour-cards as game pieces, a passenger player piece to place on the track on the wall game board and a custom game piece for co-creators. Typically, I explained the roles of the game to be played, inviting healthcare professionals to play, placing cards and pieces on the game board on the wall. Thus, the game took the form of physical interaction. A facilitator illustrated the healthcare professionals' ideas on post-its and placed them on the game boards on the wall. The dialogue was audio-recorded following ethical procedures.

Figure 5.33 Tools used to conduct the workshop with healthcare professionals.

This workshop was planned to take place over two hours (see Table 5.2). Here I will demonstrate how I planned each activity, as a game, in time. It was envisioned that the amount of time allocated to each action was would provide opportunities to explore a diversity of issues.

Table 5.2 Timetable used to conduct the workshop with healthcare professionals

Time	Action	Checklist
5 min	Introduction	Explaining the set of activities, goals and that they are in a different role
5 min	Exercise 1: playing *What if?*	Showing a familiar mealtime scenario through a fictional user character, explaining three levels of experience at the mealtime and prompting the question *What if…*it was made by your favourite chef?
10 min	Healthcare professionals' voices	
15 min	Break	
5 min	Summary	Showing visually what healthcare professionals have done on the first part
10 min	Discussion	Exploring the healthcare professionals' voices
5 min	Exercise 2: playing the Roller Coaster game	Inviting patients to play the Roller Coaster game and explaining the instructions
40 min	Healthcare professionals' voices	
10 min	Discussion	Exploring the healthcare professionals' voices
5 min	Conclusion	Summarising the day and thanking all healthcare professionals for their invaluable contribution

Games

To get a sense of what such designed games may mean in this workshop, I will describe my rationale in conceiving of the two games (see Figure 5.34). In the first, I again used the idea of "*what if?*", as a game, because I also intended to allow healthcare professionals to think from a chef's perspective. Hence, I used a similar prompt question as a source of inspiration, "*What if it was redesigned by your favourite chef?*" Prompting this question, as a game piece, I also aimed to invite healthcare professionals to change their position of expertise. Here the purpose was to create an opportunity to move the healthcare professionals' thoughts away from their work practices and inspire them to a more "familiar" experience of the mealtime. Given that this time it was a more familiar situation,

I envisioned they would reflect about designing the mealtime as involving different levels of experience, for example, an anticipation, encounter and reflection. Creating rules in different ways could possibly support creativity.

The second game was focused on provoking healthcare professionals' thoughts to generate ideas to suggest opportunities in order to promote the quality of the patient experience at the mealtime in hospital, as I will demonstrate in Chapter 9. In generating ideas, I created the Roller Coaster game. Here I used "roller coaster" in a sense of constructing "levels" for experiencing. Every time the healthcare professionals generated an idea, I envisioned that they were building an element within a level for experiencing. In fact, they were generating a number of elements, or "points" throughout the mealtime stages. The aim of designing this game through the ideal experience scenario was to help make idea "levels" visible throughout the mealtime stages (before, during and after), as I will demonstrate in Chapter 9.

I initially intended to conduct the workshop with a group of four healthcare professionals, involving a nurse, a speech therapist, an occupational therapist and a dietician. However, grouping four clinical stroke rehabilitation practitioners together at the same time can be a challenge and is time-consuming due to their busy schedules. In addition, I envisioned that taking the healthcare professionals out of hospital and their daily work environment could inspire and stimulate their participation for thinking about a different role about design. By changing the healthcare professionals' environment, I imagined that that could possibly stimulate their thinking about the designing of the mealtime experience. Therefore, the workshop was instead purposely designed better to engage and encourage healthcare professionals' participation in the design activity. In what follows, I will look further into how the information collected will be analysed.

Figure 5.34 "Thinking and Suggesting" framework that I used when conceptualising design games for the workshop with healthcare professionals.

5.4 Analytical method

So far I have discussed the study design within this view of infrastructuring to envision how design takes place in order to elicit the patients' and healthcare professionals' voices. I have considered thinking about designing a temporary platform, using infrastructuring based on prior infrastructure, to start to understand the present in order to explore new possibilities for the future. For now, I will narrow the focus to describe the analytical method that I adopted to demonstrate the "voices", or in other words, to produce the findings. In Chapter 4, I discussed, highlighting issues and concerns, the justification for adopting a framework analysis in this study. Hence I will describe step-by-step how the information collected in each phase of this research was analysed. There was a point to the method of collecting this information, as I wanted to make sure that what I would demonstrate in this design research process is the patients' and healthcare professionals' voices. Green and Thorogood (2004) suggest, in a framework analysis of how to preserve the integrity of the study participants' accounts, that these participants' accounts have to be managed in different stages to become transparent. Moreover, the National Centre for Social Research further suggests that being transparent and rigorous is possible by developing a process of summarisation which uses a method based on a matrix to organise

data according to key themes, concepts and emergent categories. Hence, I acknowledge that one analytical method employed in this research was developing a hierarchical thematic framework that was classified and organised to become robust.

I will now explain how I conceptualised all of the information collected in each phase of the study through the development of an analytical process (see Figure 5.35). This process involved creating an "analytical hierarchy" to gain an overview to make sense of the data (Ritchie and Lewis, 2003). In this analytical hierarchy, Ritchie and Lewis (2003) suggest three main stages of analysing: data management, descriptive account and explanatory account. In the first stage, the process involves managing and organising the raw data to make them more manageable while also generating a set of themes and concepts according to which the data are labelled, sorted and synthesised. In the second stage, the data are synthesised to prepare descriptive accounts in order to identify key dimensions and to map the range and diversity of each phenomenon. In the third stage, patterns of association are identified within the data and then an attempt is made to account for why those patterns occur. Applying this analytical method, I will explain now how each stage of this study was analysed.
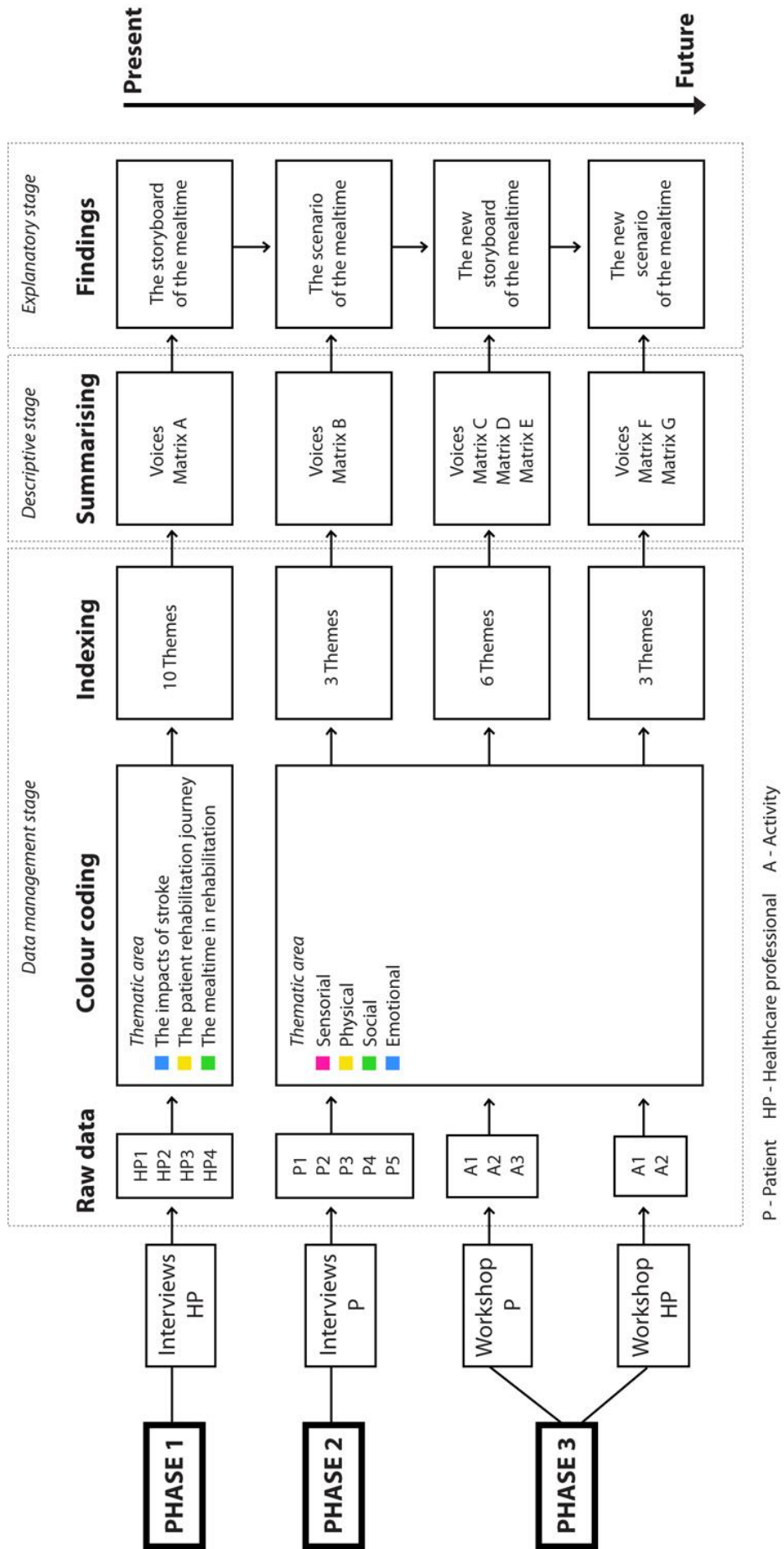
Figure 5.35 An overview of the analytical method

5.4.1 Phase 1: Exploring the existing mealtime situation with healthcare professionals

In this first phase of the research, I used semi-structured interviews to collect data from four healthcare professionals, as discussed in section 5.3.1. Using a framework method I took an approach to analysis that enabled themes to be developed both from the research questions and from the healthcare professionals' accounts (experiences and views).

Stage 1: Data management

I transcribed verbatim all the audio-recorded interviews with healthcare professionals and read and re-read the transcripts several times to become familiar with the data. I coded each healthcare professional transcript as HP1, HP2, HP3 and HP4 to ensure their anonymity and to assign the information to the corresponding individual. I started to colour code three emerging themes: 1) the main impacts of stroke (blue); 2) the stroke care pathway (yellow); and 3) the mealtime in hospital (green). These themes were predetermined by the study aims and the research questions. Using predetermined goals allowed me to begin organising and managing the information collected. After coding the same four transcripts, I then systematically went through each transcript, highlighting each meaningful passage of text and attaching (indexing) sub-themes (codes) related to the detailed accounts in each theme (see Table 5.3) (see Appendix G).

Table 5.3 Developing a working analytical framework

Theme	The main impacts of stroke	The stroke care pathway	The mealtime in hospital
Sub-themes	Neurological Physical Social Psychological	Hospital Day hospital Home	Eating difficulties Team assessment Eating process

Stage 2: Descriptive

When all data had been coded using the analytical framework illustrated in Table 5.3, I summarised the data into framework Matrix A using Microsoft Word (see Figure 5.36). Matrix A comprised one row per healthcare professional and one column per theme and within each theme, one column per sub-theme. A separate sheet was used for each theme. I then extracted data from the transcripts for each participant and sub-theme, summarising

these by using healthcare professionals' direct quotes or "voices", or, in other words, verbatim speech, and inserted them into the corresponding cell in Matrix A.

	The main Impacts of Stroke				The Stroke Care Pathway			The Mealtime in Hospital		
	Neurological	Physical	Psychological	Social	Hospital	Day hospital	Home	Eating difficulties	Team Assessment	Eating process
HP1										
HP2										
HP3										
HP4										

Figure 5.36 Matrix A used to summarise the information reported by the healthcare professionals.

At the same time, I developed a visual map (see Figure 5.37), grouping the information in each theme and sub-theme by each individual and also the information collected using a notebook and digital camera. By organising and mapping the data in this way, I thought it might help to highlight new insights. Fundamentally, it helped me make sense of how the healthcare professionals used their knowledge and experiences of stroke, rehabilitation and the patient experience at the mealtime in a stroke rehabilitation unit in hospital.

Figure 5.37 Mapping the information reported by the healthcare professionals and collected in the notebook and by the digital camera. Here the healthcare professionals' voices were underlined as HP1 (rose), HP2 (green), HP3 (orange) and HP4 (yellow) to help identify who the insights come from.

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Stage 3: Explanatory

Themes were generated from the dataset by reviewing Matrix A and making connections within and between healthcare professionals and categories. At the same time, I intended to build a storyboard of the mealtime; I thought it might help to look at the information as a whole. Fundamentally, it was simply to develop a tool to work with in the next research phase. During this stage, I tried to go beyond descriptions of individual cases towards developing themes, which offered possible explanations for what was happening within the data. Insights were generated and explored through diagrams and tables, as demonstrated in Chapter 6, section 6.3.

5.4.2   Phase 2: Exploring the patients' experiences

In this second phase of research, I used semi-structured interviews to collect data from five patients, as demonstrated in section 5.3.2. Using a framework method, I took an approach to analysis that enabled themes to be developed both from a thematic framework (see Figure 5.17) and from the patients' accounts (experiences and views).

Stage 1: Data management

I began by developing transcripts of all the interviews audio-recorded with patients and read and re-read them several times to become familiar with the data. I coded each patient transcript as P1, P2, P3, P4 and P5. As I have already mentioned, this strategy was employed to ensure the patients' anonymity and to assign the information to the corresponding individual. I started to colour code four themes: sensorial (pink), physical (yellow), social (green) and emotional (blue). These themes were predetermined by the thematic framework (see Figure 5.17). Using predetermined goals, as mentioned earlier, allowed me to begin organising and managing the information collected. After colour coding the same five transcripts, I then systematically went through each transcript, highlighting each meaningful passage of text and attaching (indexing) three themes (codes) related to each of the mealtime stages (before, during and after). In doing so, I intended to group the themes extracted from these detailed accounts within each mealtime stage (see Table 5.4) (see Appendix H).

Table 5.4 Developing a working analytical thematic framework

Thematic colours	Description
Sensorial	Perception of sensory elements (e.g. sights, smells and sounds)
Physical	People, spaces and objects interact with one another
Social	Social relationships and interactions (e.g. patient, healthcare professionals, family and/or friends)
Emotional	Emotional reaction of an experience (e.g. using products and/or the aesthetic of products)

Themes	Description
Before	Waiting for food
During	Receiving food and eating
After	Eaten food

Stage 2: Descriptive

When all data had been coded using the analytical thematic framework illustrated in Table 5.4, I summarised the data into framework Matrix B using Microsoft Word (see Figure 5.38). Matrix B comprised one row per patient and one column per mealtime stage. A sheet was used for each mealtime stage. I then extracted data from each patient where there were multiple thematic colours surrounding each mealtime stage. I summarised these using the patients' direct quotes or "voices" and inserted them into the corresponding cell in Matrix B.

Figure 5.38 Matrix B used to summarise the information reported by the patients.

At this time, I developed five visual maps, grouping the information reported by each patient (see Figure 5.39). By organising and mapping the data in this manner, I thought it

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might help to highlight new insights. In doing so, it helped me to see how patients made sense of their experiences at the mealtime during their stroke rehabilitation in hospital. At this stage, it became evident that patients in different health circumstances were experiencing the mealtime differently.
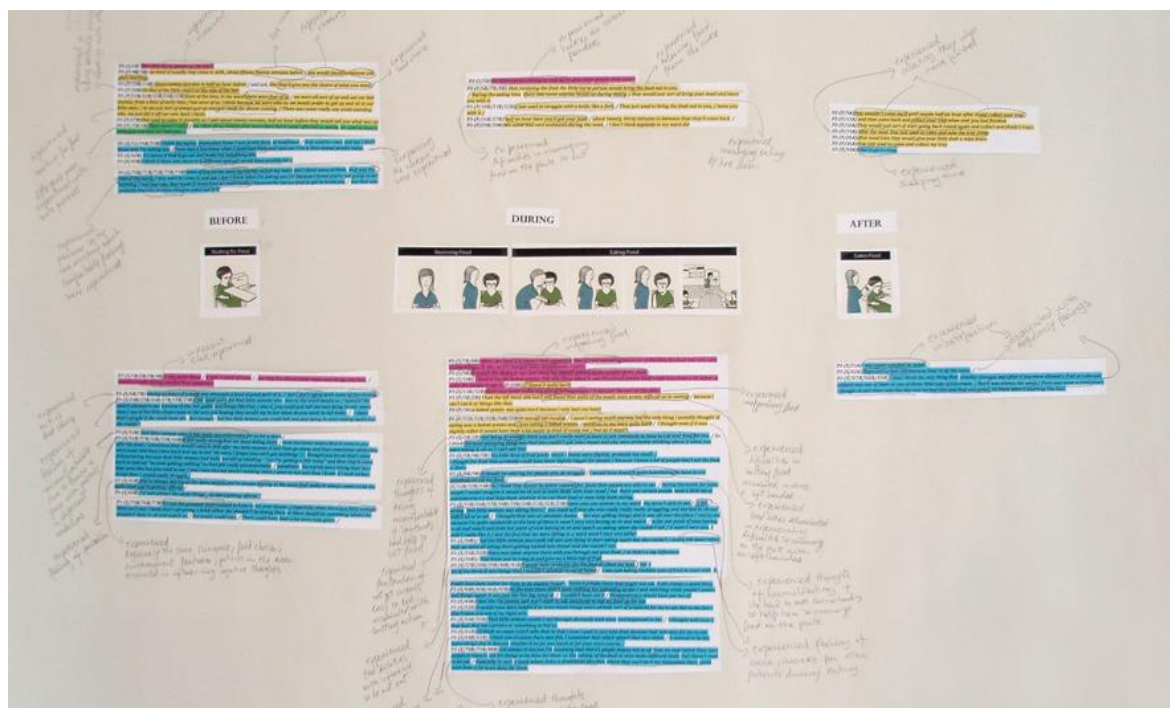
Figure 5.39 Mapping the information reported by patient P3.

Stage 3: Explanatory

Themes were generated from the dataset by reviewing Matrix B and making connections within and between patients and categories. During this stage, I found a need to explore descriptions of individual cases towards developing themes, which offered possible explanations for what was happening within the data. Insights were generated and explored through diagrams and tables, as demonstrated in Chapter 7, section 7.5. At the same time, I intended to build a scenario of the mealtime to look at the present situation as a whole, involving both the healthcare professionals' and patients' voices. Overlapping both perspectives allowed me to provide a deep understanding of the current situation at the mealtime. Constructing the present mealtime scenario was a significant way to allow me to reflect about the future. What would make a significant difference in the future mealtime experiences? How would patients change the mealtime experience for the better in stroke rehabilitation? How would they suggest ideas about experiential aspects? Why? This

process also helped to highlight directions to infrastructure the following research investigations in Phase 3.

5.4.3 Phase 3: Exploring future possibilities with patients and healthcare professionals

In this third phase of research, I used two separate workshops to collect data, as demonstrated in section 5.3.3. The first collected data from a group of patients and the second from a group of healthcare professionals. Here, I also took an approach to analysis that enabled themes to be developed both from a thematic framework (see Figure 5.17) and from the patients' and healthcare professionals' accounts (ideas and opinions).

5.4.3.1 The workshop with patients

Stage 1: Data management

Once again, I began by transcribing verbatim the full audio-recorded workshop with patients, which involved three activities, and read and re-read these several times to become familiar with the data. I coded each patient dialogue in the transcript as P1, P2 and P4. Afterwards, I started to colour code four themes: sensorial (pink), physical (yellow), social (green) and emotional (blue). As mentioned earlier, these themes were predetermined by the thematic framework. I then systematically went through each activity (*What if?*, and the Magical and Map games) on the workshop transcript, highlighting each meaningful passage of text and attaching (indexing) themes (codes) related to the aims of the game. Consider, for example, in the first activity (*What if?*), how I indexed three themes: environment, food and staff. In the second activity (the Magical game) I indexed three individual cases for their "imagined experiences": P1, P2 and P4. In the third activity (the Map game) I indexed three mealtime stages: before, during and after. This process allowed me to begin organising the information collected (see Table 5.5) (see Appendix I).

Table 5.5 Developing a working analytical framework

Activities	*What if?*	Magical game	Map game
Thematic colours	Sensorial, physical, social and emotional		
Themes	Environment Food Staff	P1 P2 P4	Before During After

Stage 2: Descriptive

When all data had been coded using the analytical framework illustrated in Table 5.5, I summarised the data related to each activity into three framework matrices: C, D and E, using Microsoft Word. Matrix C (see Figure 5.40) related to the first activity (*What if?*) comprised of one row per thematic colour and one column per theme. A sheet was used for each theme. I then extracted data from the collective patients where there were different thematic colours surrounding each theme. I summarised these using the patients' direct quotes or "voices" and inserted them into the corresponding cell in Matrix C.

	Environment	Food	Staff
Sensorial			
Physical			
Social			
Emotional			

Figure 5.40 Matrix C used to summarise the information reported in W*hat if?* game by the patients.

Matrix D (see Figure 5.41) related to the second activity (the Magical game) and comprised one row per patient and one column per thematic colour. I then also used a sheet for each patient to extract data where these different thematic colours surrounded each patient. I summarised these extracts by using the patients' direct quotes or "voices" and inserted them into the corresponding cell in Matrix D. At this moment, the information revealed individual aspirations, or, in other words, how patients made sense of an enjoyable mealtime experience.

	Sensorial	Physical	Social	Emotional
P1				
P2				
P4				

Figure 5.41 Matrix D used to summarise the information reported in Magical game by the patients.

Matrix E (see Figure 5.42) related to the third activity (the Map game) and comprised one row per thematic colour and one column per mealtime stage. I then extracted data from the collective group of patients where there were different thematic colours surrounding each

mealtime stage. I also summarised these using patients' direct quotes or "voices" and inserted them into the corresponding cell in the Matrix E.

	Before	During	After
Sensorial			
Physical			
Social			
Emotional			

Figure 5.42 Matrix E used to summarise the information reported in the Map game by the patients.

At the same time, I developed a visual map for each activity, grouping both the information gathered from the transcripts and collected on the game-boards in the workshop (see Figure 5.43). As mentioned earlier, by mapping data in this way, I thought it might help to highlight new insights. At this stage, it became evident how the patients made sense of their ideas and opinions on how they see what would make a significant difference at the mealtime in future experiences.

Figure 5.43 Mapping the information reported by playing the Map game with the patients.

Stage 3: Explanatory

Themes were generated from the dataset by reviewing each matrix, C, D and E, and making connections within and between each activity and categories. At the same time, I intended to build a storyboard of the mealtime; I thought it might help to look at the information as a whole. Building a new storyboard based on the patients' ideas enabled me to reflect about important points to structure the next workshop with healthcare professionals. During this stage, I also tried to develop themes, which offered possible explanations for what was happening with the data. Insights were generated through diagrams and tables, as demonstrated in Chapter 8, section 8.2.4.

5.4.3.2 The workshop with healthcare professionals

Stage 1: Data management

I began by developing a transcript of the audio-recorded workshop with healthcare professionals and read and re-read it several times to become familiar with the data. I coded each healthcare professional's dialogue in the transcript as HP1, HP5 and HP6. Afterwards, I started to colour code the four themes: sensorial (pink), physical (yellow), social (green) and emotional (blue). I then systematically went through each activity "game" (*What if?* and the Roller Coaster game) on the workshop transcript, highlighting each meaningful passage of text and attaching (indexing) themes (codes) related to the aims of each game (see Table 5.6) (see Appendix J).

Table 5.6 Developing a working analytical framework

Activities	*What if?*	The Roller Coaster game
Thematic colours	Sensorial, physical, social and emotional	
Themes	Before During After	

Stage 2: Descriptive

When all data had been coded using the analytical framework illustrated in Table 5.6, I summarised the data related to each activity into two framework matrices, F and G, using Microsoft Word. Matrix F (see Figure 5.44) related to the first activity (*What if?*) and comprised one row per thematic colour and one column per mealtime stage. A sheet was used for each mealtime stage. I then extracted from the collective speech of the healthcare professionals where there were different thematic colours surrounding each mealtime stage. I summarised these using the healthcare professionals' direct quotes or "voices" and inserted them into the corresponding cell in Matrix F.

Figure 5.44 Matrix F used to summarise the information reported in the W*hat if?* **game by the healthcare professionals.**

Matrix G (see Figure 5.45) related to the second activity (the Roller Coaster game) and comprised one row per theme question card, as question cards were tools devised to reveal information, and one column per mealtime stage. A sheet was used for each mealtime stage. I then extracted data from each question card where there were different thematic colours surrounding each mealtime stage. I summarised these using the healthcare professionals' direct quotes or "voices" and inserted them into the corresponding cell in Matrix G. At the same time, I also developed a visual map for each activity, grouping both sets of information reported; in the transcripts and illustrated on the game-boards (see Figure 5.46). In doing so, I thought it might help to highlight new insights. At this time, it became evident how the healthcare professionals made sense of their ideas and opinions for new possibilities for future experiences at mealtimes in stroke rehabilitation in hospital.

Figure 5.45 Matrix G used to summarise the information reported in the Roller Coaster game by the healthcare professionals.

Figure 5.46 Mapping the information reported by playing the *What if?* game with the healthcare professionals.

Stage 3: Explanatory

Themes were generated from the dataset by reviewing each matrix, F and G, and making connections within and between each activity and categories. During this stage, I also tried to develop themes, which offered a possible explanation for what was happening within the data. Insights were generated and explored through diagrams and tables, as demonstrated in Chapter 8, section 8.3.4. At this time, I intended to build a new mealtime

scenario of the mealtime to look at the envisioned situation for the future as a whole, involving the patients' and healthcare professionals' voices. Overlapping both ideas allowed me to provide an understanding of the desirable situation at the mealtime in the future. Constructing the new scenario was a significant way to reflect about new opportunities and concepts on how to promote the quality of life for those patients and healthcare professionals in stroke rehabilitation in hospital. Fundamentally, this method enabled me to see what patients and healthcare professionals might expect as a future mealtime scenario in hospital in this context of stroke rehabilitation.

Here I have demonstrated the analytical approach that I used in this research to access different types of understanding of patients' and healthcare professionals' experiences, as a model to illustrate voices in participatory design research, as I discussed in Chapter 4, section 4.4. By using design situations, as games, involving this notion of the socio-material, I was able to provide different levels of knowledge about experience. The knowledge gained through these different methods allowed the revealing of a picture of the mealtime experience in relation to the patients' and healthcare professionals' own views, which started from the present and then looked forward to the future. Here knowledge about experience is defined as the types of information that healthcare professionals and patients reported using their own knowledge and experiences.

5.5 Summary

This chapter began by demonstrating how the study was conducted to bring the healthcare community collaboration within the stroke rehabilitation unit. By bringing collaborators together in this study, I demonstrated how making design proposals consider ethical and practical issues that attributed meaning to this research. Subsequently, I demonstrated how the study was designed to access different levels of knowledge about experience where research into infrastructuring involves spaces of interaction, such as design situations, to open up dialogues with patients and healthcare professionals. In this idea of the socio-material, I demonstrated adaptations to better accommodate the patients' needs at the time. Combining patients, healthcare professionals, tools and techniques, I envisioned collecting a diversity of information about patient experience at the mealtime. I concluded by showing that an analytical approach using a framework analysis was adopted to illuminate the patients' and healthcare professionals' voices. These voices, as I see it, highlight here a kind of contestation. In the following chapter I will demonstrate these voices of "contestation", or, in other words, the findings produced in each phase of the study.

6

Findings from Phase 1: Exploring the present mealtime situation with healthcare professionals

6.1 Introduction

Previously, in Chapter 5, I presented a framework, demonstrating that this research began with explorations about the present. In exploring the present, I aimed to demonstrate the healthcare professionals' experiences. In doing so, a design situation was created to intertwine interviews with observations in order to build the present mealtime storyboard. As I discussed in Chapter 4, a storyboard can provide valuable information to obtain an understanding of the mealtime in stroke rehabilitation in hospital.

In this chapter, therefore, I aim to present the healthcare professionals' voices in order to develop the present mealtime storyboard. Within Phase 1 of this research, I intended to expose and collect information about the present situation. In other words, to reveal what is happening in "the real world". The healthcare professionals' voices and my observations illustrate the work practices and experiences within stroke care but also, fundamentally, highlight issues about the patient experience at the mealtime. With such a research approach, I intended to show perspectives from those who work day-to-day with patients under stroke rehabilitation conditions. Most importantly, however, I inted to create a design situation that would allow generating new insights to infrastructure further design situations to proceed into explorations about the future (Binder, et al., 2011b).

This chapter begins by describing who participated in this study, which is demonstrated by professional expertise within the Stroke Rehabilitation Unit, as I mentioned earlier in Chapter 5. By presenting the findings from this study, I will illuminate the healthcare professionals' voices related to three main themes: i) the main impacts of stroke, ii) the stroke pathway, and iii) the mealtime for patients in hospital, as I mentioned in Chapter 5, section 5.4. In exploring the main impacts of stroke, I identified issues that highlight attention to the social impact. With the stroke pathway, I found the patient care journey illustrating two main paths: i) from hospital to home, and ii) from hospital, to day-hospital, to home. In following issues about the mealtime for patients, I identified three main themes

related to the mealtime: i) patients with eating difficulties, ii) a multidisciplinary team in planning the mealtime and iii) the mealtime as a care event involving three stages (before, during and after).

I will demonstrate that by using intertwined information from healthcare professionals' accounts and observations, a clear picture of what the healthcare professionals' experiences are and how the patient experience seems to be will be revealed. This research study considers the healthcare professionals' experiences as being valuable to illustrate the present situation.

In conclusion, this chapter will illustrate how these healthcare professionals' voices and observations were significant to obtain an initial understanding of the current situation and consequently highlight further investigations into the patients' experiences at the mealtime.

6.2 Who participated?

Participants in this study were four healthcare professionals: all clinical practitioners in the stroke rehabilitation unit, as described in Chapter 5 (see Table 6.1). These healthcare professionals were a nurse, a speech therapist, an occupational therapist and a dietician, as these individuals are considered to constitute the multidisciplinary team who work with patients at the mealtime within stroke rehabilitation.

Table 6.1 The healthcare professionals who participated in the interviews.

Healthcare professionals	Specialism	Work experience (in years)	Gender
HP1	Nurse	6	Woman
HP2	Speech Therapist	17	Woman
HP3	Occupational Therapist	2	Woman
HP4	Dietician	7	Woman

The table above illustrates who participated, demonstrating the characteristics of the healthcare professionals in relation to their unique identifier code, specialism, work

experience and gender. The following sections will focus on describing how the interviews intertwined with observations were conducted.

6.3   Conducting interviews intertwined with observations

Previously, in Chapter 5, section 5.3.1, I discussed how I conceived this study.   Table 6.2 below gives an overview of each interview and observation to demonstrate each design situation: who was interviewed and who was observed, in which space, and the length of time.

Table 6.2 Conducting interviews intertwined with observations.

Interviewing		*Observing*	Interviewing	*Observing*	Interviewing
Occupational T.	Nurse	*Cook*	Dietician	*Patients and Healthcare professionals*	Speech T.
25 minutes	19 minutes	*1 hour*	46 minutes	*2 hours*	38 minutes
Room	Room	*Kitchen*	Room	*Ward*	Room
Hospital – Stroke Unit					

Before I start to describe how the interviews intertwined with observations were conducted, it is important to explain first how these socialised and materialised situations were created in order to promote valuable dialogues and collect useful information (see Figure 6.1)

Figure 6.1 The environmental overview of the interviews with healthcare professionals and the observations in hospital.

This process started with me individually interviewing the occupational therapist and nurse. After I interviewed the nurse, I observed the central kitchen in the hospital. As I discussed in Chapter 5, by doing it this way, it provided the opportunity to explore issues from my observations in the following interviews with the dietician and so on. Interviews took place in the healthcare professionals' workplaces. In each interview, I began by thanking the healthcare professional for her participation and recapitulating the initial information given to them in order to clarify any issue. Afterwards, they signed a consent form (see Appendix K).

Starting the dialogue with each healthcare professional, I invited her to talk about her experiences and practices in stroke rehabilitation following the topic guide, as I discussed in Chapter 5, with an aim to explore information related to the three themes: i) the main impacts of stroke; ii) the stroke pathway; and iii) the mealtime for patients in hospital. In what follows I will illustrate the healthcare professionals' voices from their participation in these interviews as well as my observations at the time and place.

6.4 Findings

6.4.1 The main impacts of stroke

Using the topic guide (see Appendix E), the first issue explored was: *What, in your opinion, are the main impacts of stroke on patients that you treat, for each of the following elements: neurological, physical, social and psychological?*

The following section provides, from the analysis of the data, the themes and issues which were identified, using samples of quotes/statements made by the healthcare professionals. In their responses, the healthcare professionals expressed their views demonstrating the neurological impacts associated with physical and cognitive impacts. In other words, they revealed stroke as a neurological injury which has an impact on areas such as those related to the cognitive, physical and psychological.

Cognitive impacts connected to the patients' capabilities to understand and communicate

Cognitive impacts are those related to the relationship between patients' difficulties in understanding and communicating with others, while the evidence of physical impacts were shown to have a strong link to patients who presented swallowing difficulties.

> *HP1_Nurse: Understanding that they've had a stroke with their communication or dysphasia. (Line 25)*

> *HP2_Speech therapist: The neurological impact is why they have swallowing difficulty. (Line, 149)*

> *HP3_Occupational therapist: Perceptual or cognitive, sometimes it's kind of higher level more like the executive functioning it might be more they don't know how to plan a journey. (Line 65)*

> *HP4_Dietician: The neurological impact of dysphasia is a big thing, so a lot of the patients that have swallowing problems (...) they're not able to take a normal diet (...) there's the patients that can't eat. (Lines 62, 66)*

Physical impacts connected to the patients' bodily functions

The healthcare professionals revealed their views, demonstrating the importance and prevalence of physical impacts being connected to "bodily function". For example, the healthcare professionals described how these physical impacts cause patients' difficulties in seeing, swallowing and moving some parts of their bodies, such as an arm.

> *HP1_Nurse: Eyesight, their weakness, their swallowing. (Line 160)*

> *HP4_Dietician: Obviously a lot of patients (...) have an affected side, some of them (...) have difficulty (...) to eat to (...) manage to eat properly. (Line 78)*

Psychological impacts connected to the patients' emotions

Regarding psychological impacts, the healthcare professionals showed their views by demonstrating how these are connected to the patients' emotions. For example, they described psychological impacts by patients being depressed and demotivated due to the results of stroke.

> *HP1_Nurse: It's their understanding of the stroke and it's like (...) a grieving process that they're going through, their loss of limb function. (Line 40)*

> *HP2_Speech therapist: You're asking them to change something that was previously normal to them and eating and drinking is such a big accepted part of life, everybody does it, everybody does it every day. (Line 182)*

> *HP3_Occupational therapist: People think that they are different. (Line 85)*

> *HP4_Dietician: Psychologically, a lot of patients are very depressed after a stroke (...) whole life is changed (...) you can't do the things that you were able to do (...) their mood going down. (Lines 114, 117, 121)*

These examples seem to describe an "alienation effect" that serves to distance people from their previous conception of normality and normative expectations of themselves. Perhaps, these perceptions draw attention to how it would be beneficial to support "positive emotions".

Social impacts connected to the patients' participation in social situations

Additionally, the healthcare professionals' views revealed that people affected by stroke are also subject to cognitive, physical and psychological issues that cause further impacts. These include social impacts that having a strong connection to the patients' emotions and their subjective appreciation of self. For example, the healthcare professionals described social impacts, demonstrating how patients experience the discomfort of what they called "embarrassment".

> *HP1_Nurse: If there's problems with their eating and drinking, feeding themselves, not being able to see the other side of the plate or see their stuff in front of them,*

also a bit embarrassed if they are dribbling or if they can't, if they're not able to feed themselves. (Line 33)

HP2_Speech therapist: Eating and drinking is a very social thing if someone's on a textually modified diet it looks different from what other people are getting (...) visually has an impact on patients, so patients who have a facial droop or weakness can be quite embarrassed about eating and drinking in front of people because of loss of liquid, food, they might mess their top. (Lines 168, 175)

HP4_Dietician: A lot of patients have communication difficulties, a lot of them obviously can't feed themselves and drop food all over them and dribble that can put them off they don't want to be in a ward environment other people seeing them like that it can be quite embarrassing for them. (Line 95)

These views highlight attention to the patients' emotions at and during the mealtime. Healthcare professionals show that they know about patients' emotions but they seem not to emphasise any focus on how to support patients to feel comfortable rather than "embarrassed" at the time.

With such descriptions, the idea of sharing a meal, in this form of social interaction which brings people together, requires attention in order to explore to what extent the current mealtimes are encouraging socialisation rather than solitude post-stroke. In other words, supporting positive emotions in togetherness rather than loneliness.

In exploring the main impacts of the stroke, I intended to gain a comprehensive understanding of how the patients' conditions at the mealtime might be, post-stroke. These healthcare professionals' views revealed the issues (see Table 6.3) in relation to cognitive, physical, psychological and social impacts (see Figure 6.2). What this finding implies is an understanding that there are a number of issues that patients face at the mealtime.

Table 6.3 The types of impacts reported by healthcare professionals.

Healthcare professional	Frequency of mentioning impact	Impacts described in relation to cognitive, physical, psychological and social
HP1 (2x) HP2 HP4	4	Swallowing (physical/neurological)
HP1 HP2 HP4	3	Feeling embarrassed (social)
HP1 (2x) HP3	3	Understanding (cognitive)
PH1 PH4	2	Speaking (cognitive)
PH1 PH4	2	Weakness on one side of the body (physical)
PH1	1	Seeing (physical)
PH4	1	Low mood (psychological)
PH3	1	Feeling different (psycological)
PH4	1	Depression (psychological)
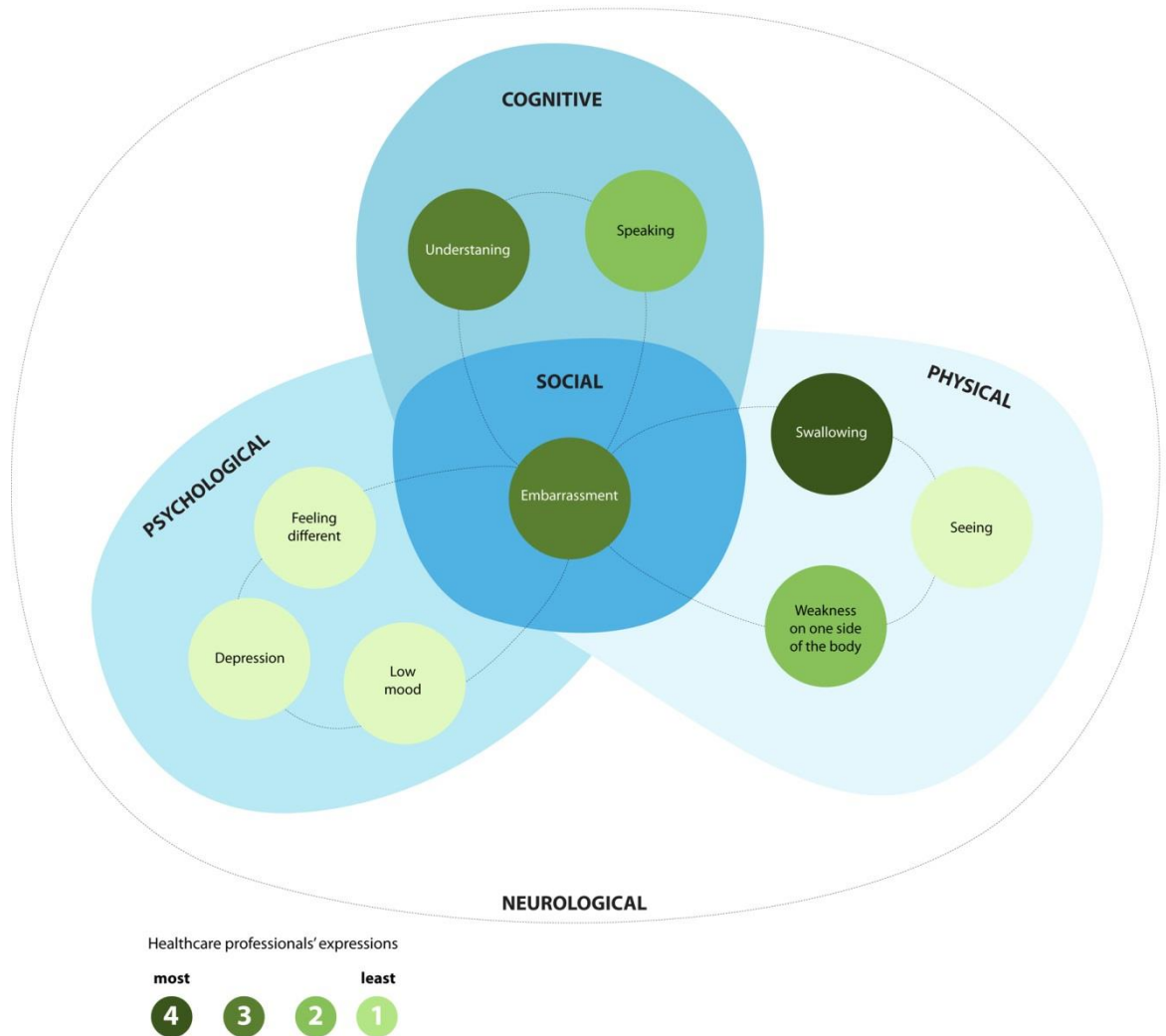
Figure 6.2 The healthcare professionals' views in the interview focusing on the main impacts of stroke.

The diagram illustrates what was revealed about cognitive, physical, psychological and social impacts through the healthcare professionals' voices. With such a visual illustration it is possible to identify clearly which elements were most or least often expressed by the healthcare professionals as discussed and evidenced through their dialogues. The visual characterisation of verbal responses is a valuable way to elucidate certain underlying concerns. By using a gradually deepening green, we can see, represented by the darkest green, which are the most frequently expressed issues regarding the impacts of stroke and the consequences for convalescence and recovery, in particular, as revealed in the mealtime experience. Consider, for example, how the issue of swallowing was expressed 4 times and that it is related to the physical impacts of the ability to eat. However, general bodily weakness and weakness on one side of the body were other issues associated with the physical. Speaking and understanding were identified as cognitive impacts,

demonstrating associations with communication and participation. This diagram (6.2) presents a visual organisation of stroke impacts in order to draw attention to the importance of the social impacts, which receive cumulative effects from the cognitive, physical and psychological impacts. However, this view of patients feeling embarrassed focuses attention on psychological issues, in particular because it was shown to be a frequently expressed issue. This diagram (Figure 6.2) also illustrates how social impact might possibly affect, in turn, psychological impacts. Think, for example, if a patient is suffering from depression and feels embarrassed in a social context, this might influence a focus on negative rather than positive emotions. The frequency of the mentioning of feelings of embarrassment on behalf of the patients in the dialogues revealed a strong emphasis on this issue, as perceived by healthcare professionals. From this illustration (Figure 6.2), we find that physical and psychological stress related to the mealtime is an issue that must be addressed in order to support and motivate patients as they enter the post-stroke recovery phase. Most importantly, it demonstrates that attention should be paid to how the mealtimes should support and encourage patients in ways that they can be made to feel more comfortable in socialising because this is part of the normalities of life. Before we start to explore these issues at the mealtimes in hospital, we will explore the stroke care pathway to better understand its role in stroke rehabilitation.

6.4.2   The stroke pathway

The second prompt question was: *Is this how you see the stroke pathway? If not, how would you draw this? Are there any stages missing?* In answering this question, the healthcare professionals expressed their views through discussing a diagram that illustrated the stroke care pathway which involves three phases: stroke treatment, stroke rehabilitation and stroke care at home (see Figure 6.3).
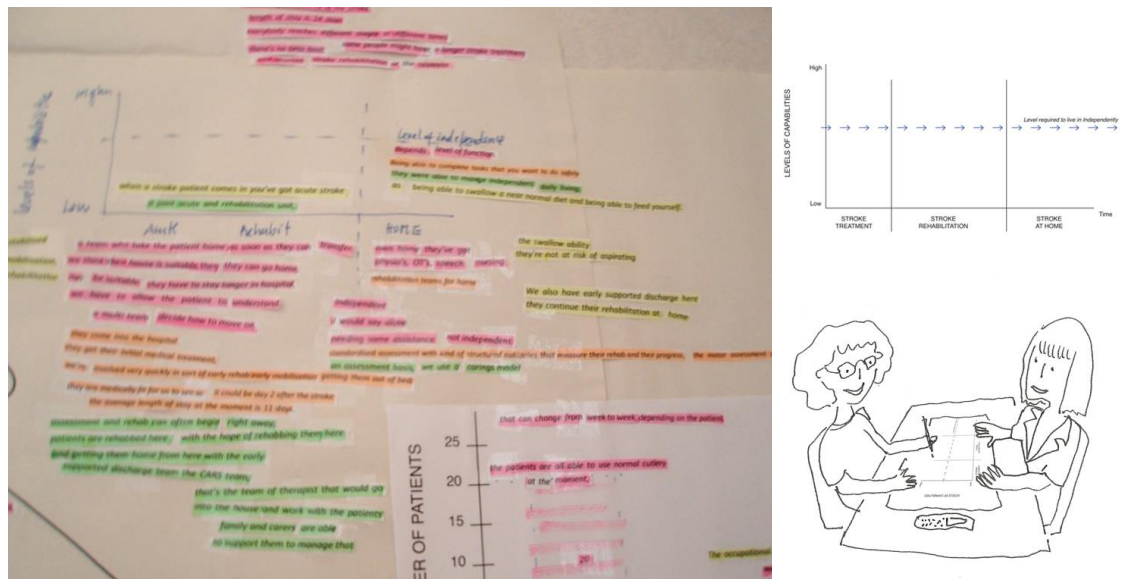
Figure 6.3 The healthcare professionals' views in discussing the stroke pathway diagram at the interview.

The use of this diagram in this question was integral to supporting communication between the researcher and the healthcare professionals. For example, illustrating the stroke pathway in sequential phases allowed the clarification of any issues. The healthcare professionals showed their views by demonstrating that stroke treatment and stroke rehabilitation are linked in the acute phase in hospital, which revealed a connection with stroke guidelines in healthcare (Scottish Intercollegiate Guidelines Network 118, 2010). In reference to acute care for stroke in hospital, the healthcare professionals described their day-to-day work experiences, for example, patients being admitted to hospital for diagnosis and the subsequent initiation of a treatment regime that was tailor-made to their individual needs. Regarding rehabilitation, they expressed it as a process that is introduced as soon as the patients are medically stabilised.

> *HP1_Nurse: We're acute stroke ward (…) we see them from the very start, from within 4 hours of their stroke. (Line 86)*

> *HP2_Speech therapist: The patients who come into the hospital who are suspected of having a stroke have a differential diagnosis of stroke have a water swallow test, a water screening by the nursing staff and myself and colleagues train the nurses to provide the screen, screening assessment (…) at an earlier stage I would say assessment and rehab can often begin right away, we use the early mobilisation*

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model (…) CT scan diagnosis(…)the rehab phase starts right away as soon as you put someone on recommendations. (Lines 48, 217, 222, 224)

HP3_Occupational therapist: They come into the hospital and they get their initial medical treatment, involved very quickly in sort of early rehab early mobilisation getting them up getting them out of bed. (Line 113)

HP4_Dietician: Initially (…) you've got acute stroke treatment medically (…) they've got to be stabilised (…) and then (…) they like to get them early mobilisation (…) acute can kind of overlap with rehabilitation. (Lines 133, 137, 140, 146)

In our understanding of these healthcare professionals' views of the stroke care pathway, the initial focus involves treatment and rehabilitation of those patients as, on the one hand, the healthcare professionals are treating patients recovering from stroke early on in the process. Acute care in the hospital setting, then, has a potentially significant role in the evolving patient "rehabilitation".

Through the dialogue, the healthcare professionals revealed that patients would also continue their rehabilitation, for example, at home and/or in a day hospital.

HP1_Nurse: We have a team who take the patient home as soon as they can transfer (…) they go to discharge and treat them from their own home, they've got physios, OT's, speech and language and nursing in that team. (Line 74)

HP2_Speech therapist: Getting them home from here with the early supported discharge team, the CARS team, that's the team of therapist that would go into the house and work with the patients, the intensity of therapy is much less. (Line 247)

HP3_Occupational therapist: They can then be referred onto rehabilitation teams for home but that's not always appropriate for everybody. They can also be referred to our day hospital. (Line 118)

HP4_Dietician: We also have early supported discharge where they go home maybe slightly earlier but they continue their rehabilitation at home and physios and occupational therapists will go into the home and they'll basically rehab at home. (Line 192)

Another important benefit of this understanding is the attention it draws to the patient rehabilitation journey. Fundamentally, as the healthcare professionals underlined, there is a patient rehabilitation journey from hospital to home, an issue which healthcare professional 3 reported did not always happen directly; patients might be required to go to a day hospital to continue their rehabilitation after acute care in hospital. With such a view, the stroke care pathway, in the form of demonstrated phases that involve hospital, day hospital and home, draws attention to the patient stroke rehabilitation journey (see Figure 6.4).
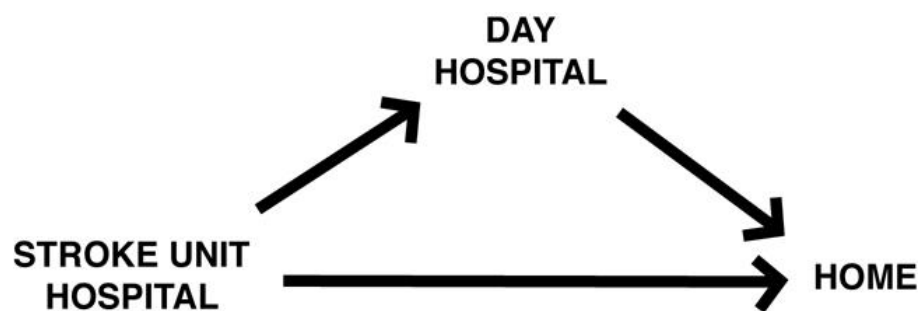
Figure 6.4 The healthcare professionals' views in the interview focusing on the patient rehabilitation journey after rehabilitation care at the stroke unit in hospital.

In this understanding of the patient stroke rehabilitation journey, as illustrated, recovery from stroke can be a lengthy process, involving the patients moving from acute care in hospital, possibly to a day hospital and at last to home to continue their rehabilitation. We found that the time involved in stroke rehabilitation was associated with individual needs; the healthcare professionals constantly revealed that "everybody's different". The time spent in each phase (acute care in hospital, day hospital and home) will depend on the impacts of stroke in each patient. In acute care in hospital, stroke rehabilitation tends to involve at least two weeks. Hence, in this research study, it was important to explore how the mealtimes are experienced by those patients who are recovering in acute care in hospital and, at the same time, to understand the healthcare professionals' roles within the mealtimes in order to support the patients' experiences, as we saw earlier when presenting special conditions.

6.4.3   The mealtime in rehabilitation at stroke unit in hospital

Initial explorations began by understanding the patients' experiences of the mealtimes. For example, the researcher initiated the dialogue by prompting the question; *How do these stroke conditions affect people at mealtimes?* The healthcare professionals expressed their views by demonstrating how the mealtime is associated with the patients' experiences of cognitive, physical and psychological difficulties in eating (see Table 6.4).

Table 6.4 The healthcare professionals' views in the interview focusing on the stroke conditions at mealtimes.

Cognitive	Physical	Psychological
Understanding	Swallowing	Low energy
Perceptual	Handling food on plate	Low mood
	Transporting food to the mouth	Depression
	Opening and closing mouth	
	Seeing food on plate	

Cognitive difficulties, as revealed by Healthcare Professional 2, were associated with the patients' abilities to understand when they would perform tasks.

> *HP2_Speech therapist: They might have cognitive problems where they might be confused about mealtimes and still not sure how to use cutlery or use it in the right way. They might just look at the plate and not do anything with it. (Line 346)*

This healthcare professional's view highlights attention to explore how the mealtime might be improved by possibly considering alternatives to guide patients who experience confusion or misunderstanding while eating.

All healthcare professionals highlighted in their dialogues that patients experience physical difficulties. The healthcare professionals expressed their views by discussing physical difficulties associated with swallowing, handling food on the plate, transporting food to the mouth, opening and closing the mouth and seeing food on the plate. Significantly, swallowing difficulties were described as being problematic, involving patients eating texture-modified food (food as treatment) called "textures" and requiring controlled eating, as also described in stroke guidelines (BDA 2009; Scottish Intercollegiate Guidelines Network 118, 2010). Issues around handling food on the plate, transporting food to the

mouth and opening and closing the mouth were related to paralysis and/or weakness on one side of the body. For example, the healthcare professionals expressed their views, describing how the patients experience reduced physical mobility while eating. The patients also experienced difficulties in being able to see food on the plate according to the healthcare professionals.

> *HP1_Nurse: Swallowing, seeing the food in front of them, actually managing to feed themselves, textures. (Line 174)*

> *HP2_Speech therapist: Swallowing difficulties so they might only manage a small proportion of what they've been given to eat, they might be given a full meal and they only manage little bits of it. (Line 334)*

> *HP3_Occupational therapist: It can include visual problems, so if they have a hemianopia they won't see everything that's on their plate so they would only be eating half of what they were getting. The physical problems of not being able to actually physically eat or drink, swallowing. (Line 215)*

> *HP4_Dietician: a lot of them, might dribble or lose a lot of food out of their mouth, won't actually be able to manipulate the food and move it round their mouth adequately (...) not being able to actually feed themselves (...) there's some patients who lose a lot of their food from their mouth if they've got spatial awareness problems like hemianopia the would only see half the plate (...) some of them their coordination really bad (...) they'll miss their mouth so physically there can be a lot of problems (...) blurred vision they can't see what they're eating. (Lines 80, 382, 384, 388, 391)*

These healthcare professionals' views draw attention to the importance of physical interaction with food and tableware in order to support patients. Physical interactions, as described, might possibly influence the patients' emotional reactions to unpleasant experiences, such as dribbling and losing food out of their mouths, rather than pleasant experiences.

One healthcare professional expressed the difficulties that occur at the mealtimes that are associated with the patients' emotions. The patients' emotions were described as being low, post-stroke.

HP1_Nurse: Energy, their mood's low due to their stroke they don't want to eat, don't want to drink. (Line 186)

Hence, the mealtime might become significant in order to stimulate the patients' thoughts in more positive ways. By beginning the mealtime exploration through an understanding of the patients' conditions while eating was important. This view generated an interest in exploring how the current mealtime is planned in order to support cognitive, physical and psychological needs in the acute care setting in hospital. The following explorations will show who plans the mealtimes and also what their roles are within stroke rehabilitation in acute care in hospital.

The following question was posed: *Can you describe a typical mealtime assessment session with a stroke patient?* In their answers, the healthcare professionals revealed their views associated with their roles within stroke rehabilitation with a special focus on the mealtimes in acute care in hospital (see Table 6.5).

Table 6.5 The healthcare professionals' views in the interview focusing on their roles during mealtimes.

Healthcare professional	Role
Nurse	To assess, record, monitor and assist the patient's ability at mealtimes every day.
Speech Therapist	To assess, manage and treat the patient's communication and swallowing difficulties.
Occupational Therapist	To assess the patient's physical and functional ability to perform eating to identify their disabilities and plan goals to recovery.
Dietician	To plan and monitor the patient's dietary and nutritional requirements every day.

HP1_Nurse: We actually stand with them for their first time to see what they can do for themselves, we bring their food over to them, we cut their food up, we see if they need fed, we see if they can see the things in front of them. (Line 134)

HP2_Speech therapist: I would do an oral motor examination, which would involve looking at all the musculature for eating and drinking, so lips, tongue, jaw, cheeks (...) so I can grasp the range, strength and movement. Is there a weakness on one

side move, difficulty with lip sealing (...) also looking at a patient's voice quality, their ability to cough effectively (...) I need to look at the clinical picture, are they currently receiving antibiotic therapy for chest problems (...) all make my decision around whether or not I would go ahead and give them something to eat or drink at that stage. I then would try them with different textures of food (...) I would decide on what texture diet (...) they can be (...) I usually would then feed back (...) to the nursing staff. We have boards that we use at the bedsides which are speech and language therapy feeding guidelines (...) I would make recommendations. (Lines 68, 72, 76, 81, 91, 121, 139)

HP3_Occupational therapist: We have a discussion with the patient about what their perceptions of how they were doing before (...) what they want to focus on, a lot of the time in here one of the focuses is getting to the toilet so managing their clothes themselves managing to get on and off the toilet or it might be washing and dressing (...) we would identify with the patient what we were going to aim to do so what goals and we would just document them all down and share them with the multidisciplinary team. (Lines 41, 47, 51)

HP4_Dietician: I would prescribe a treatment plan for these patients and then I would monitor their weight, monitor their bloods look at what activities that they're being able to engage in and also check their intake that they are meeting their requirements fully and then I would alter the treatment plan accordingly. (Line 53)

What seems to be illustrated here is an understandbly "medical" approach to stroke rehabilitation, involving multiple disciplines at the mealtime. Taking into consideration this view of the mealtime as a multidisciplinary approach, which advocates the contribution of different healthcare professionals involved in different responsibilities, we understand that the nurse participates in the process as a deliverer of the patients' meals as well as in supporting and helping them while eating. In contrast, the speech therapist contributes as a food planner in recommending the most appropriate food textures with the aim of treating swallowing difficulties. The occupational therapist provides the role of the "personal trainer", working with the patients physically in order to help them to be able to manage their tasks within their daily activities. The dietician takes on the role of the diet planner in providing a nutritional meal. Hence, we can understand that the mealtime might involve three stages: before, during and after (see Table 6.6). The stage "before", involves

the speech therapist, the occupational therapist and dietician in meeting patients to plan

their meals as well as providing them with training for their physical performance. In the

"during" stage, the nurse is involved in delivering meals and also supporting patients while

eating. The stage "after", involves the team meeting together to evaluate the patients'

performances. The following explorations will show a plan of the healthcare professionals'

roles in each mealtime stage.

Table 6.6 The mealtime showing the healthcare professionals' roles in three stages: before, during and after the meal.

Before	During	After
Speech therapist Occupational therapist Dietician	Nurse	Nurse Speech therapist Occupational therapist Dietician
Planning and producing meals Training patients' physical performance	Delivering meals Supporting patients eating	Evaluating patients' performance

Before

Understanding this plan led to explorations where the food and the tableware became

important elements to understand. As we mentioned earlier, patients are experiencing a

diversity of difficulties in their ability to eat during their stroke rehabilitation. In answering

the question, *Is this how you see the texture of food for patients with stroke? If not, how*

would you explain this? Is there any type of food missing?, the healthcare professionals

expressed their views through a diagram that illustrated different types of food involving

six scales of textures: a) smooth and pourable; b) smooth and thin; c) smooth and thick

purée; d) moist and some texture; e) soft moist; and f) solid (see Figure 6.5).
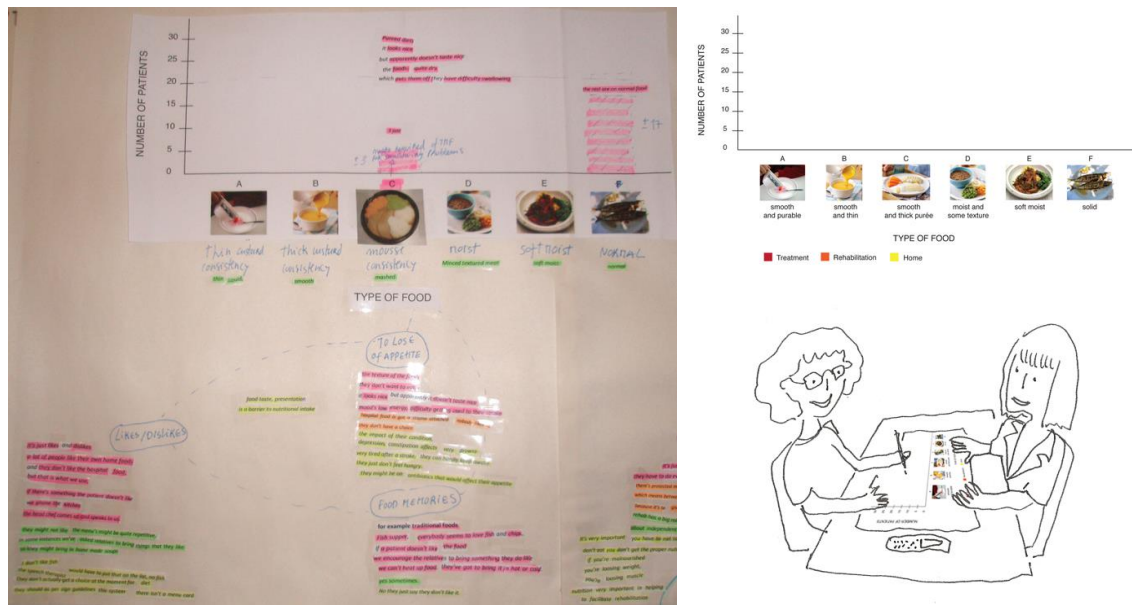
Figure 6.5 The healthcare professionals' views in the interview focusing on the texture of food for patients affected by stroke.

Using this diagram helped to obtain a better understanding of the types of food that patients are experiencing in rehabilitation. For example, by illustrating the different texture of food allowed clarification of what is habitual. The healthcare professionals showed their views connected with the national descriptions for texture-modified food as guidelines to provide food in hospital (British Dietetic Association, 2009).

> *HP4_Dietician: A lot of stroke patients actually manage thicker purée better than thin (...) a lot of patients (...) don't tolerate normal fluids, the diet has to be thickened or pureed because if it's fluid it would just trickle into the airway (...) a lot of the stroke patients might be on thickened fluids (...) if you can imagine like, say a soup that has potato or pasta in it, liquidised it would be kind of thick, kind of puree, smooth or like a custard consistency or like a yogurt consistency where it just doesn't run there is a thickness there that can be I mean you take that into the mouth it forms more of a bolus (...) a kind of a ball (...) it gives you more control as it goes down so that's better than a thin liquid (...) there are national descriptors the speech therapists, that's what we follow. (Lines 452, 455, 459, 461, 467, 475)*

This healthcare professional's view demonstrates the significance of texture-modified food in describing the scale of textures in order to eat safely. In reference to texture of food, two healthcare professionals described it as being associated with the sensorial experience.

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HP1_Nurse: Pureed diets, it looks nice but apparently doesn't taste nice and sometimes the food's quite dry as well which puts them off, they have difficulty swallowing and it's just likes and dislikes a lot of people like their own home foods and they don't like the hospital food, but that is what we use (...) I think there are 3 just now that are on textured diets the rest are on normal food. (Lines 195, 207)

HP4_Dietician: They don't like the food a lot of the texture modified diets are not particularly nice looking (...) so a lot of them just look at it and they think I don't want that, a lot of them say I'm not eating that main course I don't like the look of it, I don't like it. (Lines 311, 348)

This view draws attention to the patients' emotions at the mealtime where food seems to be discouraging rather than encouraging. However, as we understood earlier, food shows significance at the mealtimes in order to keep patients nourished and safe. In attempting to understand the sensorial aspects related to food, the researcher requested permission to observe the preparation of the texture-modified food (see Figure 6.6).

Figure 6.6 The researcher's observations in the kitchen focusing on the texture-modified food.

The figure illustrates a type of texture-modified food as a meal for patients. Although the researcher was looking at potatoes, carrots, peas and meat, they all have the same grade of

texture suited to a particular patient's needs. Observations were performed in the kitchen environment, which identified a food system, demonstrating that food is kept in frozen storage and regularly defrosted.

In this exploration, we understood that this is what patients can experience at mealtimes in rehabilitation day-to-day, perhaps over weeks and/or months. Hence, one reflection resulted in our attempting to understand the patients' thoughts of these mealtime experiences. Prompting the question, *How would you take into account patients' likes and dislikes about food?*, the healthcare professionals expressed their views related to the food system in hospital.

> *HP1_Nurse: We ask and then if there's something the patient doesn't like then we phone the kitchen and the head chef comes up and speaks to us (...) if a patient doesn't like the food we encourage the relatives to bring something they do like we can't heat it up they've got to bring it in hot or cold. (Lines 212, 220)*

> *HP2_Speech therapist: We're guided by what they, kitchen, are preparing, however, obviously if someone is showing signs that they are not eating (...) we can't directly address it but we would speak to the patient and if they were saying but I don't like that we're getting the same thing all the time (...) I would phone our diet chef and speak to them about it and say can we send up an alternative (...) we would also speak to the family members (...) they might bring in home-made soups. (Lines 407, 411, 416, 421)*

> *HP4_Dietician: If a patient said to the speech therapist I don't like fish then she would have to put that on the list, no fish. They don't actually get a choice at the moment for diet but ideally they should as per SIGN guidelines but the way this system is set up at the moment there isn't a menu card as such that you can say I want chicken today so at the moment (...) they wouldn't get that particular food. (Lines 537, 544)*

These healthcare professionals' views demonstrated that currently, food choice is limited at the mealtimes for patients. However, a healthcare professional revealed that it should be provided following National Health Service (NHS) guidelines. Alternatively, it draws attention to the importance of the patient's family in playing a significant role at the mealtime in order to provide food the patient likes. In fact, as we saw, food for patients has

specific recommendations, in particular for those who have difficulty swallowing. Hence, providing food that is appetising seems to become an important issue at the mealtime in stroke rehabilitation. In attempting to understand the question, *What causes them to lose appetite and interest in eating?*, the healthcare professionals added views demonstrating the relationships between patients' conditions post-stroke as well as about food.

> *HP1_Nurse: A lot of the time it is the texture of the food (...) it looks nice but apparently it doesn't taste nice (...) energy (...) their mood's low due to their stroke they don't want to eat, don't want to drink. (Lines 183, 184, 186, 187)*

> *HP3_Occupational therapist: I think hospital food has got a stigma attached (...) nobody likes it (...) it is quite repetitive (...) they don't have a choice (...) mood post-stroke is obviously a big issue so that could affect their appetite as well. (Lines 247, 250, 256)*

> *HP4_Dietician: Just the impact of their conditions, depression, constipation affects your appetite (...) very drowsy a lot of them are very very tired after a stroke, they can hardly keep awake some of them they just don't feel hungry. They could have an infection somewhere, they might be on antibiotics that would affect their appetite, various things. (Line 227)*

According to the healthcare professionals' views, we understand that the mealtime does not just focus on food. This seems to highlight a view of the mealtime as an activity where patients practice their swallowing and chewing, perhaps, redeveloping the strength of their facial and mouth muscles, for example, in the same way as they have to relearn walking. These views also draw attention to the need to stimulate and encourage patients in order to improve their mood and potentially get them interested in eating. In attempting to explore eating, another element to consider is the tableware. In understanding the tableware for patients, we prompted the question, *Is this how you see the stroke tableware standards? If not, how would you show this? Is there any type of product missing?* The healthcare professionals expressed their views through a diagram that illustrated three different types of tableware: a) standard tableware; b) standard tableware with adaptations; and c) specialised (or specially adapted) tableware (see Figure 6.7).
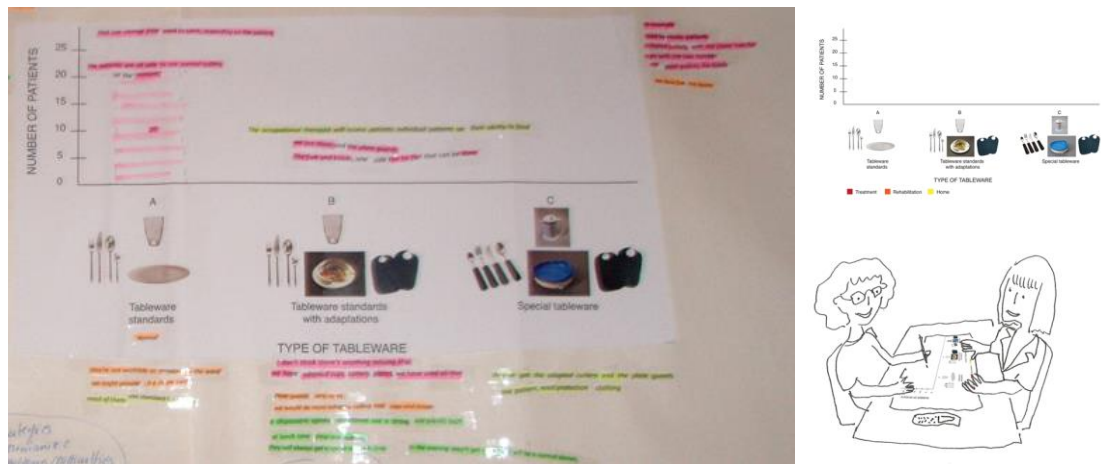
Figure 6.7 The healthcare professionals' views in the interview focusing on the tableware.

Using this diagram helped to bring forth a more rich dialogue about the tableware, where illustrating alternatives allowed the identification of what patients are using or not at their mealtimes. The healthcare professionals showed their views, demonstrating a relationship between usual and adapted tableware.

HP1_Nurse: The plate guards we use them (...) we would contact the occupational therapist to get these provided (...) adapted cutlery, with the foam handles, our cups with the two handles and the spout, the plate guards, the bowls that don't slide. (Lines 233, 236, 255)

HP2_Speech therapist: A disposable apron (...) cutlery (...) an adapted cup or sometimes use a straw, perhaps a special straw that's got like a vacuum in it, or I would encourage people as much as I can to use a normal cup (...) because of the connotations of child (...) they would probably use plastic cups rather than glassware. (Lines 438, 440, 447)

HP3_Occupational therapist: In this ward they have like a blue plastic (...) everybody gets (...) the dycem mat that sticks (...) we would do more adapted cutlery and cups and straws and things and dycem mat rather than the plate guards but they are available should they need to be. (Lines 276, 282, 291)

HP4_Dietician: They've got the adapted cutlery and the plate guards (...) it depends on the patient (...) if you're only using one side then you'll probably need a non-slip and the plate guard but you might be alright with normal cutlery (...) the occupational   therapist will assess (...) individual patients on their ability to feed

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and (...) they would organise (...) equipment at ward (...) if they maybe needed anything different. (Lines 559, 562, 568, 575, 579)

These healthcare professionals showed that tableware for patients can possibly involve a range of adaptations in order to address individual needs. Hence, the mealtime draws attention to the need to provide more personalised rather than general tableware. However, a healthcare professional pointed out the importance of encouraging patients using standard tableware in order to reduce stigma at the mealtime.

During

With such understanding of tableware to support patients' needs, we wanted to understand how tableware is supporting patients' eating, but also how the healthcare professionals are seeing the best way to do it. The healthcare professionals showed their views demonstrating stronger descriptions of patients eating.

> *HP1_Nurse: If they need assistance to cut up their food, if they're needing to be fed by staff (...) if the person needs their stuff put to the other side of the, that's not affected (...) our domestics come round and put their food on their table, they're not allowed to put it in front of them until we go there and assess the patient (...) cutting up food, putting in over on their table, making sure they've got it in front of them (...) physically doing what they can't do for themselves (...) and making sure things are in place (...) to encourage them to do it best as they can for themselves (...) keep their mood up. (Lines 125, 142, 149, 153, 164, 262, 264)*

> *HP2_Speech therapist: On the ward they probably get assistance with cutting foods up (...) you can have times where there is 5, 6, 7 patients requiring feeding on a 22, 24 bed ward (...) need assistance with positioning, getting them up into an upright position but often (...) they can feed themselves, depending on what hand that's been affected it might be their non-dominant it might be their dominant hand. (Lines 464, 323, 325, 327)*

> *HP3_Occupational therapist: I think you need to (...) assess what they can do for themselves first and allow them to do that safely and the parts that they are not able to do, you need to look at modifying it and in what way can we change it to allow them to be independent (...) there going to be someone (...) to do the cutting up (...)*

opening bottles, opening their jars if there's a sensory loss sometimes people don't know that they're holding the cup too tight and it's over spilling and things like that (...) just give them assistance when cutting up, provide them with equipment to overcome these problems. (Lines 316, 221, 236)

HP4_Dietitian: They've just got their own way of eating and their own style of eating some people like to have a drink in-between (...) you would want the patient to be as independent as they possibly can because I think they will eat more that way (...) it depends on their functional ability and whether they're safe enough to do that (...) a lot of patients are very drowsy, they need to be reminded to swallow, a lot of them forget the food's in their mouth, you've got to check their mouths you think they're actually swallowing and chewing but they're not (...) they would have to be supervised at mealtimes because of the risks associated with aspiration. A lot of patients need a lot of encouragement, a lot of those that are quite depressed you know they can't be bothered they would maybe need to be kind of encouraged with their meals. (Lines 601, 609, 612, 363, 367, 373)

From these healthcare professionals' views, we understand that patients experience personal assistance to eat with a strong emphasis on having their food cut up (Westergren et al, 2001a and 2002a). Alternatively, two healthcare professionals emphasised the importance of providing safe alternatives in order to allow patients to be more independent at their mealtimes, which healthcare professional 4 viewed as a stimulus to eat. These healthcare professionals' descriptions of what is happening also highlight a strong human interaction around the patients, providing supervision, support, help and encouragement during the mealtime (Perry and McLaren 2003; Medin et al., 2010). In order to obtain a clear picture of the patients eating at the mealtime, I requested permission to observe a mealtime in hospital, for example, at lunchtime. The figures below illustrate notebook notes taken and illustrations made in the stroke ward environment, which shows the mealtime as an experience involving three stages: before, during and after. In the stage 'before', the observations revealed patients waiting for food (see Figure 6.8).
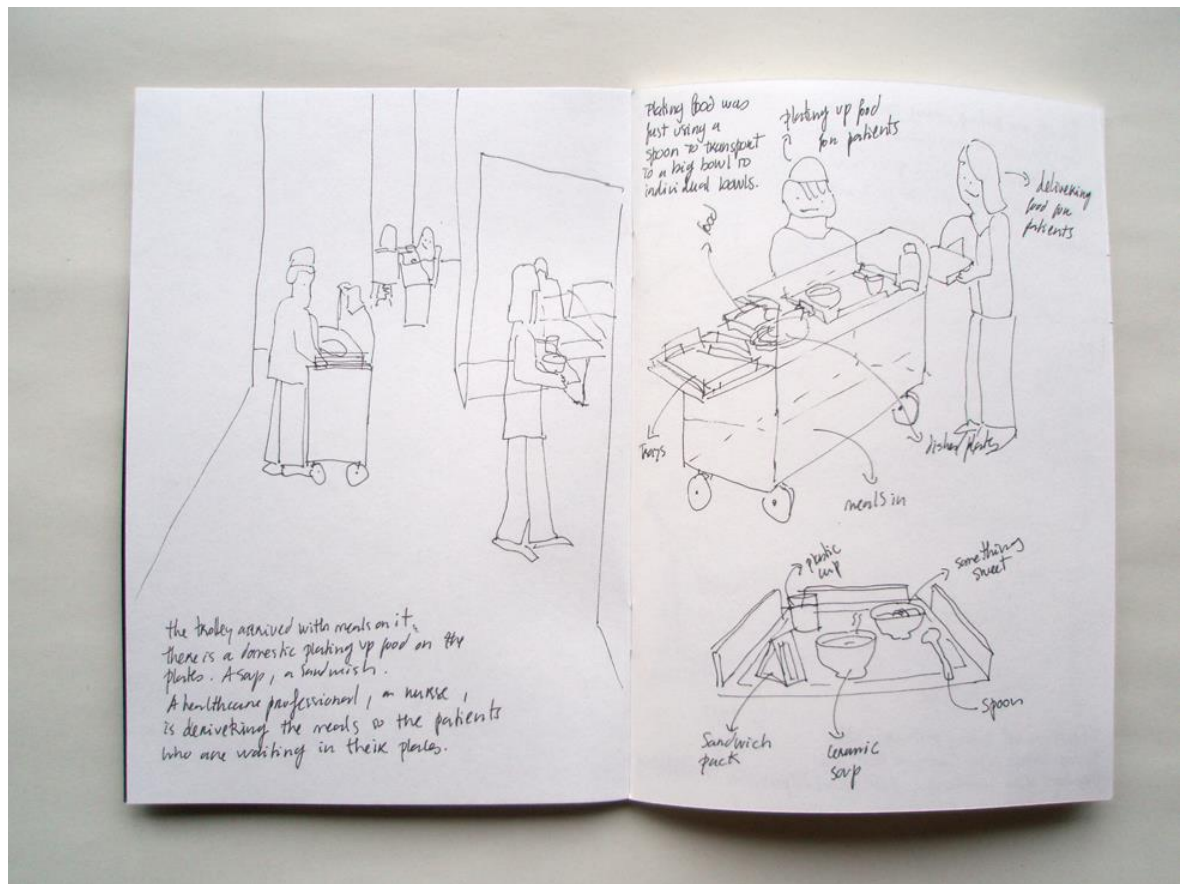
Figure 6.8 The researcher's observations at lunch time focusing on patients waiting for food while healthcare professionals preparing their food on a trolley.

While they were waiting at their bedside, the staff came with a trolley with food on it, which was stopped in each of the entrances to the patients' rooms in the ward environment. A dynamic of human interaction among healthcare professionals and catering staff was observed. The catering staff, also called "domestics", were plating up food on the trolley and healthcare professionals went in and out of the room speaking with patients. In the "during" stage, patients received their meals and were eating. The healthcare professionals, those who are referred to as nurses, delivered trays with food for each patient in their "4-bedded rooms" in the ward environment. Patients then ate at their bedside (see Figure 6.9).
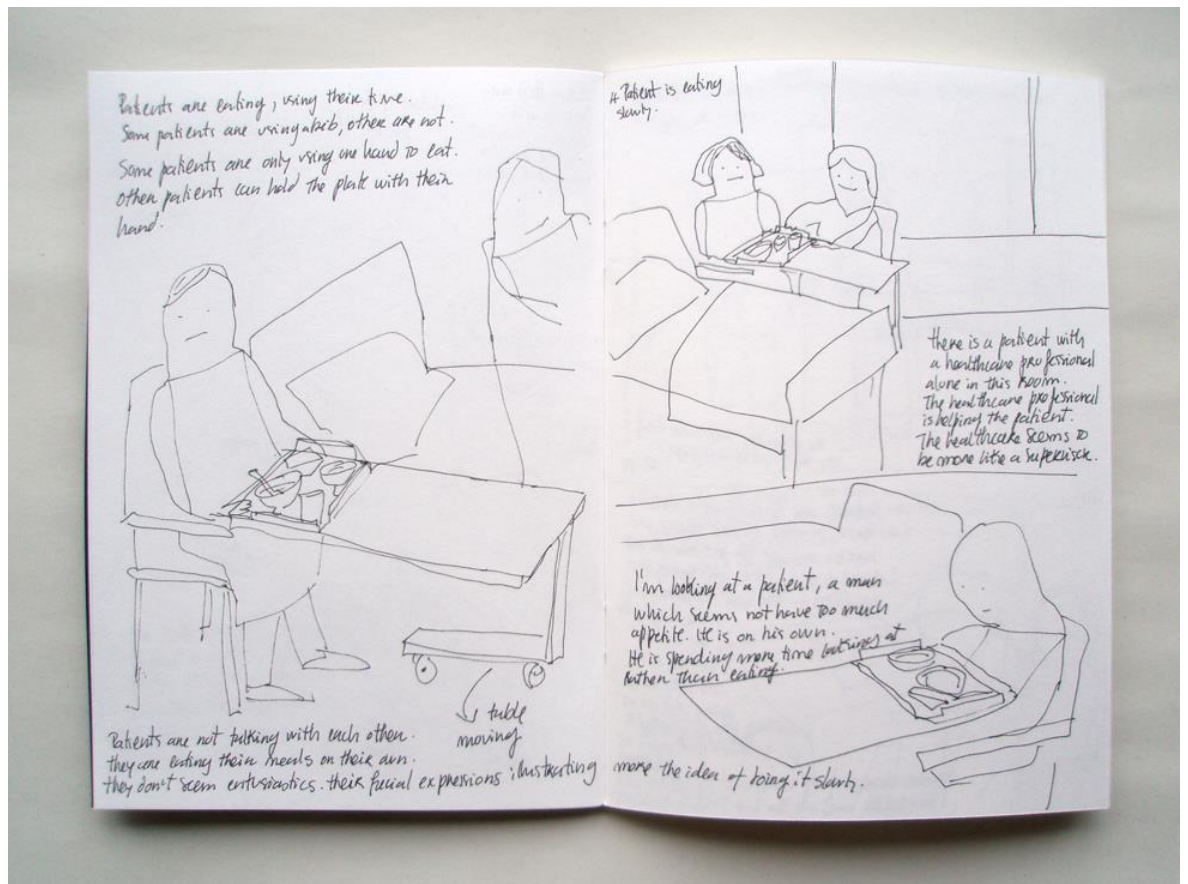
Figure 6.9 The researcher's observations at lunch time focusing on patients eating.

Patients appeared to focus on eating; they were not seen to be interacting with each other, for example, chatting. I found myself thinking about does it suggests that multi-tasking is difficult? Could patients only concentrate on a single task? Observations also identified a patient receiving assistance from a healthcare professional, by being fed in a separate room. Observations identified that the meal was the same for all patients; soup and a sandwich. After approximately 30 minutes, the catering staff came to take back the patients' trays (see Figure 6.10). Some patients remained in their seats doing nothing in particular, while others were watching TV.
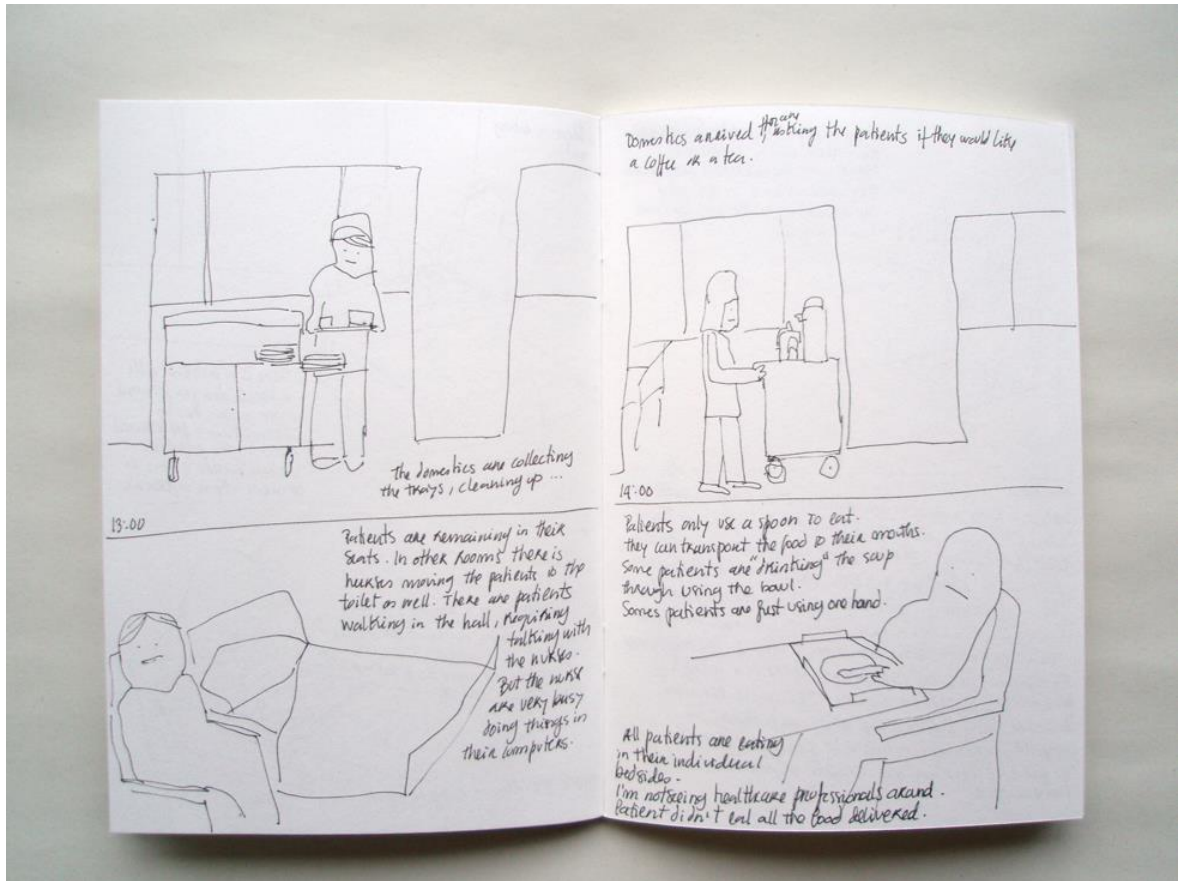
Figure 6.10 The researcher's observations at lunch time focusing on patients finishing their mealtime.

Observations were conducted in the ward corridor rather than in the patients' rooms (see Figure 6.11). The patients' rooms had big windows, which allowed good vision of what was going on from the corridor.
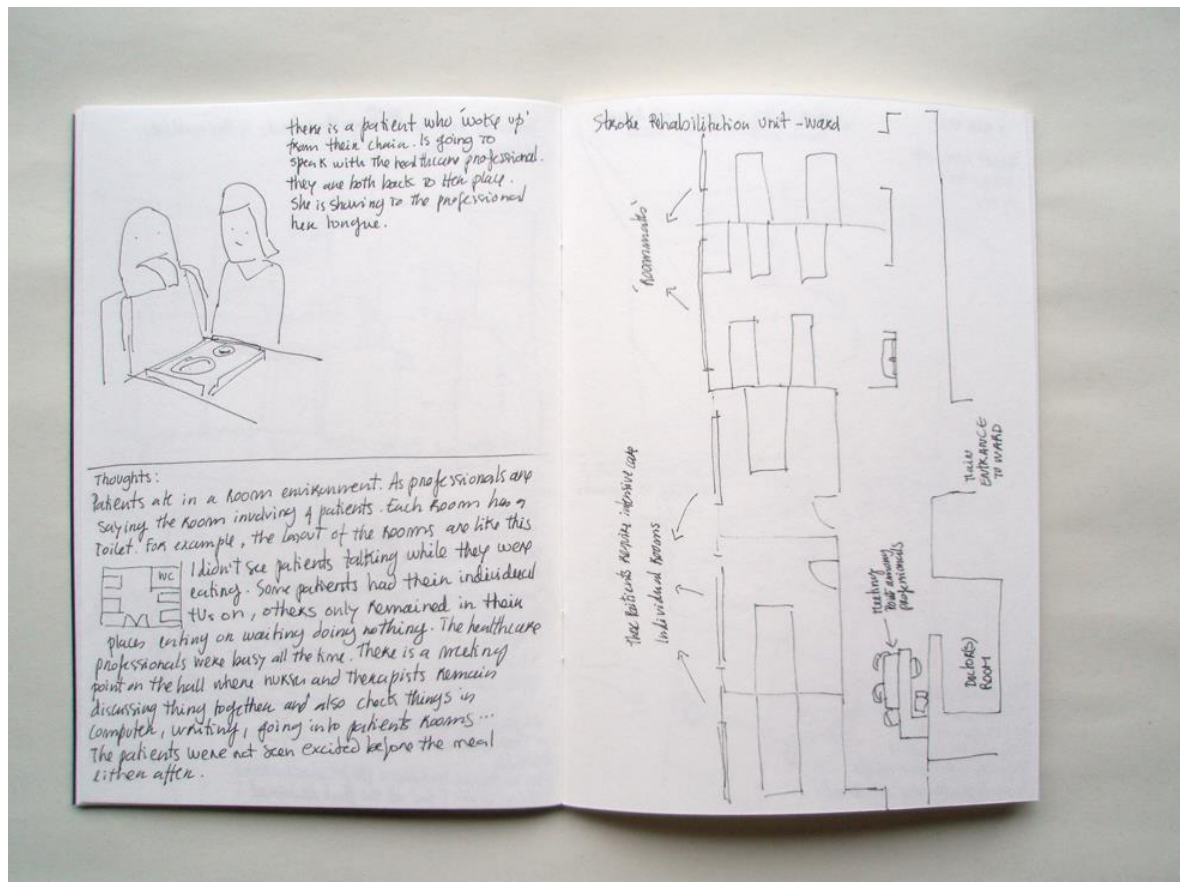
Figure 6.11 The ward environment.

In addition, mealtimes for patients in stroke rehabilitation follow special requirements, as one healthcare professional described below.

> *HP2_Speech therapist: We have protected mealtimes in the hospital (...) Patients aren't supposed to be getting therapy. They're not supposed to have visitors to allow them to have the time to be able to eat and drink and not feel embarrassed that there're people about coming in and out a hospital ward. (Lines 292, 303)*

Through observations, the mealtime was perceived with the strongest focus on a process of feeding patients, as also revealed by one healthcare professional.

> *HP4_Dietician: There are protected mealtimes, you don't get any interruptions at mealtimes (...) where the concentration is mealtimes (...) the main focus is eating. (Lines 683, 687, 691)*

However, as we mentioned earlier, the mealtime is not only about feeding. Issues such as those of the sensorial, physical and emotional require reflection, especially for those

patients affected by stroke. Views into this notion of evoking stimulation were considered significant in order to encourage and possibly motivate patients' interest in eating. Alternatively, the mealtime was displayed as a social experience. One healthcare professional viewed that social interaction happens at the mealtime, for example:

> *HP1_Nurse: They're all in the 4-bedded area rooms (…) they do tend to speak to each other during mealtimes and the staff pitch in with the conversations as well. (Lines 299, 300)*

From observations, I found that patients might possibly experience more loneliness rather than sociability. Consequently, this situation might adversely affect patients' motivation. However, the healthcare professionals viewed the mealtime as "a very social thing". Additionally, observations also revealed the patients' environment in transformation from a room with a more individual eating-place instead of a more communal one. Regarding the mealtime environment, one healthcare professional also highlighted the relevance of the sensorial experience.

> *HP4_Dietician: Other people doing the toilet in the ward at mealtimes, you know smells in the ward making them feel sick. (Line 317)*

This view draws attention to sensorial issues at the mealtime environment in order to provide a pleasant experience in hospital. The following explorations will show the healthcare professionals' view of the period after the mealtime.

After

In stroke rehabilitation, we understand the mealtime as being important to ensure the patients' recovery progress. As we mentioned earlier, it involves the patients' requirement for food as treatment, tableware to support individual needs, and also a multidisciplinary team with different responsibilities to ensure that patients are following an effective rehabilitation plan to aid recovery of their eating difficulties. Hence, the healthcare professionals' views within rehabilitation at the mealtime revealed the importance of day-to-day personal assessment.

HP1_Nurse: It's a multidisciplinary team approach, the physio's assessment and the speech and language assessment, the occupational therapist assessment and the nursing staff assessment (...) you take it on goals for each one (...) each area feeds back their findings for that day and we decide how to move on. (Line 45)

HP2_Speech therapist: Reassess if they are managing on that texture (...) they're reported to be managing by nursing staff (...) they need to be showing that they are not aspirating (...) they would need to be sustaining themselves nutritionally (...) they also might be getting monitored for progression of diets, there needs to be a nursing staff on their feed, monitor for signs of aspiration. (Lines 196, 198, 205, 275, 349)

HP3_Occupational therapist: We discuss progress on a daily basis (...) with physical problems we can compensate we can teach the patients compensatory strategies we can provide equipment to help (...) with feeding. (Lines 93, 73)

HP4_Dietician: I would monitor their weight (...) check their intake (...) I would alter the treatment plan accordingly (...) you've got to look at what they're actually managing and how we can supplement their diet that their meeting their requirements (...) we would discuss with the multi-disciplinary team then decide whether it was appropriate to put them on an anti-depressant, if their moods low that will affect their nutritional intake (...) I would look at the nutritional value of that intake (...) the nursing staff would feed back if there were any issues (...) they are assisted at mealtimes it's recorded exactly what they're eating because you need evidence to state the nutritional content of that meal. (Lines 54, 56, 50, 90, 121, 125, 214, 290, 396, 403)

What is highlighted here is a clinical control in order to maintain the patient's safety and to keep them on the right path to recovery. Furthermore, the healthcare professionals tend to often express concerns about the patients' "low mood". Stimulating the patients' emotions, as the healthcare professional above revealed, might be focused on taking medication, but it was revealed earlier that taking medication such as "antibiotics" can lead to patients' loss of appetite. Hence, the patients' emotions seem to be an important issue in design research into the improvement of the mealtime experience in order to stimulate more positive patients' emotions.

From such a perspective, the mealtime in hospital seems to present a picture in a way (see Figure 6.12) that draws attention to the patient experience. Illustrating the mealtime using a storyboard technique (Martin and Hanington, 2012) allowed me to map and see the emerging issues visually. This understanding revealed what is currently happening at the mealtime throughout the three stages: before (patient waits for his/her food), during (patient receives his/her food and eats it) and after (patient has eaten his/her food). Through these healthcare professionals' views, I found that the mealtime is approached predominantly with a clinical focus and any emerging issues are dealt with in a clinical manner. Although the healthcare professionals revealed some awareness of patient experiences more usually associated with the normalities of life, for example, using "normal" tableware, this situation reveals that there are other emerging issues, which need to be reflected upon. In what follows, I will underline the extent of these different issues, cumulatively, at the mealtime.
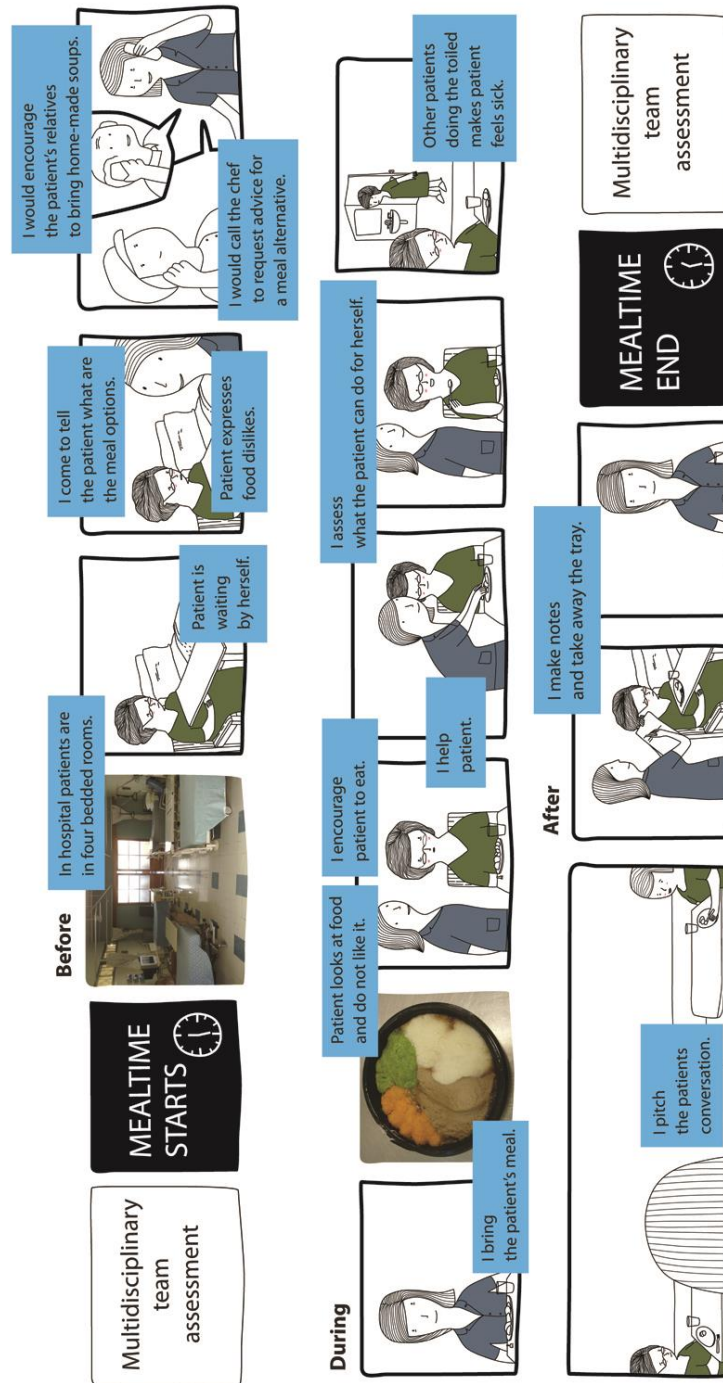
Figure 6.12 The present mealtime storyboard.

6.5   Giving healthcare professionals a voice

In this first phase of the research, as outlined earlier in this chapter, I aimed to elicit the healthcare professionals' voices to obtain an understanding of the mealtime from their experiences and also to allow building a storyboard (see Figure 6.12). Fundamentally, this

understanding allowed me to identify a number of issues (see Table 6.7) demonstrating how the mealtime is problematic in relation to the patient experience (see Figure 6.13).

Table 6.7 The extent of different issues at the mealtime that have emerged from the healthcare professionals' voices.

KEY ISSUES	HP VOICES
Swallowing difficulties	Patient needs texture modified food to restore functional swallowing
Difficulty with tableware	Patient needs help to cut up food and/or open bottles Patient needs adaptations
Unappetising food	Food not particularly nice-looking
Lack of personalisation	Patient would not get particular food Patient does not have a choice It is quite repetitive
Depression	Patient is taking anti-depressant
Infection	Patient is taking antibiotics
Fatigue	Patient needs to be reminded Patient needs to be supervised Patient needs to be encouraged
Lack of social dimension	Patient has protected mealtimes Patient does not get any interruptions The main focus is eating
Bad smells	The toilet in the ward makes patient feel sick
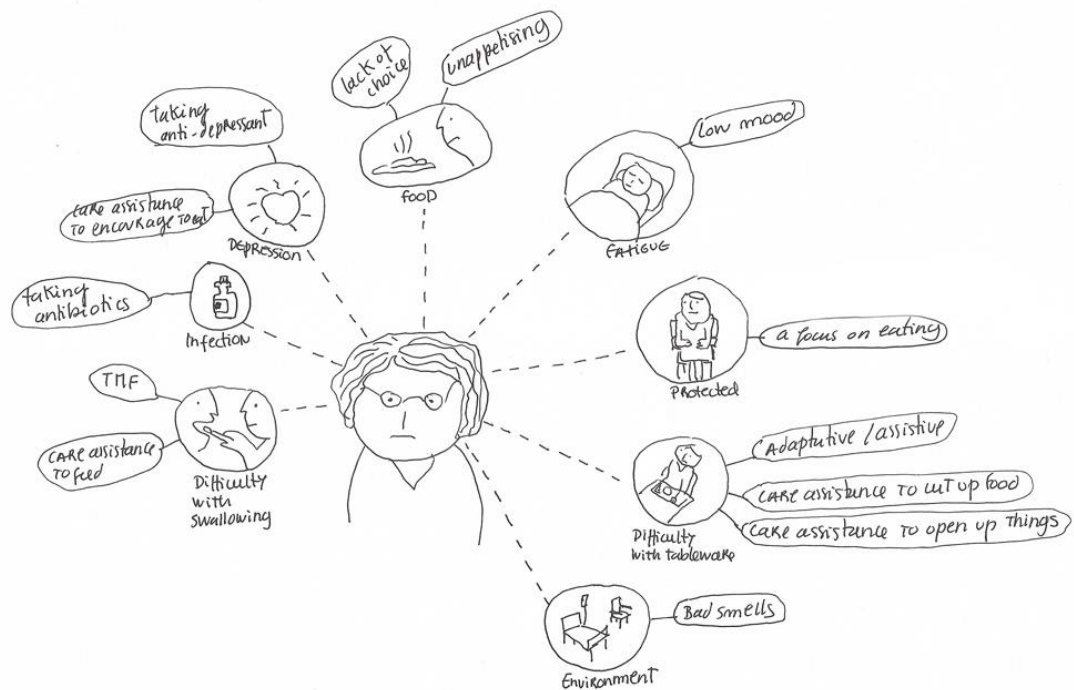
Figure 6.13 A conceptualisation of the main issues at the mealtime that have emerged from the healthcare professionals' voices.

In this visual illustration (Figure 6.13), it became apparent that the mealtime is considered from a medical approach and emerging issues are "medically" treated (Medin et al., 2010; Perry and McLaren, 2003; Westergren et al., 2001a). Consider, for example, how patients with an infection and/or depression might take antibiotics and/or anti-depressants. In fact, patients with swallowing difficulties require eating Texture Modified Food (TMF) to restore functional swallowing (Wright et al., 2005). Although clinical considerations are essential to survive and functionally recover, there are experiential considerations that seem to be missing in the present situation. Think, for example, of the appearance of the current food provided in hospital; as healthcare professionals expressed, it seems to be of poor quality and discourages the patients from eating so that healthcare professionals see the need to encourage patients by explaining the importance of eating. However, how can patients be encouraged to eat when they dislike the idea of eating and find the food unattractive? As healthcare professionals explained, food in hospital follows standard rather than personalised preparation and presentation. By doing so, patients "don't have a choice". Can receiving verbal encouragement make them feel motivated to eat in this way? Eating brings another issue: using tableware. Healthcare professionals indicated adapting tools for patients who have difficulty in using "normal" tableware. However, there is a pre-occupation in encouraging patients to use normal tableware rather than using adapted

tableware due to its association with "the connotations of [a] child". In exploring the social context at the mealtime we found that it is protected (Naithani et al., 2008). In other words, patients "don't get any interruptions" at the mealtime, as the main focus is on eating. Although healthcare professionals recognise that the mealtime is "a very social thing", the patients' socialising shows a lack of dimension. However, social issues seem to be important as healthcare professionals indicated that patients can experience feelings of embarassment when they reveal their conditions in public (Perry and McLaren, 2003). In hospital, as we understood earlier, patients share the mealtime space, for example, healthcare professionals illustrated an element of socialisation, indicating that patients should talk with each other from their bedsides and the nurse should start the conversation. Is this how patients see themselves socialising? Tiredness and fatigue are other issues. According to healthcare professionals, the patients' emotions post-stroke are "a big issue" which can affect their motivation to eat.

What this research study supports here is the need to explore how the mealtime could potentially play a more important role in promoting enjoyment and improving subjective well-being at this time. Could looking at the inter-relation of physical, sensorial, social and emotional issues enable us to identify further issues about the patient experience at the mealtime in hospital? It is relevant to address issues, not only of functionality, but also of enjoyment and pleasure (Norman, 2005) because a person's emotional response reveals the quality of their experience. What it highlights here is the importance of understanding, from the patients' perspectives, what they think and feel (Sanders, 2001) about the mealtime as an everyday experience in hospital and how such experience is perceived in terms of emotional response. Is it positive or negative? Why? This part of my research explored how patients make sense of their experiences at the mealtime in order to understand the quality of experience in the present situation. Understanding the patients' emotions and motivations when experiencing the mealtime allowed me to build a scenario of the existing mealtime (Truong et al., 2006). Constructing a scenario, as I discussed in Chapters 4 and 5, allowed me to accomplish the aim of revealing valuable information from both healthcare professionals' and patients' voices, each of whom have different roles at the mealtime. Moreover, this method might help to evoke reflections on the context of design (Carroll, 1999) while also supporting the next designed situations to proceed into explorations for the future.

6.6 Summary

In summary, I have presented the findings from the first phase of the research, which were the main impacts of stroke, the stroke pathway and the mealtime for patients in hospital. In describing the findings from the impacts of stroke, I illustrated cognitive, physical and psychological impacts and found that healthcare professionals' voices highlight attention to the patients' emotions. By examining the stroke pathway, I found that patients in stroke rehabilitation units in hospital tend to follow two care paths: to go directly home, and/or attend day hospital first and then go home. In the findings associated with the mealtime experience I found that patients face a number of eating difficulties, a multidisciplinary clinical team with different roles in planning the patients' meals, and the mealtime involving three stages: before, during and after. I concluded by demonstrating the development of the mealtime storyboard as a device that allowed me to reflect and highlight aspects of the mealtime experience that require further consideration in order to "infrastructure" (Bjögvinsson et al. 2012) the subsequent investigations in this research. In the following chapter I will present the next phase of the investigations, designed to obtain an understanding of the patient experience from the patients' views because they are "the virtuosos of the experience" (Sanders, 2001).

7

Findings from Phase 2: Exploring the patients' experiences

7.1 Introduction

In the previous chapter, a representation of the present mealtime was illustrated through a storyboard based on the healthcare professionals' voices and my observations in hospital. I identified that the current mealtime reveals a focus on physical and clinical aspects of eating and the mealtime in stroke rehabilitation. In reflecting on these healthcare professionals' views, the issues that they raise draw attention to the patients' emotions in experiencing this situation; fundamentally, how they (healthcare professionals) view the patients' situation. Patients are those who live and relive temporary experiences at the mealtime in hospital. Hence, they are considered a significant source to understand experiences at the mealtime, and, most importantly, the importance of their voices in developing the present mealtime scenario must be acknowledged.

In this chapter, in contrast to the previous chapter, I will show the patients' voices, revealing their views and perspectives about the mealtime during stroke rehabilitation in hospital. With this research, Phase 2, I aim to demonstrate the patients' experiences and how these differ from those of the professionals. Fundamentally, I aim to understand their experiences before, during and after the meal. The patients' voices illustrate personal experiences while recovering from stroke in hospital. With such an approach, I intend to show perspectives from those who live and relive experiences at the mealtime while undergoing stroke rehabilitation, as I mentioned in Chapter 5, section 5.2.3. Furthermore, it is a research process which begins to obtain information to build the present scenario as a basis to explore the future.

This chapter begins by describing who participated in this study, presenting a diversity of patients under different stroke care circumstances within the Stroke Rehabilitation Unit, as I mentioned in Chapter 5. By presenting the findings from this study, I illuminate individual experiences perceived throughout the mealtime stages. In these individual experiences, I found emotional responses, both positive and negative. Emotional response is related to experiential issues such as those of the sensorial, physical and social.

I will demonstrate that when combining the mealtime storyboard with the conceptual framework, as I discussed in Chapter 5, section 5.3.2, it helps to show a clear picture of the experiential issues associated with the quality of the patient experience. As I discussed in Chapter 5, the patients' experiences brings forth different perspectives from those of healthcare professionals because they play a different role at the mealtime. This research study considers both the patients' and the healthcare professionals' voices as being valuable to provide an understanding of what is happening at the present time.

In conclusion, this chapter will demonstrate that the patients' voices were significant to reveal the present mealtime scenario, perhaps illuminating ways to explore the future in order to explore how to promote the quality of the patient experience at the mealtime in stroke rehabilitation in hospital.

7.2   Who participated?

The participants in this phase of the study were five patients; at the time they were all outpatients of the stroke rehabilitation unit but still patients undergoing a recovery process at home and/or in day hospital-based care, as described in Chapter 5 (see Table 7.1). These patients presented an array of different needs during their stay in hospital, and, as such, these patients are considered to represent "the real virtuosos" (Sanders, 2001) of the mealtime experience within stroke rehabilitation.

Table 7.1   The patients who participated in the interviews.

Patients	Time in hospital at time of interview (in weeks)	Stroke conditions	Age	Gender
P1	15	Swallowing difficulties Cannot speak Cannot walk	66	Woman
P2	15	Swallowing difficulties Cannot get up out of bed	52	Man
P3	2	Paralysed on right-hand side	26	Woman
P4	5	Swallowing difficulties Weakness on one side	75	Man
P5	1	Paralysed on left-hand side	61	Woman

The table above illustrates who participated in this phase of the research, illustrating the characteristics of the patients in relation to their unique identifier code, time spent in hospital (at time of interview), stroke conditions presenting difficulties to eat, age and gender. By illustrating the patients' characteristics, I have introduced those who participated in this part of the study, endeavouring to include a sample with wide-ranging difficulties and experiences. The following sections will focus on describing how the interviews were conducted.

7.3 Conducting interviews, combining tools and techniques

Previously, in Chapter 5, section 5.3.2, I discussed how I conceived this study. Here I will demonstrate how the interviews, combining tools and techniques, were conducted (see Table 7.2) and what the findings are from them.

Table 7.2 Conducting interviews with patients

Interviewing				
Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
46 minutes	25 minutes	27 minutes	49 minutes	22 minutes
Home	Home	Home	Home	Home

The table above illustrates each design situation, revealing who was interviewed, the length of the interview and where it took place. Before I start to describe how these interviews were conducted, it is important to explain first how these socialised and materialised situations were created in order to support and promote a dialogue (see Figure 7.1)

Figure 7.1 The environmental overview of the interviews, involving the researcher (R), nurse (N) and patient.

A nurse attended each interview in the patient's home in order to indirectly support communication and assist the patient in any health circumstance if needed. Patient 1, who could not talk, used an iPad to write her views on the device and then the nurse would verbalise what she was writing. Next I interviewed Patient 2 who presented a sort of "dribbling mouth", and so I experienced some difficulty to understand his speech. The nurse would verbalise what he was saying to me when required, but also, verbalising what I was saying to him when required. Next I interviewed Patient 3, who presented weakness on one side of the body. The nurse would support any need that the patient had. With Patient 4, who presented a sort of "slurred speech", I also found some difficulty to understand his speech. Here, the nurse would verbalise what he was saying to me when required, but also, verbalising what I was saying to him when required. In interviewing Patient 5, the nurse would support any need that the patient had. In interviews with Patient 2 and Patient 4, the patients' relatives were around at the time, not directly participating, but assisting with our dialogue.

In each interview, I began by thanking the patient for her/his participation and recapitulating the initial information given to them in order to clarify any issues. I emphasised that his/her views were fundamental to this research study and that nothing that they would say would interfere or affect his/her rehabilitation care, which the nurse who attended the interview also confirmed. Afterwards, they signed a consent form (see Appendix D). When starting the dialogue with each patient, I invited him or her to talk about his/her experiences during a typical mealtime when he/she was in hospital, for

example, an evening meal. The discussion followed a topic guide and a storyboard, as I discussed in Chapter 5 (Appendix F), with an aim to explore information related to his/her perceptions of experiencing the mealtime throughout the three stages, such as before, during and after the meal. In what follows I will illustrate the patients' voices from their participation in this research study.

7.4 Findings

This section will discuss, in turn, the findings from the discussions with each of the patients who participated in the interviews. All patients were interviewed within six months of leaving the hospital.

7.4.1 Patient 1

Before

Patient 1 revealed that she had spent three-and-a-half months in hospital where she had had a Percutaneous Endoscopic Gastrostomy (PEG). A PEG, as the nurse explained, is a procedure to insert a feeding tube into the stomach that allows liquid feeds to be put directly into the stomach. However, the patient explained that she had also eaten some other food under strict supervision. For example, she said, "I could only eat a small amount when I started eating" as she could not swallow safely. Does eating food as opposed to being fed by tube make life better/easier/enjoyable? With such an understanding of the patient's conditions for eating, we wanted to explore how she perceived the mealtime as an experience. In showing her the picture (see Figure 7.2) illustrating the first stage of the mealtime, that is, before, when patients are waiting for their meals, I prompted the question *What happened before, when you were waiting for your food?*

Figure 7.2 Patient 1 in discussing her experience before the meal at the interview.

> *P1: Just organised myself (…) sitting there waiting for (…) food (…) I was hungry. (Lines 69, 72, 98)*

In discussing the moments immediately preceding mealtime, the patient revealed that her thoughts related to what she was doing and thinking at that time. Consider, for example, how the patient describes attention to the contextual environment and her state of mind in her quotation below. She also added:

> *P1: It was quiet (…) In bed [where she was sitting] (…) The toilet was next door to my bed (…) urine (…) the door was always open (…) Rattling of dishes (…) inconsistent (…) did no bother me [associations with the sound] (…) I was asked [associations with the act of receiving information about food]. (Lines 106, 113, 121, 128, 137, 140, 162)*

This view from Patient 1 shows a more individual experience. For example, the patient described a variety of experiences of sitting in her bed, listening, smelling and receiving verbal information. In our discussion, the issues related to the environment seem to highlight this issue of bad smells; in other words, unpleasant rather than pleasant experiences. According to the healthcare professionals, bad smells, those from the toilet, would make patients "feel sick", as demonstrated in Chapter 6. What seems to be highlighted in this view of the patient experience is her emotional response in confirming what healthcare professionals indicated was a poor quality environment at the mealtime, which is related to feelings that evoke displeasure rather than pleasure. The quality of experience here reveals how the patient is making sense of the moment of her experience. Fundamentally, it draws attention to environmental factors; those that can influence the patient to become demotivated instead of motivated to start the mealtime.

In prompting the question, *What kind of social interactions did you have at the mealtime in hospital?*, the patient expressed her thoughts in this way:

> *P1: The care assistants would talk to me (…) what they were doing outside the hospital, their children, etc. (…) I could not talk to the other patients [associated with her disabilities after stroke]. (Lines 185, 193, 189)*

In discussing the social context, the patient revealed her experiences of socialising associated with her disabilities. For example, the patient described experiences of listening rather than taking part in the conversation due to her inability to speak.

During

In showing the picture (see Figure 7.3) illustrating the second stage of the mealtime to the patient, that is*, during*, when patients are receiving their meals and, consequently, eating, I asked the question; *Is this what the food looked like? If not could you describe it?* Asking this question immediately triggered an emotional reaction from the patient.

Figure 7.3 Patient 1 in discussing her experience during the meal at the interview

> *P1: Not appetising, not appetising (...) not appetising, it looked like a normal meal but not looked at (...) it looked like vegetables mashed and in the shape of meat (...) did not look appetising (...) it was not nice (...) I could not eat like other (...) watching other patients (...) to see what they were eating (...) I imagined I was eating (...) I wish I could eat normal meals (...) I could see other patients eating normal meals (...) and I couldn't. (Lines 210, 216, 220, 226, 239, 104, 149, 151, 9, 274, 280)*

What the patient shows here is her emotional response to the food's presentation. Her comments seem to reveal a lack of visual pleasure but also the lack of an appropriate environment suited to the patient's needs. Think, for example, how the patient reveals her emotions while "watching other patients" eating "normal meals" when she could not. Once again, the mealtime draws attention to the patient's emotions by highlighting that she feels socially excluded. This example also illustrates the common perceptions of unappetising food described by both the patients and the healthcare professionals, as demonstrated in Chapter 6. The healthcare professionals also highlighted that patients do not like the food but, according to healthcare professionals, eating is important to the patient's recovery

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because it restores functional swallowing and supplies vital nutritional benefits. However, this example draws attention to the relative likelihood of eating what is perceived to be unappetising and how it can make you feel sad, "do you eat when you feel sad?" (Vogelzang, 2008). What is emphasised from this view is that the current situation of the mealtime in hospital might not benefit the whole patient's needs; recovery is thus regarded as more functional, not taking into account that it is also a social and emotional activity. However, as demonstrated in Chapter 6, the mealtime is a normal day-to-day patient experience and should form a significant part of the patient's recovery process in hospital, in particular for those patients who present swallowing difficulties who might see their normalities of lives modified (National Stroke Association website). What these findings highlight here is the need to promote patients' well-being at the mealtime, and to ask if design can play a role here.

In attempting to understand what happened after, I asked the question; *Did you express your dislikes about the appearance of food to anyone?*

> *P1: No (...) did not think there was nothing that I'd get otherwise. (Lines 232, 234)*

What seems to be highlighted in this view is that the patient does not expect that her views about the food will be addressed. In fact, as demonstrated in Chapter 6, the healthcare professionals revealed views of food following standard rather than personalised service in stroke rehabilitation in hospital. This draws attention to the power of voices at the mealtime, revealing a "mute" patient who is denied a voice or who believes that their voice will not be listened to. This research study, in giving a voice to the patient, can empower the patient's voice. Healthcare professionals see the mealtime from a professional perspective, while the patient sees it from an individual view. Although healthcare professionals discussed pre-occupations with issues of personalisation, they revealed that the mealtime follows guidelines. However, the National Clinical Guidelines for Stroke recommends that rehabilitation care follows certain models so as to guarantee the delivery of the most effective care to individual patients (ISWP, 2008). From this patient's voice, personalisation of care in the context of the mealtime seems to reveal a gap between the guidelines/policy and what happens in practice. In asking; *Can you tell me about the care assistance during your meal?* She said:

> *P1: They would sit on a chair beside me (...) they would feed me with the aid of a teaspoon (...) just took my time to swallow (...) I was just starting to take a small*

amount of food (...) I was ok with them feeding me (...) they did not talk while I was
eating. (Lines 204, 175, 79, 167, 256, 206)

The view above shows the patient in physical contact with healthcare professionals and receiving assistance during the mealtime. In other words, it highlights that the mealtime is focused on the patient's eating and the consumption of nutrition rather than on socialising. Consider, for example, how the patient expressed physical experiences in her points about feeding, swallowing and eating. Although she expressed views such as "I was ok" associated with receiving assistance, being "ok" does not clearly reveal that she was pleased at that moment. As was garnered earlier, she does not like the food, she cannot talk and she needs help to eat: these physical disabilities may well have psychological and emotional consequences. Can we imagine the patient's state of mind at this stage? Think, for example, if the patient receives a high quality of food presentation, listening to music that she likes while at the same time someone helps her to eat, surely this would provide a more appropriate experience to promote recovery. Although the healthcare professionals demonstrated the importance of the patient concentrating on eating to restore the functional ability to eat, how can concentrating on solely this aspect of eating also allow them to experience personal pleasures of eating? Furthermore, how can personal pleasures contribute to their subjective well-being?

In describing the opportunities for socialisation or interaction during the mealtime, the patient expressed the limitations saying:

P1: No interactions (...) I can't talk. (Lines 266, 269)

What is emphasised from this patient's voice (and its silence) is that socialising is heavily reliant upon verbal expression during situations such as these. According to the patient, not being able to talk inhibits your ability to socialise, either with healthcare professionals, fellow patients or friends and family. However, socialisation can also involve an interaction between the social and the material (Ehn, 2008). In this example, the mealtime in hospital is an example of socio-material interaction as the precursor to the experience of socialisation; but without the ability to use the things (speech) that enable her to participate (interact) in the act of socialisation, the patient feels unable to take part. How, then, can the patient participate in the experience of socialisation by using more than the verbal interaction? Could design play a role in supporting patients to socialise? I continued to explore this possibility in discussing what happened *after* the meal.

After

In discussing the patient's experiences *after* the meal, I placed another picture on the table (see Figure 7.4) and prompted the question; *Can you tell me what kind of thoughts came to mind after this mealtime in hospital?* The patient immediately expressed her views, revealing her emotional response to the quality of experience.

Figure 7.4 Patient 1 in discussing her experience after the meal at the interview.

> *P1: None of them were better than the other (...) not good (...) half an hour, I took a rest. (Lines 288, 295, 91)*

In this description, this patient seems to demonstrate her experience at the mealtime in hospital in a way (see Figure 7.5) that draws attention to the emerging issues in relation to the patient's emotional states, as positive or negative, throughout the mealtime stages: before, during and after. Looking at the illustration below (Figure 7.5), it is clear that this issue requires attention, in particular when we consider that the patient spent three-and-a-half months in hospital recovering from stroke. This issue of time seems to be important in this context of the mealtime, as it becomes a normality of the patient's life. Although the patient revealed her experiences to be negative, she also recognised the importance of eating in order to recover faster. For example, she reported:

> *P1: The meal was recorded on a chart, what I eat (...) I was improving more by eating more each time. (Lines 81, 315)*

Emerging issues
1 Ambience (bad smells)
2 Food (unappetising)
3 Environment (watching other patients to see what they were eating)
4 Personal assistance (feeding)
5 Social (no interactions, she cannot talk)
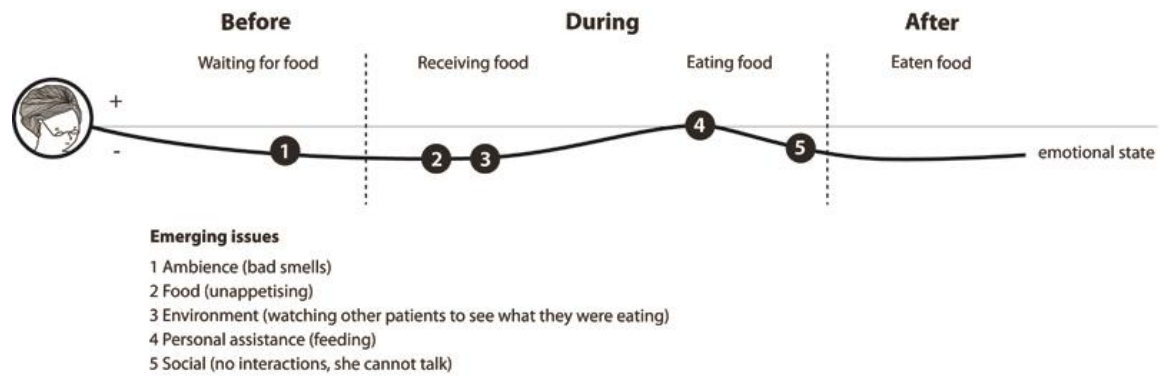
Figure 7.5   A conceptualisation of the main issues that have emerged from Patient 1's voice in discussing her experience at the mealtime in hospital at the interview.

In concluding this interview I asked the patient her views about an enjoyable experience at the mealtime and she drew attention to considerations such as "sitting at the table (…) to see food on the table". Here the patient seems to relate to thoughts associated with prior or perhaps familiar experiences. The mealtime is a normality of life where little pleasures such as sitting at the table can create moments for people celebrate life. Can design promote the improvement of such experiences for people affected by stroke at mealtime in hospital?

7.4.2   Patient 2

Before

Patient 2 and his experiences of eating and the mealtime revealed some similarities with those of Patient 1, however, he expressed this by saying, "I didn't eat anything in the hospital, I got a tube". This experience is similar to that of Patient 1, because the act of eating is a social one and, just as Patient 1 was unable to interact by taking part in the socio-material act of speaking, Patient 2 was excluded because he was physically unable to eat. The nurse who attended the interview added to this observation, by saying, "He was still there at the mealtimes although he wasn't given anything, he was with other patients". This issue draws attention to an interesting element: the patient is present but not participating, central to the activity but yet on the periphery. This led to revelations of a mealtime experience where the patient is not seen to be eating but is still involved at the mealtime by his physical presence in the environment. The design challenge for this interview with Patient 2 was prompting questions in order to explore his experience at the mealtime, following the topic guide. Using the topic guide was not often appropriate for this patient because of the particular pattern of care that he had undergone. For example, questions such as, *Is this what the food looked like?* were not appropriate ones to prompt

because the patient revealed that he was not eating any food, at least in the traditional sense. Therefore, this interview (see Figure 7.6) followed a more open structure in order to explore what happened, where he was and what he was doing during the three mealtime stages.

Figure 7.6 Patient 2 in discussing his experience at the mealtime at the interview around the nurse, researcher and his wife.

When discussing *before*, the patient revealed:

> *P2: In bed (...) I couldn't get up (...) I was generally lying there waiting for the visitors at night (...) that was all (...) I was always like that. (Lines 69, 127, 135)*

The view from this patient shows his daily routine at the mealtime during his time in hospital and how it is devoid of any social experiences, including anticipating the mealtime. Think, for example, how the patient expressed "I was always like that". Here the patient shared thoughts about his contextual environment and his thoughts at this time. In continuing our dialogue, the patient added his views in this way:

> *P2: It was a hospital ward (...) It's not where I want something to eat. (Line 76, 78)*

What is emphasised from this comment is an emotional response, revealing negative views about the mealtime environment in which he finds himself, perhaps alluding to an unattractive environment. Our dialogue proceeded to explore those feelings associated with the sensory dimensions of experience. He recalled:

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P2: Food smells (...) they were consistent (...) there was fish one time, there was mince and potatoes (...) I could smell the soup but I wasn't allowed any of those things even if it was really fine and blended (...) I mean you could tell if it was Monday or a Tuesday 'cause of the meals. (Lines 87, 90, 96, 98)

What emerges in this view is a patient who cannot eat but who seems to be constantly experiencing the sensory in relation to food and to the participation of other people in the mealtime experience. In particular, for example, the patient's recollection revealing his knowledge about the meals and their indication as to which day of the week it was. From this patient's voice we can see how a lack of personalisation and environmental adaptation to accommodate his needs can impact on his emotional levels, in particular, when we are talking about a patient who spent three-and-a-half months in hospital without eating "normal" meals. The patient's emotional state of mind draws attention to thinking about considerations of one's "normal" state and dependence upon others or on technology such as "tubes" to eat. This situation might affect the patient's quality of life during their recovery because these environmental factors might create moments when the patient experiences emotional levels that make him feel vulnerable. Think, for example, if you are in hospital, sharing a room with other patients and you cannot eat and suddenly a food smell comes along and influences your desire to eat; certainly this would change your mood at this time. Therefore, what can be done here? This issue of personalisation seems to require more investigation in order to explore how to promote patients' well-being, in particular, how to better accommodate individual needs. As demonstrated previously, in Chapter 6, the mealtime places significance on eating but this patient highlights attention to those who cannot eat – the mealtime goes *beyond* eating, it is sensorial and social. In continuing the dialogue, Patient 2 became emotional in recounting his experiences.

P 2: I had a guy opposite me who was…[he becomes emotional]. (Line 104)

At this particular moment, the nurse, who knew the patient, immediately expressed empathy by saying, "Take your time, you're doing well, really well". The patient continued by saying:

P 2: He made quite a bit of noise but he wasn't well (...) it [the environment] was quite quiet. (Line 108)

This patient draws attention not only to the need to support the patients' emotions post-stroke at the mealtime in hospital but also to support his own participation through this

dialogue, his participation in this research study. In this context of stroke, the nurse made a significant contribution to support the patient's emotions and help the patient to continue to be motivated to participate. Regarding the social context at the mealtime, I continued to explore the opportunities for socialising or interactions at the mealtime, and the patient revealed:

> *P 2: Where I was, everybody was in bed, you couldn't move, you couldn't get up.*
> *(Line 240)*

Issues about mobility, lack of autonomy, reliance upon others, and the absence of "voice" are all uncovered by addressing the mealtime experience. Once again, the patients' voices highlight attention to their health conditions at the mealtime, which affect how they socialise, or are unable to. Not being able to verbalise and/or physical move from the bed are characteristics which need to be addressed in order to explore possibilities to socialise. Adapting the socio-material dimension can be a significant way to create normalities of life in hospital, in particular for those patients who have the same characteristics of Patient 2, when eating is conducted through medication or care technology such as a "tube".

During

In discussing participation in the mealtime experience *during* the meal, the patient revealed thoughts associated with his experience of observing others eating at the mealtime. He said:

> *P2: I wasn't eating. I didn't lie there thinking, oh, I wish I could have that. (Line*
> *245)*

The view from this patient highlights his emotional state of mind in thinking of what he would like to have but he was unable to do. Once more, the lack of personalisation and/or environmental adaptation to accommodate the patient's need draws attentions to his emotional levels at this stage. This observation was supported by the comments that he made when exploring his experiences of *after* the meal.

After

In discussing the *after* the meal, the patient characterised his views in this way:

P2 (A): Jealousy (…) because the rest of them have had something to eat and I haven't, I never had any food at all (…) I think if you were able to get up and for instance sit at the table and talk that would be good, but we couldn't do that, not because we weren't allowed, because we couldn't do it (…) it's hard when you, the table and chairs are there to do these things, to talk to one another but (…) physically you can't get up to do it, so you don't do it. (Lines 199, 201, 230, 233)

With such an illustration of his emotional state, Patient 2 seems to reveal his experience at the mealtime in hospital as mostly negative (see Figure 7.7). The diagram below illustrates the main issues that emerged in relation to the patient's emotional states, as positive or negative, throughout the mealtime.
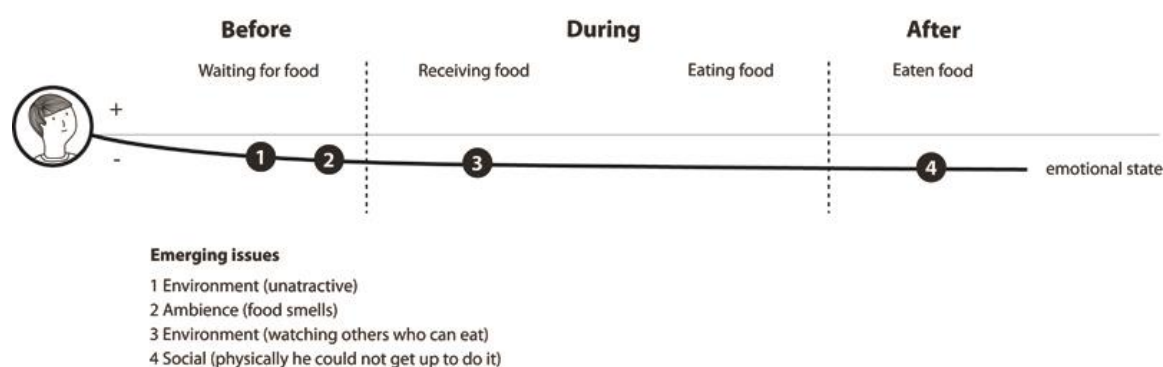
Figure 7.7 A conceptualisation of the main issues that have emerged from Patient 2's voice in discussing the mealtime in hospital at the interview.

This patient indicated a contrasting view about the mealtime. Think, for example, how the healthcare professionals' views place a focus on the importance of food/nutrition as opposed to participation in the meal experience. What is emphasised from this patient's voice is the need for the mealtime in hospital to address or respond to issues of subjective well-being, which are greater than the imbibing of nutritional content and physiological recovery. Looking at the diagram in Figure 7.7, the issues that emerge highlight a lack of personalisation, and that a lack of involving an environmental and social dimension can influence emotional levels to being negative rather than positive. Although healthcare professionals have described their experiences of encouraging patients to eat, as recorded in Chapter 6, this patient highlights his experiences from a different perspective, one which requires considerations of recognising that the quality of patient experience must include a consideration of each individual patient's needs. How can design contribute to how the mealtime in hospital can consider patients as individuals with individual needs? In particular, how do you involve a patient in the social activity of the mealtime when he is

unable to eat? In what follows, I will continue to explore these emerging themes by presenting another patient's view of the mealtime.

7.4.3 Patient 3

Before

Patient 3 had spent two weeks in hospital. She described her ability to eat at that time by stating, "I [had] only lost the right, the kind of right-hand side of me". Therefore, I understood that I was starting a dialogue with a patient who presented paralysis on one side of her body, highlighting the possibility for revealing issues about mobility. In showing her the image of the time *before* the meal (see Figure 7.8), we began to discuss her experiences of what happened when she was waiting for her meal.

Figure 7.8 Patient 3 in discussing her experience before the meal at the interview.

> P3: Usually they came in with, about fifteen, twenty minutes before (...) like they'd give you the choice of what you want (...) half an hour later you'd get your food. (Lines 55, 77, 79)

What is apparent from this patient's recounting is the manner in which the patient comes in contact with the mealtime service, how that service is constructed as a temporal and sequential process. Following this, the patient indicated her thoughts in this way:

> P3: Having a choice of a meal was obviously a kind of good part of it, but I don't agree with some of the choices (...) I think the nurses themselves knew I was pretty fussy (...) at mealtimes, they used to come and say I don't know why I'm asking you

(...) there was a few times when I surprise them and said can I try a little potato today (...) It's not as if they'd go out and make me something else (...) I think if there was more or a different option I would have possibly let it (...) sometimes the nurses were trying their best, they were like, but you need to eat and I was like, but there's nothing there I want to eat and then I knew if I took certain things then I would really struggle (...) it always seems to be the same food you're getting offered. (Lines 88, 282, 311, 316, 417, 430)

Patient 3 draws attention to recognise the patient as an individual with individual likes and dislikes. Consider, for example, the patient's expression, "there's nothing there I want to eat". At the same time, she recognises the challenges that healthcare professionals continuously face in attempting to encourage stroke recovery patients to eat every day. But this patient also indicates that motivating patients to eat requires more than verbal encouragement from healthcare professionals, it must encompass issues of personalisation and autonomy. As we can see, the nurses were trying to encourage the patient by explaining the importance of eating but they seem to not have been successful because of lack of response to the patient's likes and autonomy, as she described, choosing food would bring certain challenges, as she sais, she would "really struggle". This view seems to highlight attention to the patient's goals at the mealtime, aiming to experience food that they like and eating it in ways that are easy to control with one hand. She continued to relate her thoughts about the mealtime but finds a way to make the experience more social (and thus positive), as she revealed in this excerpt:

P3: Some of the nurses were incredibly nice in my ward (...) and I think some of them (...) was the joke of the ward, they used to come in and say I don't know what I'm asking you for because I know you're not going to eat anything but that was, that made it more kind of comfortable because the nurses tend to get to know you (...) but that was probably the only positive thing to come out of it. (Lines 472, 475)

Issues about social interaction, involving the physical, verbal and emotional, seem to relate here to positive moments. Despite finding the food unappetising, here this patient highlights attention to how social interaction can create positive emotions and meaning in this context of the mealtime, for example, the healthcare professional in verbally *playing* by "making jokes" with the patient can show how social interaction can promote the patient to feel "comfortable". Most importantly, the patient seems to appreciate the healthcare professionals' incentives. This appreciation seems to highlight the importance of obtaining an understanding of the patient, as a person with individuality and feelings.

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The healthcare professional, by *playing* verbally with the patient, can also promote their entertainment and perhaps create a sense of conviviality at the mealtime such as bringing little pleasures to life. She also draws attention to the importance of the nurses getting "to know you" which emphasise the relevance of the healthcare professionals' voices in taking part of this research. In further exploration of this line of thinking, the dialogue proceeded to discuss how the patient socialises with other patients at this time.

> *P3: There wasn't really (...) the other three women that were there but it never affected us eating (...) we used to have a little gab (...) but that was it. (Line 234, 237)*

In discussing social issues with patients at the interviews, I found that they provided generally short responses. Although Patient 3 demonstrated here ways of socialising by talking with patients, she also revealed that these moments tended to be limited and/or did not really happen. In discussing the environmental mealtime issues, this patient revealed her views associated with physical routines and senses, such as smells, in this way:

> *P3: Most of the time, in my ward there were four of us (...) we were all sort of up and out our bed anyway from a kind of early time but most of us, I think because we were able to, we would prefer to get up and sit in our little seats so we just sort of always got up and got ready for dinner coming (...) It was quite bland (...) It didn't smell of roses, see they [use] disinfectant wipes and things like that, there's a really strong smell of that sometimes. (Lines 123, 154)*

What emerges from this patient's view is the mealtime within a set of physical routines where the patients move from bed to bedsides where the patient is situated to experience the mealtime. In this way, Patient 3 describes similar experiences and echoes the previous comments made by Patients 1 and 2 regarding the mealtime environment, involving being in bed and/or at the bedside. Simultaneously, she also draws attention to the sensory at this stage by discussing the environmental smells. According to her, the contextual environment revealed issues about the sensory, such as "disinfectant" rather than "roses" and by refering to issues of unpleasant and pleasant smells; perhaps relating to a sense of being in hospital which demonstrates a "cleaned" rather than perfumed ambience. This patient's voices seem to draw attention to the quality of the mealtime environment being based on those dictated by a "medical" model; the hospital. In our dialogue, the patient also revealed her thoughts associated with sharing the physical space with other patients. She stated:

P3: I felt dead sorry for that little woman who was in the ward beside us because she wasn't allowed to eat because of her gullet (...) you could just tell she was dying to eat every time one of the little chaps came in she was just hoping they would say to her what do you want to eat today (...) that little woman who, it felt really uncomfortable for us for a start (...) it felt really wrong that we were sitting there (...) you're always staring at the same people, you're always staring at the same four walls, it always seems to be the same food you're getting offered (...) it's not the greatest environment to have to eat your dinner, especially when there is a little woman who can't eat. I think that's all wrong I think either she shouldn't be sitting there or (...) she shouldn't have to sit and watch us. (Lines 191, 193, 400, 407, 429, 484)

What seems to be highlighted in this view is the patient objecting to a lack of environmental conditions such as a space adapted to accommodate individual needs at the mealtime. Consider, for example, how the patient focused attention upon sharing a physical space with those patients who cannot eat. This indicates an emotional and empathic attitude. According to her, this situation is not comfortable or fair because it creates a sentiment of both inequality and compassion. As she said, "she shouldn't have to sit and watch us". This patient's view is similar to the view expressed by Patient 2, who indicated experiences of "jealousy" to see that others could eat and he could not. What emerges here are these emotional states in the context of the mealtime which, on one hand, reveal a patient feeling "envious" of other patients' achievements, and on the other hand, reveals an empathic patient who understands and identifies with the feelings of another. This situation demonstrates that attention must be given to these patients' emotions because the mealtime, in this way, tends to promote negative rather than positive emotional responses. Fundamentally, these examples show how patients' voices are continuously bringing forth issues of subjective well-being, enjoyment or pleasure at the mealtime as opposed to the alienated experience of the clinical environment and personal experience of physical impairment that otherwise prevails. Future investigations need to pay attention to exploring opportunities on how to enhance the quality of the patient experience in order to better accommodate individual needs and it should do so by engaging these patients in co-design activities to think of what can be done to change it for better. These patients might highlight relevant points that can make a significant difference to explore for the future

During

In showing the image of *during* the mealtime (see Figure 7.9), I posed the question; *Is this what the food looked like? If not could you describe it?* This was an attempt to understand her experience of receiving her meal.

Figure 7. 9 Patient 3 in discussing her experience during the meal at the interview.

The patient immediately expressed her views in this way:

> *P3: When I get food if it doesn't look appealing then it's not appealing and a lot of the time the food was very* very *unappealing. It was as if it had just been slapped onto a plate (...) It wasn't the shape, it was just like a big bundle slatted on the middle of the plate (...) I used to try the baked potato (...) there was never really any sort of arrangement it was just thrown on the plate. (Lines 259, 264, 268, 274)*

This view raises issues about visual quality, presentation, lack of care and their relationship to the sensory experience of eating. What is emphasised from this patient's comments is her emotional response when receiving the food. Patient 3 shares common perspectives at this stage with Patient 1. Fundamentally, it also reveals attention to the emotional response to the quality of food presentation as being "very *very* unappealing". Poor quality of food presentation seems to influence patients' emotions to become negative rather than positive. According to this patient, the food's visual appearance, as she expressed, was "a big bundle slatted on the middle of the plate" which affects the patient's appetite. Afterwards, the patient revealed:

P3: The only thing about it was the actual potato itself could have been a lot softer in order for people to eat it (...) I found it quite hard (...) I had the left hand side but I still found that some of the meals were pretty difficult as in cutting (...) because I can't cut it (...) a baked potato (...) was quite hard because I only had one hand (...) I just used to struggle with a knife, like a fork (...) It was all left handed (...) I wasn't eating much anyway but the only thing I possibly thought of eating was a baked potato and I love eating a baked potato (...) potatoes to me were quite hard (...) I thought even if it was slightly softer it would have been a lot easier to kind of scoop out but no, it wasn't. (Lines 268, 270, 10, 17, 30, 70, 336, 341)

The lack of presentational attention to detail was mirrored by the difficulty that Patient 3 had in using the tableware. She draws attention to the consistency of items like the potato and her difficulty in using tableware in a traditional sense, including a fork and knife. What emerges here is this lack of care in providing appropriate food and tableware to facilitate the patient's autonomy. Consider, for example, how the patient revealed that she had experienced difficulties in cutting up her food with only the one hand available to her owing to her condition. According to her, all the patients in her room used only one hand to eat, so the problem is obviously a widely encountered one. Why is food in hospital not provided in patient-friendly ways to facilitate eating for those patients with physiological difficulties or impairments? As we know, hospitals are places where people go for clinical reasons, in this particular case, for those affected by and recovering from stroke. Might the remedies to such problems within the hospital context also have an application outwith the hospital, such as in domestic convalescence? What can be gleaned from this patient's testimony, from listening to that voice, is the importance of promoting autonomy, in particular *during* the mealtime as a part of the day-to-day patient experience. In continuing the discussion, the patient revealed an emotional response in this way:

P3: The little nurse (...) would bring the food out to you. During the eating time (...) there was never anyone beside us (...) they would just sort of bring your meal and leave you with it (...) we never had care assistants during the meal. (Lines 58, 60, 326)

P3: Being so young [age of 26] I think you don't really want to have to ask somebody to have to cut your food for you. So I think the most annoying thing was that you couldn't get some meals and you were probably thinking about it when you were seeing it, oh no I can't eat that. I would have found it quite humiliating to have to ask somebody to cut my food. I feel like I'm twenty-six I don't want to ask

somebody to cut my food up for me. It would have been helpful if at some meals things were already sort of prepared for me to eat due to the fact I didn't have any use of my right arm (...) that's how I used to just take fruit because that was easy for me to eat. There's people maybe worse off than me and rather than have people to have to ask for things to be done for them for example the cutting of the food or even make different foods that doesn't need to be cut (...) especially in such a ward where there is disabilities like that, where they can't do it for themselves. (Lines 12, 422, 498)

Autonomy, self-reliance, dignity and self-worth are issues highlighted here. What seems to be continuously highlighted in this patient's view is the significance of promoting the quality of the patient experience (there is a physical and sensorial experience of eating, but there are emotional experiences that are contingent upon this physicality) to eat. Consider, for example, that the patient does not eat certain meals in the knowledge that she will face difficulties with these, or, in other words, she will require assistance. This view indicates that the youngest patients who might require such assistance to cut up food avoid this scenario, which could cause them to experience feelings of being "humiliated", perhaps highlighting links between age and autonomy. The mealtime, in particular for young patients, might need to recognise the importance of providing self-control can help them to focus on eating. According to Patient 3, the food in hospital should be prepared in order so as not to need cutting up, or, in other words, arranged on the plate in ways that facilitate eating. Food would be prepared in ways to better accommodate individual capabilities, in particular those affected by stroke, who might present one side of the body being paralysed (Stroke Association, 2008b). This view of promoting autonomy, self-control, or as healthcare professionals also say, independence, shows links between patients' and healthcare professionals' perspectives. For example, healthcare professionals, as demonstrated in Chapter 6, have suggested strategies such as tableware adaptations in order to promote independence in eating. This patient's perspective revealed different ways on how these strategies should be provided in order to promote the patients' well-being. For example, the patient highlighted attention to the way food is plated up in order to facilitate eating. What is emphasised from these two different roles is the significance of their voices in order to explore issues and future possibilities for the patient experience, as they seem to express their views on what would make a difference. In attempting to explore issues of socialising at this stage, the patient here indicated a lack of environmental conditions that respond to or accommodate individual needs, or, in other words, disabilities to eat. She revealed:

P3: It felt wrong that little woman was sitting there (...) you could tell that she was really really really struggling and she had to sit and watch all of us eat (...) I thought that was an absolute shame (...) she was spilling things and it was all over the place and to me because I'm quite squeamish at the best of times it wasn't very nice having to sit and watch so from our point of view having to sit and watch and from her point of view having to sit and watch us eating when she couldn't eat it wasn't very nice, I didn't really like it and the fact that we were sitting in a ward wasn't very nice either. (Lines 137, 140)

For this patient, in having to live and relive this situation, the mealtime can contribute to low morale during her recovery in stroke rehabilitation. This issue might affect the "acceleration" of patients' recovery because it not only involves functional but also emotional and social restoration. Simultaneously, in this excerpt there is a sense of being made to feel inadequate, not only by the environment, but also in terms of having empathy in understanding and sharing the feelings of another patient. This finding opens up ways to think about how to explore new possibilities to promote patients' collective and individual well-being.

After

Exploring this patient's experience of *after* the meal, I also showed her the image of *after* (see Figure 7.10), and began a dialogue to understand the patient's thoughts regarding her experiences of finishing her meal.

Figure 7.10 Patient 3 in discussing her experience after the meal at the interview.

The patient's *voice* draws attention to a set of routines, revealing the healthcare professionals' role at this stage. She said:

> *P3: They would just sort of start going back round again and collect everybody's trays. After mealtime they would give your little desk a wipe down. (Lines 82, 162)*

Hygiene and cleanliness are issues highlighted here through these healthcare professionals' interactions. This patient has views similar to those of Patient 1, which seems to emphasise the idea of patients experiencing a sort of environmental transformation at the end of the mealtime. Patients 1 and 3 indicated that *before* the meal they were in bed (treatment environment) and then they either remained there or moved to their bedsides (mealtime environment). Patient 3 seems to demonstrate here that there is a routine to put patients back into the treatment environment. For example, she revealed that the healthcare professionals start to collect the patients' trays and clean their individual spaces. The environment seems to adapt to different services, as either treatment or therapy, and mealtimes. Again, this patient recalls:

> *P3: I was never satisfied by meals. There isn't a best one because they're all the same. There was never a time where I thought, oh, and there was this day and we had this and that was great, no, there wasn't anything like that. (Lines 381, 428, 439)*

Repetition, lack of choice, variety and agency are emerging issues in this example. What is emphasised from Patient 3's comment is the emotional response, a negative one, to the quality of experience at the mealtime. By saying "I was never satisfied", she shows her demotivated state during her recovery, at least as regards the mealtime experience. In reflecting on her discussions of the mealtime experience as a whole, Patient 3 seems to demonstrate her experience at the mealtime in hospital as demonstrated in figure 7.11, which draws attention to the emerging issues in relation to the patient's emotional state, as positive or negative, throughout the mealtime stages: before, during and after.

Before — Waiting for food
During — Receiving food / Eating food
After — Eaten food

1 2 3 4 5 6 7 8

emotional state

Emerging issues
1 Food (She does not agree with some of the choices)
2 Personal care (the nurses were incredibly nice)
3 Ambience (strong smells)
4 Social (just a little gab)
5 Environment (watching others who cannot eat)
6 Food (unappealing)
7 Difficulty with tableware (cutting)
8 Environment (watching others who cannot eat)

Figure 7.11 A conceptualisation of the main issues that have emerged from Patient 3's voice in discussing her experience at the mealtime in hospital in the interview.

Here the issue of promoting the quality of the patient experience is voiced. These patients' experiences (1, 2 and 3) reveal that there is a need to address the issues of subjective well-being, enjoyment and pleasure at the mealtime in hospital in order to support their physiological, psychological and social needs. As discussed in Chapter 2, patients affected by stroke tend to be emotionally vulnerable due to the impacts of stroke. For example, the healthcare professionals indicated that patients can suffer from depression and/or fatigue. In other words, there can be a loss of sense of self, identity and relationship to the wider world and their previous role within it, and such alienated responses require attention. The mealtime is of great significance to the patient's recovery but the issues raised here must also to be addressed in order to improve quality of life during recovery. Think, for example, that patients, before they became patients, were ordinary people with individual lifestyles where the mealtime was part of their daily lives (social context/relationships and sense of self). What seems to be relevant here is to think about how having those patients who know all about mealtimes can contribute to exploring new possibilities to promote the quality of the patient experience at the mealtime in hospital.

By prompting the question; *How do you see the best mealtime?*, the patient immediately expressed her views by demonstrating emotional reactions such as laughing. Laughter is important because it can make people feel good and positive, in particular when they are facing difficult situations in their lives. At this time, the patient revealed her thoughts in this way:

> *P3: I'm a real lover of things like spaghetti bolognaise, that's my favourite meal*
> *ever and that's quite easy for me to eat (…) I like just sitting in quiet (…) on the*

couch with a little French stick (...) it's a meal that I know I can sit down and I don't need to be fussy about it (...) that's what I really enjoy so I don't have to worry about sitting picking things off it (...) I can just sit down and enjoy it. (Lines 445, 451, 456, 460)

By asking this question, I sought to gain an understanding of what the patient, as an individual, most values as an experience during the mealtime. Fundamentally, the purpose of this question was to give her the opportunity to express her opinions about that. From this patient's dialogue, the importance of recognising the person behind the patient emerges; the importance of understanding their lifestyle, their unique and personal likes and dislikes, and their individual goals in life.

7.4.4   Patient 4

Before

Patient 4 revealed that he had spent five weeks in hospital as part of his stroke recovery therapy prior to being interviewed. The mealtime, as a matter of discussion, elicited emotional reactions from the start, and he asserted that, *"There was a total lack of choice [I] didn't eat anything"*. Remember, this patient remained in hospital for five weeks. I met with some challenges in conducting this interview, such as sometimes not clearly understanding what the patient was saying due to his speech and the strength of his accent. Therefore, the nurse supported our dialogue as a verbal translator. As mentioned earlier, I found this patient presenting a sort of "slurred speech". In showing him the image of *before* (see Figure 7.12), we began a dialogue about his experiences *before* the mealtime in hospital.

Figure 7.12 Patient 4 in discussing his experience before the meal at the interview around the nurse, researcher and his daughter.

The patient revealed his views, demonstrating a set of routines and the sequential process of the mealtime service in his experience. He said:

> *P4: We were in our bed waiting (...) maybe five or ten minutes (...) and when the trolley came around, and on the trolley there would be meals on it (...) you'd be in your bed and they just come round and ask you what you wanted, the nurses asked what you wanted and we'd tell them (...) about four or five choices, no menu (...) by oral. (Lines 100, 112, 101, 115, 498, 500)*

The patient has earlier stated that there was no choice. What emerges here are facts versus emotions. What seems to be highlighted in this view of the patient is how he *experiences* the mealtime service. Consider, for example, that the patient revealed the components of the service, involving spatial position and a set of routines to verbally give and collect food choices. In addition, the patient revealed:

> *P4: Most of the time it was soup and it was all I could really take (...) they said it was vegetable but you didn't know what kind of vegetable it was (...) some days it's barley, I hate barley. (Line 41, 51)*

This view from the patient draws attention to issues of menu choice as agency and self-determination linking to the spatial position and control over his location. What emerges here is this absence of the patient voice. Instead, the patient is subordinate to the routine and hospital priorities, not a person with individuality, feelings, and their own agency in

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their recovery. This becomes an environmental factor that might undermine appetite. Our dialogue proceeded onto discussing environmental issues. He expressed:

> *P4: With my chair here and the toilet right there (...) in and out, in and out, in and out all day (...) it was just a smell of a toilet (...) really a nasty smell (...) a toilet smell (...) all the time, I was right next to the door (...) I didn't really have much of an appetite. (Lines 299, 302, 312, 315, 324, 322)*

Within this excerpt, it is possible to identify a lack of ambience (bad smells). Bad smells at the mealtime have also been emphasised by Patient 1 and healthcare professionals, as demonstrated in Chapter 6. This lack of ambience (bad smells) is a factor that also affects appetite. The patient continued:

> *P4: There's people walking up and down (...) nurses going in and out of doors doing different thing (...) a cleaner hoovering up or wiping the place down (...) watching the trolley and listening to what the meals are, just watching what they are doing (...) and see some of the things they've got (...) mashed potatoes (...) put out with a ladle (plopping noise) big blob of mashed potatoes. (Lines 351, 347, 412, 416)*

Here the patient has had a very poor sensory experience, further subjugated by the routines generated by the hospital's operational concerns instead of patient-centred awareness. What is emphasised from this comment is a kind of routine, revealing the healthcare professionals' roles at the mealtime. Consider, for example, the healthcare professionals as planners of the mealtime, perhaps demonstrating this idea of them being transformers, preparing, bringing, and putting things in different places. From the patient's perspective it seems to highlight his attention to understanding what is coming. In attempting to understand his social experience at this stage, he said:

> *P4: Just talking (...) patients and nurses. (Lines 381, 384)*

Again, in discussing issues of socialisation at the mealtime in this and in prior interviews with patients, the patient has given very short answers, or, in other words, not much information. Although the patients recalled socialising as talking with patients and/or healthcare professionals, they tend to be dismissive, such as saying "that was it", or "just talking", when referring to socialising, giving the sense that these events were fleeting, insignificant and unimportant. As demonstrated in Chapter 3, promoting social qualities can evoke emotional quality. What emerges here is that there is a lack of social dimension

as part of a mealtime experience for post-stroke recovery patients in hospital. However, there are socialised moments happening during the mealtime, for example, when the healthcare professionals verbally play with the patients while they inform them about and gather their food options. These social moments can bring little pleasures in life. However, I have found that the patients' feelings can change during the mealtime due to a lack of a suitable environment to accommodate individual needs. These environmental factors might be a space to provide an opportunity in which to explore what can be done to meet these individual needs in this social context of the mealtime for post-stroke recovery patients in hospital. Our discussion proceeded to discussing this patient's experiences *during* the mealtime.

During

In showing the patient the image of *during* the mealtime (see Figure 7.13) the patient reacted immediately by saying:

Figure 7.13 Patient 4 in discussing his experience during the meal at the interview.

> *P4: What really turned me it was the so-called mashed potatoes (…) it was white, white (…) they just poured them out blob blob blob (…) oh God man, and you've to eat that, no, no way, no way (…) I had a baked potato and honest to God see the best of it was tuna, it just turned my stomach (…) and I like tuna, I like baked potatoes it's just mess, total mess, rubbish (...) rubbish, utter rubbish, I'll tell you what it looked like, shite (...) It didn't even look tempting (...) an omelette, right it was like leather sole left over in your house and it wasn't right, all brown (...) all*

brown (...) burned all round (...) the mash potatoes were how do I describe that? (...) just (...) white (...) runny (...) the salad they gave you (...) it was that iceberg and the rocket salad (...) it was bad (...) I said "Am I expected to eat this?" (Lines 442, 444, 449, 452, 651, 659, 663, 668, 670, 700, 705, 921)

Here Patient 4 describes food that is reduced to nutritional content (or that is just ruined), illustrating his dissatisfaction in receiving unappetising food. This experience of unappetising food seems to be a common issue among these patients; Patients 1 and 3 shared similar thoughts. What emerges from this patient's recounting is the manner in which the patient reacted to this situation, questioning the service; "Am I expected to eat this?" This patient's voice indicates his disappointment in receiving food. Consider, for example, how negatively the patient has characterised the elements of the food's appearance, for example, he says,"turned my stomach". Does this indicate a lack of concern for the sensory experience and patient predicament? What seems to be highlighted in this view is the poor quality of food presentation, which influences patients to express food dislikes and, consequently, emphasising that they do not want to eat. Consider, for example, that the Scottish Intercollegiate Guidelines Network 119 (2010) have recommended that food in hospital should be attractive to avoid these issues. Once again, this reveals a gap or misalignment between the official guidelines/policy and what happens in practice. In continuing our dialogue the patient explained:

P4: See the roast potatoes, you can't cut an inch, can't cut them with your knife see the skins in them, solid (...) sometimes you got these packs, little packs for things like cheese and biscuits sealed (...) and you couldn't open them (...) you'd to tell the nurse to get them opened (...) I would have preferred something easier (...) I haven't got the strength in that hand and I tried to struggle with this hand I just couldn't, just had to get one of the nurses (...) to help. (Lines 425, 231, 234, 249, 252)

Here the physical presentation of the food limits the possibility of cutting/eating, rendering the patient helpless and completely reliant on others to eat. This comment demonstrates a lack of suitable conditions to allow self-efficacy that leads to poor self-esteem. Patient 4 shares similar views with Patient 3 related to experiencing low self-control and autonomy. Once again, food can present difficulties to cut it up on the plate, but also, it can be difficult to access through its packaging. Consider, for example, how Patient 4 revealed that he required assistance to get certain things done, such as those involving manual dexterity. However, he seems to be emphasising attention to the significance of promoting

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food that is easier to access and to eat. Think, for example, about a patient receiving food and experiencing patient-friendly ways to eat by those who can use only one hand; addressing and dealing with this issue might promote more positive experiences. In attempting to understand what happened next, the patient indicated:

> *P4: It was the nurses that gave you your meal (…) put it on your tray (…) and had a tray across the bed with your meals on it (…) they just leave you eating, they were there and then they went and did other things (…) they just put it down on the table and left you to it. (Lines 356, 119, 278, 280, 537, 648)*

What is emphasised from this patient's comments is the idea of the mealtime being focused on delivering food to be eaten; a service devised without an explicit address to user-experience and to the systemic requirements that are encapsulated through such an address, such as patient well-being, self-regard, psychological well-being, and accelerated recovery. Additionally, the patient revealed:

> *P4: You eat alone in your bed. (Line 129)*

This view shows the patient eating in a more individual, in other words, lonely, experience, raising issues about the mealtime as a social event; is the patient being alienated, or is the intention to provide privacy? His comment, however, draws attention to his emotions at this time. As understood earlier, the patient is not motivated to eat. Subsequently, he added:

> *P4: Somebody would come round and say did you enjoy that meal? (…) I'd say to the nurse, "That meal was rotten." (Lines 73, 64)*

Is the voice being heard? What seems to be highlighted here is the patient's voice in demonstrating his disappointment about the food to the healthcare professional. However, it also shows that the patient's socialising is related to healthcare professionals' roles in delivering and checking patients' eating. In addition, the patient also expressed:

> *P4: The man across from me was really big, really quite ill (...) he couldn't help himself, couldn't eat anything (…) It worried me (…) I was ok, my wife brought meals to me and I used to get her to cut it up for him to see him alright. (Lines 176, 182, 198, 201)*

Once again, attention is drawn here to the environmental conditions, which might not accommodate all patients' capabilities, perhaps showing that patients do have different

needs. In addition, it raises similar issues around emotional elements such as empathy for other patients and an understanding of these individual needs. This patient's comments also demonstrate that the senses such as vision, sound and smell are not addressed and how this affects psychological and physical well-being and the patient's engagement with "recovery". What seems to be emerging here is to find ways to explore new possibilities in order to promote subjective well-being to support patients in their pursuit of a pleasurable and satisfying life in this context of stroke rehabilitation. Most importantly, these findings might contribute to revealing a different view of how the patient might socialise in the future.

After

Our dialogue then proceeded into discussing the patient's experience *after* the meal. Hence, I also showed him the image of *after* the meal (see Figure 7.14) and began a dialogue by raising issues around what kind of thoughts came to his mind at the stage *after* the meal, and also what kind of interactions occurred then.

Figure 7.14   Patient 4 in discussing his experience after the meal in the interview.

The patient revealed a negative emotional response to the quality of his experience; in particular, he was influenced by having experienced poor food presentation. He said:

> *P4: Thank God it's over and done with (...) because the meal's absolutely rotten, rubbish. (Lines 677, 681)*

The patient then revealed additional views, illustrating the healthcare professionals' roles at the end of the mealtime. He expressed:

> *P4: The nurses just took (...) your dishes away, took your cups and saucers, cutlery and plates, they took them away (...) would start clearing up, dusting, cleaning the tables (...) and asked you if you wanted a coffee or a drink (...) you were in bed you just stayed in bed. (Lines 138, 362, 264, 147)*

The views from Patient 4 reveal thoughts in common with Patient 3. Both patients highlighted views of experiencing a sense of "mechanistic" ritual, revealing how the healthcare professionals engage in transforming the environment to back to "normality" as treatment; thus addressing the body but not the person. Consider, for example, how the patient illustrated the healthcare professionals after the mealtime, collecting and cleaning things, with the emphasis upon a set of routine tasks, an industrial work experience for those delivering a service: as opposed to an address to a person suffering from severe physical impairment, psychological alienation and social displacement. Simultaneously, the patient revealed a sort of social experience at this stage. Think, for example, of the healthcare professional asking the patient if he would like to have a drink. This sort of interaction highlights attention to creating enriched moments at the mealtime; especially how to promote social qualities to influence experiences of social pleasures and simultaneously evoke emotional quality in hospital. In attempting to explore more about social experiences, the patient added:

> *P4: You'd talk individually to one of the nurses she'd ask you, "You want coffee or you want tea?" (...) "How you doing?" (...) sometimes I spoke, depends who the person, who's there some people weren't able (...) sometimes (...) there'd be football, you know, football supporters and if it was a Celtic game I'd talk to them. (Lines 389, 398, 552,571)*

These social moments described here can create little pleasure for patients to celebrate life throughout their mealtimes and possibly create space to enjoy their stay in hospital.

With such an illustration, Patient 4 seems to present his experience of his time in hospital in a mostly negative way (see Figure 7.15). The diagram below illustrates the main issues that have emerged in relation to the patient's emotional states, as positive and negative, throughout the mealtime.

Emerging issues
1 Food (lack of choice)
2 Ambience (bad smells)
3 Social (just talking)
3 Food (unappetising)
4 Difficulties with tableware (cutting/opening)
5 Social setting (you eat alone in your bed)
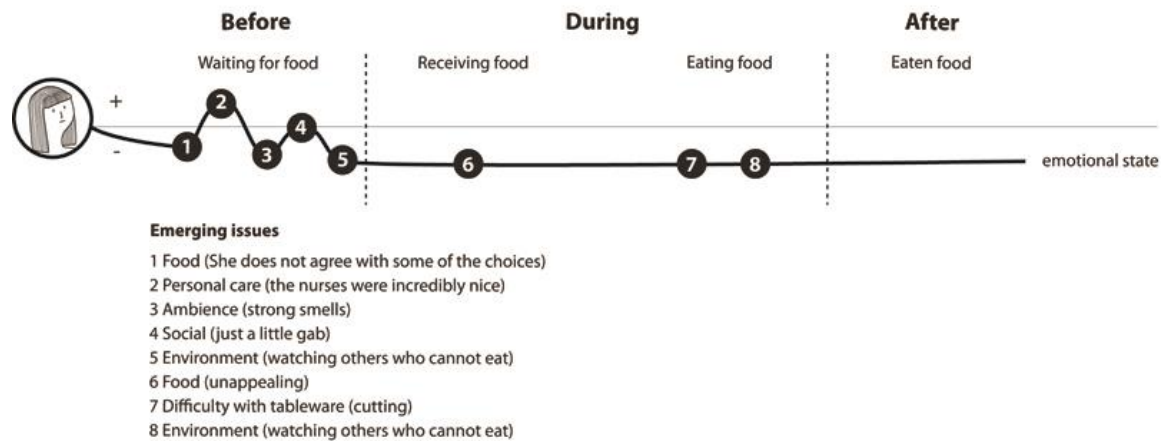6 Environment (watching others who cannot eat)
7 Social (talking)
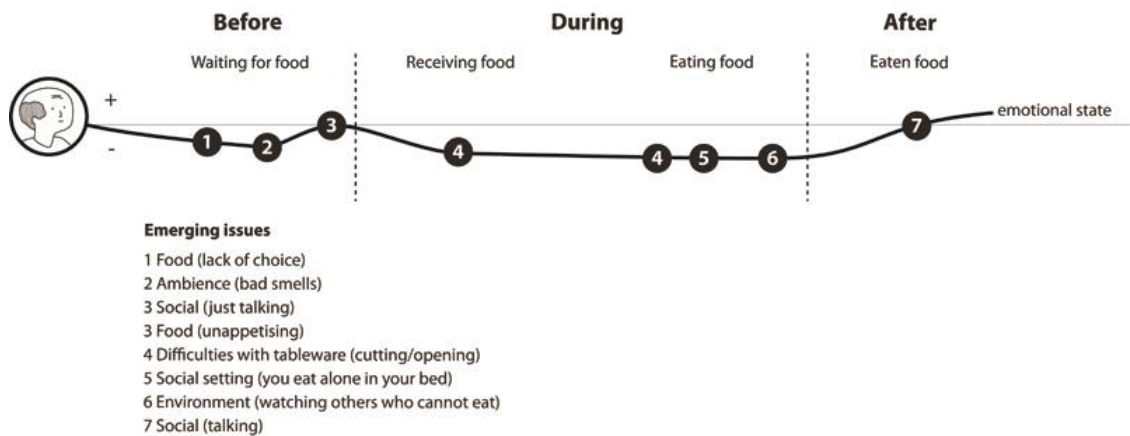
Figure 7.15 A conceptualisation of the main issues that have emerged from Patient 4's voice in discussing his experience at the mealtime in hospital in the interview.

Exploring the patient's views of an enjoyable experience, he revealed his lifestyle, such as going out to have a meal in a restaurant. He said:

> *P4: We're going out on Sunday for a meal (...) big fancy restaurant (...) classy (...) tatties and mince, lovely (...) delicious. (Lines 712, 705, 758, 726, 782)*

What is emphasised from this patient's comments is the idea of the mealtime as an experience to contribute to celebrating life. He conveys a sense of occasion, by saying "we" and a sense of ritual by saying that it is a Sunday event, "big, fancy". This example illustrates the person behind the patient, one who has rituals, habits and lifestyles, and, even more importantly, his desire to flourish. In describing an enjoyable experience here, he shows the inherent human aspiration of living a good life.

7.4.5   Patient 5

Before

Patient 5 revealed that she had spent four days in hospital as part of her recovery from stroke. Conducting these interviews required that the patients participated by expressing their own views, however, encouraging this patient's participation was challenging; she often expressed her views by saying, "No, no (...) no, I can't remember". Because stroke can often affect the memory as well as the ability to express oneself verbally, this meant that this particular patient might have difficulty remembering and discussing certain things. In showing her the image of *before* the meal (see Figure 7.16) to help her to convey what happened while she was waiting for food, she first responded by saying, "Nothing, no". In prompting further discussion to enable me to understand what she meant by saying "nothing", she revealed her thoughts in this way:

Figure 7.16 Patient 5 in discussing her experience before the meal at the interview.

> *P5: I was in the ward, four in a ward and just sitting there (...) I was just sitting on the chair (...) about twelve o'clock. (Lines 31, 119, 64)*

In fact, she was *doing* nothing while waiting for her meal. The experiences of this patient share strong similarities views with Patients 1, 3 and 4, especially those aspects associated with the patient's environmental condition and relationship to others, revealing what they were doing at this time such as "sitting there".

> *P5: They tell you what's on for the meal and you just tell them what you want (...) you don't get a menu you just get a choice (...) two, three options. (Lines 280, 271, 283)*

What emerges here is the patient's limitation for choosing food. She draws attention to the differences between the idea of a "menu" and "choice". A menu is associated with a list of food options used in a restaurant, which customers use to choose a meal that is most desireable to them at that particular time, while "choice" is instead depicted here as a limitation; the patient can choose only among "two or three options". Choosing food also indicates verbal information has been provided by the healthcare professional. Having a choice seems to highlight attention to the patient's decision-making capability about her food option – taking her condition into account, is she really free to choose? Her comment demonstrates that there are different levels of social advantage and freedom within the mealtime in hospital. In attempting to understand how the patient was socialising at this stage, she revealed:

P5: Just four women in the ward, talking and the television and that was it (...) I spoke to them (...) just everyday things. (Lines 299, 84, 87)

Once more, the patients' socialising at the mealtime seems to draw attention. This patient's answer reveals similarities with the previous comments from other patients that frame socialising as an insignificant element of the mealtime. Here Patient 5 seems to describe how the social links with the environmental. Recountings of social interactions tend to be short when compared, for example, with issues about food where patients have lots to say. Does this finding indicate the effects of a clinical approach that is focused on only the physical element of eating as recovery? Again, patients revealed elements of socialising by saying that they were "talking". In attempting to explore more about this specific social interaction, for example, Patient 5 also diminishes the importance of the social by telling how they were talking of "just everyday things". These patients' dialogues seem to illustrate a lack of social dimension at the mealtime in hospital which is incongruous, particularly when the mealtime is conducted within a social environment. Perhaps these emerging issues open up ways to think of how to explore new alternatives to allow patients' socialising? Think, for example, by placing a focus on the social, how this might influence the patients' narratives in different ways, such as revealing more detailed responses rather than just saying, "talking". What is emphasised in these patients' views by saying "talking" is that opportunities for social experiences might be given limited attention in healthcare and thus patients do not have much to recall. In discussing environmental issues, this patient said:

P5: I wasn't looking around about me (...) it's not an attractive place to eat is in the hospital (...) looking out the window (...) I was just looking out the window (...) my bed was over at the window. (Lines 78, 201, 250, 259, 263)

The comments from this patient show, once more, attention to the quality of experiencing the mealtime environment. Poor quality of presentation is expressed as unattractive and it is problematic because it discourages rather than encourages appetite. What seems to be highlighted in this view of experience is the importance of promoting the quality of the patient experience in ways that make them appreciate the environment, perhaps stimulating the patient to looking around inside the room in a social way, rather than feeling the need to look outside in an isolated way. Considerations of sensorial experience, involving sound, smell and sight, can be significant to stimulate the senses and to promote socialisation.

During

Continuing my dialogue with Patient 5, I placed this image of *during* the meal (see Figure 7.17) on the table.

Figure 7.17 Patient 5 in discussing her experience during the meal at the interview.

When asked to describe herinteractions with health professionals as experienced during the mealtime, Patient 5 recalled:

> *P5: They brought the meals to us, asked if we needed any help or if we needed a bib thing (...) the girls were nice and they always spoke to you (...) when they were giving you the dinner (...) ask how you're doing. (Lines 32, 132, 134, 139)*

What is emphasised from this patient's comments is once more the "mechanistic" ritual of delivering and receiving a meal for patients. This patient's views are similar to the views of Patients 3 and 4. However, this patient places an emphasis on the significance of experiencing social qualities at the mealtime. Consider, for example, how she expressed that the healthcare professionals are "nice" when they come in contact with the patient by delivering meals and talking to her, such as saying "how're you doing". Perhaps more interesting is that when social qualities are lived, patients tend to express emotional response as positive. Social issues became a very interesting and important subject to explore in this research study in order to explore future possibilities. Simultaneously, the patient added further thoughts, revealing her experiences of when she received her food. She said:

> *P5: I just smelled my food (...) it was different colours it depended what it was (...)*
> *I got (...) cauliflower cheese (...) and I couldn't get enough of it, it was beautiful*
> *(...) that's what's stuck in my head that cauliflower cheese (...) but I like*
> *cauliflower (...) I just started eating it (...) I was starving. (Lines 233, 323, 327,*
> *331, 335, 345, 348)*

In contrast to the previous Patients 1, 3 and 4, this Patient 5 recounted experiences which include appetising food, or, in other words, food that she likes. Promoting little pleasures, such as food likes, draws attention to how these might create a moment for the patient to celebrate life. This patient recalled her dining experience as "beautiful". Our dialogue proceeded into experiences while the patient was eating.

> *P5: I couldn't hold the fork (...) my hand shook, so I had to use my right hand with*
> *the fork because the minute I lifted that up it was going like that and the dinner was*
> *falling off the fork, so I had to sort of dig in with the fork (...) I managed (...) just*
> *cut it with the fork like that or with the knife and then lift it with the fork. (Lines*
> *154, 156, 165, 167)*

Once again, issues are raised here about the patient's difficulty in using tableware. Although the healthcare professionals indicated that, in hospital, adaptative tableware is provided, they considered how these adaptations might bring "connotations of [a]child", as demonstrated in Chapter 6. However, these views from Patient 5 illustrate the problematic situation of how to manipulate food on the plate in a traditional sense, using a fork and a knife, with only one hand. These difficulties have been identified (Westergren et al., 2002b) but opportunities to support these issues seem not be very well addressed in practice. Consider, for example, how the patient recounts that she "managed". However, eating in this way can be frustrating both physically and psychologically. Remember that Patient 3 refused to eat the food because she knew that she would find difficulties in preparing it on the plate. Moreover, Patient 4 expressed a desire to experience self-control instead of needing someone to help him to eat. This *typical* patient experience reveals a lack of care to these issues about autonomy and self-control to support physical and psychological needs. These are issues that require design attention to explore ways of promoting subjective well-being while eating.

After

In discussing the image (see Figure 7.18) illustrating '*after*' the meal, the patient revealed similar views to those revealed in prior discussions with Patients 1, 3 and 4. She reported:

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Figure 7.18 Patient 5 in discussing her experience after the meal in the interview.

> *P5: They just came and took it away (…) they just asked me if I'd enjoyed it (…) just started talking away again to the other woman that was in the ward. (Lines 95, 102, 174)*

This excerpt is an example of another patient revealing her views of experiencing a routine, or phatic conversation, or "mechanistic" rhythm; an environmental transformation to go back to "normal", as also perceived by Patients 1, 3 and 4. At the same time, she directed attention to social interactions as a result of a sequential process. What is emphasised from this patient's comments is this idea of the mealtime as encompassing an active healthcare professional and a passive patient, perhaps focusing on patients' receiving, eating and remaining. In concluding the interview, the patient expressed her views by saying, "I enjoyed it". However, it was not clearly understood whether she was telling the truth or just revealing that she was grateful for having received treatment. The time spent in recovery here can also be relevant, considering how she remained in hospital for approximately one week, while the other patients who were interviewed required more weeks and even months to recover from stroke.

Throughout her discussion, Patient 5 seems to present her experience at the time in hospital in the way illustrated below (see Figure 7.19) which draws attention to the emerging issues in relation to the patient's emotional state, as positive and negative, throughout the mealtime.

Before
Waiting for food

During
Receiving food — Eating food

After
Eaten food

emotional state

Emerging issues
1 Food (just get a choice)
2 Social (talking)
3 Environment (unattractive)
4 Personal care (the girls were nice)
5 Food (appetising)
6 Difficulty with tableware (cutting)
7 Social (talking)
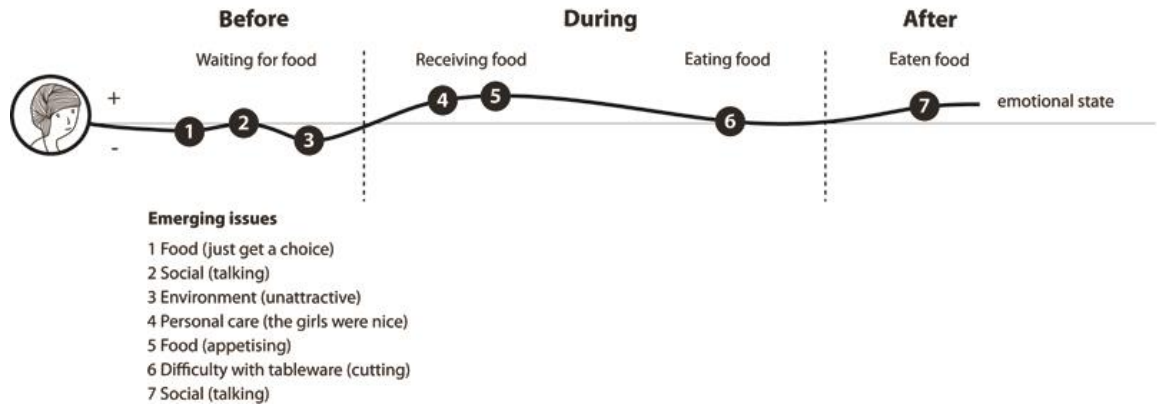
Figure 7.19 A conceptualisation of the main issues that have emerged from Patient 5's voice in discussing her experience at the mealtime in hospital in the interview.

Through these patients' voices, the patients' experience at the mealtime shows a lack of personalisation to better accommodate individuality. Recognising the person behind the patient seems to be an important way to support aspirations of life. There is a lack of social dimension at the mealtime, however, social moments, when they do happen, highlight the significance of the mealtime to evoke emotional quality. In what follows, I will underline what I found by giving these patients a voice.

7.5   Giving patients a voice

In this second phase of the research, eliciting the patients' voices helped to obtain an understanding of the mealtime from their experiences. Fundamentally, this understanding allowed me to demonstrate common and contrasting views between patients and healthcare professionals (see Table 7.3), identifying the main problematic experiential aspects (see Figure 7.20).

Table 7.3 The common and contrasting issues at the mealtime that have emerged from the healthcare professionals' and patients' voices

KEY ISSUES			HP'S VOICES	P'S VOICES
Eating	Food	Unappetising	Not particularly nice looking.	Not appetising. P1 Very very unappealing. P3 Total mess, rubbish. P4
Eating	Food	Lack of choice	Patient would not get particular food. Patient does not have a choice. It is quite repetitive.	There was nothing there that I would get otherwise. P1 I do not agree with some of the choices. P3 There was a total lack of choice. P4 You do not get a menu you just get a choice. P5
Eating	Tableware	Limited autonomy	Patient needs help to cut up food and/or open bottles. Patient uses adapted tableware.	The meals were pretty difficult as in cutting. P3 You cannot cut. You could not open packs. P4 I could not hold the fork. P5
Environment	Lack of ambience (visual)			It is not where I want something to eat. P2 It is not the greatest environment. P3 It is not an attractive place to eat. P5
Environment	Lack of ambience (smell)		The toilet in the ward made them feel sick.	The toilet was next door to my bed. P1 It was just a smell of toiled. P4 There is a really strong smell. P3
Environment	Lack of social dimension		Patient has protected mealtimes. Patient does not get any interruptions. The main focus is eating.	No interactions, I cannot talk. P1 We used to have a little gab, but that was it. P3 You eat alone in your bed. P4 Talking. P5

The difference in patient experience is important here (see Figure 7.20). Through these patients' voices, Patients 3 and 4 seems to be more outspoken than the others, in particular, Patient 4 who revealed the willingness to be heard to be critical. Some of the others may be a bit reserved in expressing their true emotions, particularly when they had a nurse present. The nurses tried to be as helpful as possible but perhaps the patients would not like to disentangle the help which nurses gave to them from the quality of the meal service. Moreover, from these patients' voices we can see common and unique issues at the mealtime.
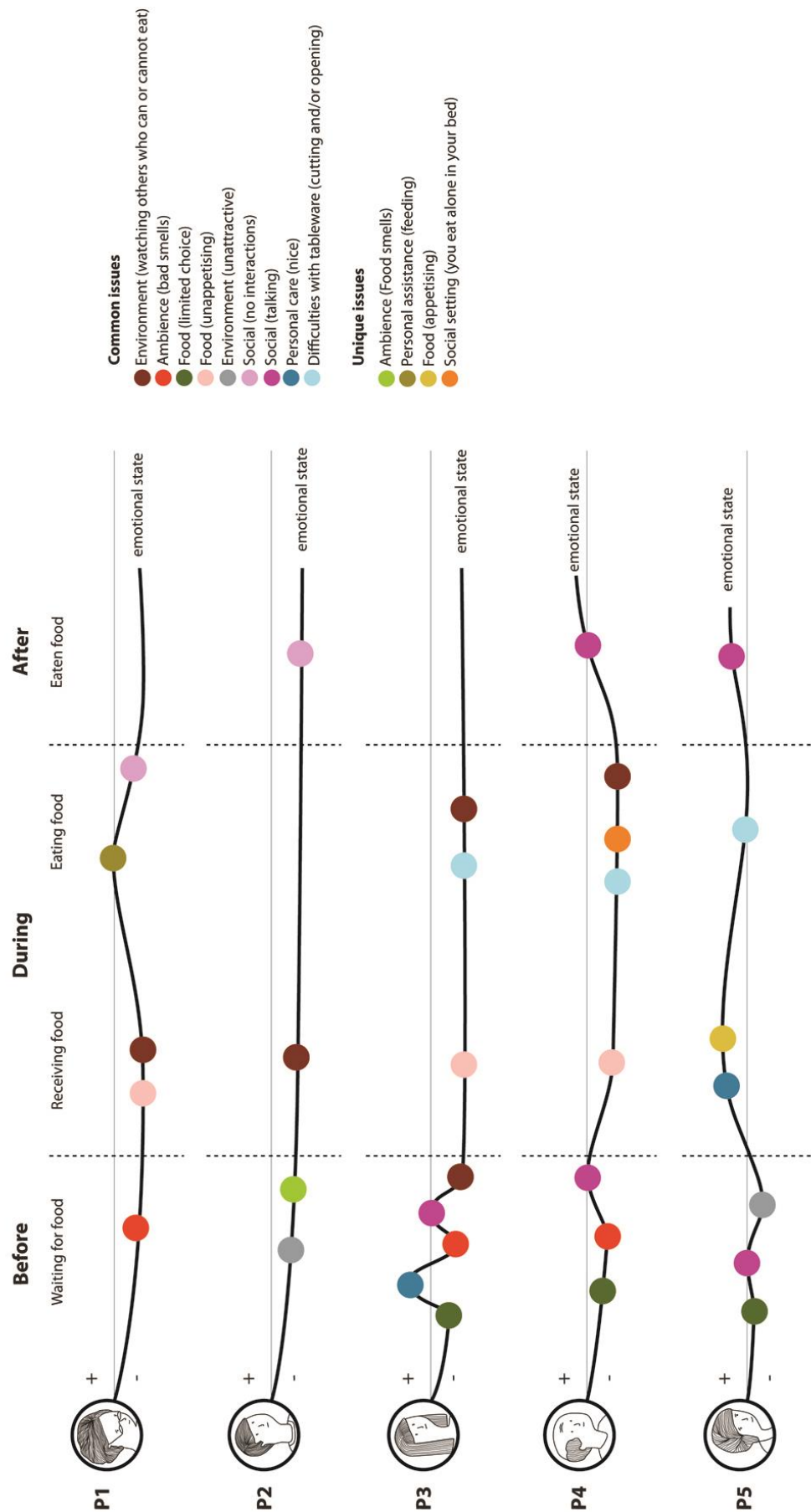
Figure 7.20 A conceptualisation of the main issues at the mealtime that have emerged from the patients' voices.
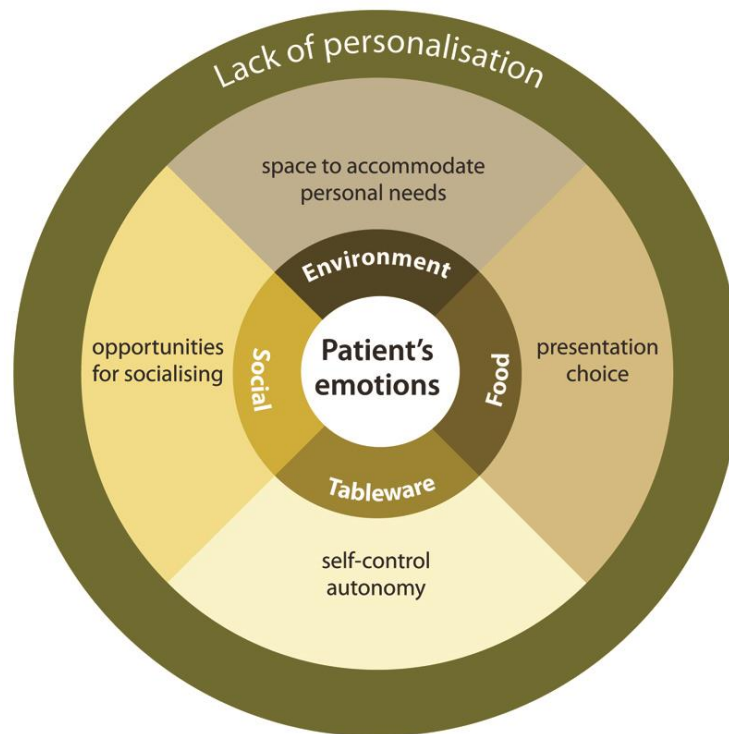
Figure 7.21 An overview of the key issues and insights.

From this diagram 7.21, it becomes apparent that the current mealtime is encompassed by a standardised approach and emerging issues in the findings highlight the need to facilitate personalisation of the environment, food, tableware and social ambience. These are issues that influence the patient's emotions. According to healthcare professionals, patients tend to be demotivated to eat due to suffering from depression, low mood and/or fatigue, as demonstrated in Chapter 6. As a result, they tend to require medication. Through these patients' voices emerged this issue of poor environment, food presentation, tableware and social ambience, which indicate that attention to issues of subjective well-being in needed in this context of stroke rehabilitation. Perhaps what is highlighted here is the idea of improving well-being using a non-medical type of intervention. Think for example, how the patients revealed their experiences of comfort and enjoyment when healthcare professionals expressed empathy at the mealtime. What is emerging here is the significance, not only of functional, but also of emotional and social restoration. Perhaps linked to this is the idea that promoting enjoyable experiences makes recovery happen faster.

7.6 The present mealtime scenario

Eliciting the healthcare professionals' and patients' voices helped in constructing the current mealtime scenario, revealing both the healthcare professionals' and patients' experiences (see Figure 7.22). Building the "scenario" provided a summary of the main issues emerged by both patients and healthcare professionals. Overlapping these voices allowed me to see "the picture" of what is currently happening. However, this visual narrative form shows the limitations in summarising what is actually a very complex situation. Furthermore, it helped to reflect and define what to explore next.

Figure 7.22 A generic example of the current mealtime scenario in stroke rehabilitation in hospital. Individualised scenarios could be constructed from the findings of each P1-P5.

In this visual narrative, the quality of the patient experience at the mealtime requires experiential considerations for the future. If we look at the scenario narrative we can see that although healthcare professionals play an important role in planning, delivering and assisting patients, this is not enough to promote a good quality of patient experience during their recovery in hospital. Consider, for example, at the beginning of the mealtime, how the healthcare professional came in contact with the patient to inform her about food options; but how did she experience it? This situation brings forth the question; by giving patients a voice, what would patients see as relevant to their experience at this moment? Regarding the quality of food presentation, it seems that both patients and healthcare professionals share common views about what it is like to experience food presentation. I find myself wondering why this experience needs to be standardised when healthcare guidelines and policy have recommended the opposite to promote a good patient experience (SIGN 118, 2010). As the mealtime is ongoing, patients come face-to-face with other patients at the mealtime, a situation which highlights social and emotional issues, in particular when they present different health conditions, or, in other words, different capabilities and needs to eat. Issues of embarrassment have previously been identified (Perry and McLaren, 2003), but what we can see here is that the patients' emotions are being affected by the way the mealtime is currently conducted. Think, for example, on the one hand, how the patient who can eat "normal" food feels when seeing patients who cannot. These individuals become pre-occupied and possibly uncomfortable to be around. On the other hand, the patient who cannot eat, seeing other patients eating, becomes demotivated due to her/his health condition. This situation highlights attention to the quality of life for those patients, in particular when they need a longer stay in hospital. What this emphasises here is how further investigation can explore opportunities in order to promote issues of subjective well-being. We can also see other issues emerging during the mealtime. For example, using "normal" tableware can be challenge for those patients. Difficulty with tableware revealed that patients "struggle with a knife" and/or "fork". In fact, some patients might be happy to have someone to help them with food but others might find it "quite humiliating". In looking at the social context it shows how the patients are currently socialising. Although healthcare professionals expressed that patients tend to talk with each other, patients demonstrated a contrasting view; a lack of ambience "you eat alone in your bed" and opportunities for socialising "we used to have a little gab but that was it". As understood in previous Chapters (3 and 4), this idea of socialisation involves not only the social but also the material (Ehn, 2008). What seems to be relevant now is to explore new possibilities to allow patients to socialise.

Illustrating these healthcare professionals' and patients' voices was a valuable way to highlight common and contrasted issues (see Figure 7.18), which need more consideration in the future. Acknowledging these voices demonstrated their value, not only to represent the present, but also to highlight the importance of involving them to explore the future. Fundamentally, this study has demonstrated how giving patients a voice can open up new opportunities to change the patient experience in desirable ways (Bate and Robert, 2007). Most importantly, it has demonstrated how such patients' ideas can be a source to explore new possibilities with healthcare professionals. In this line of thinking, the following explorations will be focused on understanding the patients' ideas with an aim to build a new storyboard. This new storyboard will allow me to understand what patients consider to be significant for their future experiences. In doing so, it can help to propose desirable futures (Krippendorff, 2006). Ultimately, it might support future design situations with an aim to envision the future mealtime scenario, revealing patients' and healthcare professionals' ideas in their "voices".

7.7 Summary

In summary, in this chapter I have presented the findings and a discussion of these from Phase 2 of the research. In describing the findings, I have illustrated five individual experiences of the mealtime. Here, I found that patients' voices highlight the importance of self-perspective, control and autonomy at the mealtime. I identified that patients sometimes experience quite miserable experiential situations. I concluded by presenting these in the mealtime scenario. By illustrating both healthcare professionals' and patients' voices, I highlighted issues that become evident at the existing mealtime situation. I also illuminated future directions in order to explore opportunities to promote the quality of the patient experience in the future. This process revealed that a design research situation with an aim of exploring the patients' ideas can be significant to propose desirable future experiences. Hence, in the following chapter, I will present investigations to obtain an understanding of the patients' ideas in order to highlight opportunities to change the current situation for the better.

8

Findings from Phase 3: Exploring future possibilities with patients and healthcare professionals

8.1   Introduction

In the previous Chapters (6 and 7), the healthcare professionals' and patients' voices were elicited to collect their experiences of the present mealtime. The aim of this exercise was to access a diversity of information in order to obtain an understanding of the current patient experience during stroke rehabilitation in hospital. These healthcare professionals' and patients' voices helped to build the present scenario of the mealtime which was used as a basis for the next research phase. By building a scenario, I was able to demonstrate a visual narrative of what is happening. Simultaneously, it allowed me to reflect on emerging issues such as how an emphasis on physical and clinical control to eat and swallow can reduce positive experiences of self-perspective, control and autonomy. At the same time, poor quality of the contextual environment and food presentation can influence patients' emotions to cause them to become demotivated throughout the mealtime. Think, for example, of how a lack of environmental factors, for example, not having a boundary between one activity (toilet) and another (eating) brings unattractive smells, diminishing the patient's appetite and reducing the enjoyment of looking forward to the meal. Most importantly, the present scenario of the mealtime highlighted the role of participatory design methods in eliciting the patients' voices as a source to explore new ways of thinking about things that matter to them.

Thus, in this chapter, I will discuss the two separate, but connected, participatory workshops, or, in other words, co-design activities. For the first of these, I will demonstrate how these activities elicited the patients' voices. For the second, I will demonstrate how they brought forth the healthcare professionals' voices. By separating these two voices, I intended to establish a more balanced power relationship between the professionals and the individual (Boyle and Harris, 2009) and able to give them equal value and prominence. In this way, the workshops could enable the patients' voices to be "loud" rather than being overlapped and subdued by those of the professionals (Donetto et al., 2014). In the discussions about both workshops I will present the patients' and healthcare professionals' voices, revealing their ideas from the perspective of what would make a significant

difference in future experiences at the mealtime. Within this third phase of this research, I aimed to collect a diversity of ideas that can be utilised to explore concepts that might help to envision a new scenario of the mealtime. In doing so, the workshops are created within this notion of "design games", which assumes that participation is playing and doing things in collective creativity (Ehn, 2008; Bjögvinsson et al., 2012).

I will demonstrate that when using design games, a diversity of information is accessed which helps in showing a clear picture of the patients' and healthcare professionals' ideas at the mealtime. In other words, how both the patients and healthcare professionals see the mealtime changing for the better in the future. This third phase of this research study considers the patients' and healthcare professionals' ideas as being valuable to the exploration of future possibilities. In conclusion, this chapter will show the contribution of patients' and healthcare professionals' voices to envisage a single future scenario as an illustration of how this could be different from the current – but there could be multiple possible scenarios. The new scenario will illuminate ways to redesign the mealtime in the future in order to support patients and healthcare professionals towards promoting the living of a good life in stroke rehabilitation in hospital.

8.2   The workshop with patients

This chapter begins by first describing the workshop with patients. Here I will start by presenting who participated in this study. Afterwards, I show how the study was conducted by playing three games (see Figure 5.20). By presenting the findings from the study, I will illuminate the patients' views related to these three design games: i) W*hat if?*; ii) the Magical game; and iii) the Map game, as I discussed in Chapter 5, section 5.3.3.1. In exploring *What if*, I found, in contrast to the findings with the healthcare professionals, that the patients' thoughts were of family rather than their favourite chefs. With the Magical game, I found that patients' aspirations rested within this idea of the memorable rather than the imagined. Here I also found that patients' thoughts were with family in mind but in a different way, related to "going out". "Going out" revealed the idea of patients going to a restaurant and/or pub, revealing their lifestyles and this idea that creating a sense of the familiar can evoke pleasurable and enjoyable experiences as well as bring a sense of rhythm and "normality" in people's lives. Lastly, in the Map game, I found patients' ideas continuously bringing forth what is familiar or previously normal in their lives. Fundamentally, this game revealed the patients' desire to experience "change" at the mealtime. Perhaps this finding brings forth this idea of having the opportunity to take a

moment to have a break from their "mechanistic" clinical routine in which they would like a sort of normality for supporting their individual aspirations of living a good life during recovery in hospital. To conclude this element of the discussion, I will demonstrate how these patients' voices were significant to suggest "design moves" (Binder et al., 2011a) and highlight further directions to conceive and structure the second workshop with healthcare professionals to proceed with explorations of possibilities to enhance the quality of the patient experience at the mealtime in stroke rehabilitation in hospital.

8.2.1 Who participated?

Initially I intended to develop this research study with all five patients who participated in Phase 2, as described in Chapter 7. Although they all agreed to participate in this study, just three patients attended on the day to take part in the workshop (see Table 8.1). The reason why two of them did not attend was unknown. This issue seems to happen quite often when working with patients, which is problematic for research. For example, research in the context of healthcare has highlighted this issue of participants' dropout in this way: "some people may refuse because they fear that this might increase their grief. Others may refuse because they have 'got over it', and do not want to look back" (Stroebe et al., 2003, p.238). In discussing this issue with one of my supervisors, I found that he had experienced similar issues in working with spinal cord injury patients. In this research study, the conditions and vulnerability of this group of people affected by stroke that I am working with they may have been perfectly happy to participate on a one-to-one basis in their homes, but would struggle to cope in a group, in particular when it required interact in social situations (Perry and McLaren, 2003). Although this phase of the research study did not involve all patients who participated in the previous phase of the research (Phase 2), the patients who turned up to the workshop included patients who had different mealtime experiences, as demonstrated in Chapter 7. Fundamentally, they were not only those who were more able to participate (Boyle and Harris, 2009) but also they were those who had key characteristics of the specific population being studied (Richie and Lewis, 2003) and their voices were an invaluable contribution to this research study in order to generate new insights.

Table 8.1 The patients who participated in the workshop

Patients	Time in hospital (in weeks)	Stroke conditions	Age	Gender
P1	15	Swallowing difficulties Cannot speak Cannot walk	66	Woman
P2	15	Swallowing difficulties Cannot get up out of bed	52	Man
P4	5	Swallowing difficulties Weakness on one side	75	Man

The table above illustrates who participated in the workshop, demonstrating the characteristics of the patients in relation to their unique identifier code, time spent in hospital, stroke conditions presenting difficulties to eat, age and gender. By illustrating the patients' characteristics, I have introduced those who participated in this study. The following sections will focus on describing how the workshop was conducted.

8.2.2 Conducting the workshop with patients

Previously, in Chapter 5, section 5.3.3.1, I discussed how I conceived this study. Structuring the workshop based on this idea of design by playing was a way to encourage patients to express their ideas in different ways. Here I will demonstrate how the design games were conducted (see Table 8.2) and will discuss the findings from it.

Table 8.2 Conducting a workshop, as a game, connected by thinking, imagining and suggesting

Playing		
Thinking	*Imagining*	*Suggesting*
Collectively	Collectively	Collectively
25 minutes	45 minutes	45 minutes
Room – Day hospital		

The table above illustrates each game, revealing the way it was played, the length of time of each, and where it took place. Before I start to describe how this workshop was conducted, it is important to explain first how this socialised and materialised situation was created in order to support and promote a collective dialogue (see Figure 8.1). Two nurses attended the workshop in order to indirectly support communication and assist patients

with any health situation if required. Patient 2, who could not talk, used an iPad to write her views on the device and then one of the nurses would verbalise what she was writing. Two design students at the Glasgow School of Art also attended to this workshop to help to facilitate and to visually demonstrate the patients' voices throughout the workshop while we were playing the games.

Figure 8.1 The environmental overview of the workshop conducted with patients, involving the researcher (R), two nurses (N), three patients (P), two design students as facilitators (F) and a patient's relative as assistant.

This workshop started with me introducing the patients to the aims of the workshop. In other words, telling them what we were going to do and why. Afterwards, I invited them to play three games. The first game was to get patients thinking about the mealtime from a chef's perspective in order to open a different way of thinking about the mealtime. Afterwards, the second game was designed to get the patients to imagine what would be the most enjoyable experience of the mealtime. This was to allow patients to express their aspirations and desires about things that motivate and inspire them. The last game was to get patients to suggest possibilities to improve the quality of the patient experience at the mealtime during stroke rehabilitation in hospital.

In this workshop, I began by thanking the patients for their participation and recapitulating the initial information given to them in order to clarify any issues. I emphasised that patients' views, opinions and ideas were fundamental to this research study and nothing that they would say would interfere or affect their rehabilitation care, which the two nurses who attended also confirmed. Afterwards, they signed a consent form (see Appendix D). In what follows I will illustrate the patients' voices from their participation in this workshop.

8.2.3 Findings

8.2.3.1 *What if*

Playing W*hat if?*, I began by showing the patients what happens at the present mealtime. Here I used a PowerPoint presentation to show the mealtime stages such as before, during and after the meal and the conceptual framework, as I discussed in Chapter 5, section 5.3.2, to get patients to reflect about experiential considerations (see Figure 8.2). Fundamentally, this game was about emphasising how these inter-related experiential aspects such as the sensorial, physical and social can be relevant to the designing of the mealtime in order to evoke emotional quality. In doing so, I presented a fictional patient character called "Sandra". I initiated this workshop with this presentation to stimulate patients' reflections about design for experiencing. Following this, I aimed to get patients thinking about the designing of the mealtime in this way: *What if it was made by your favourite chef?*
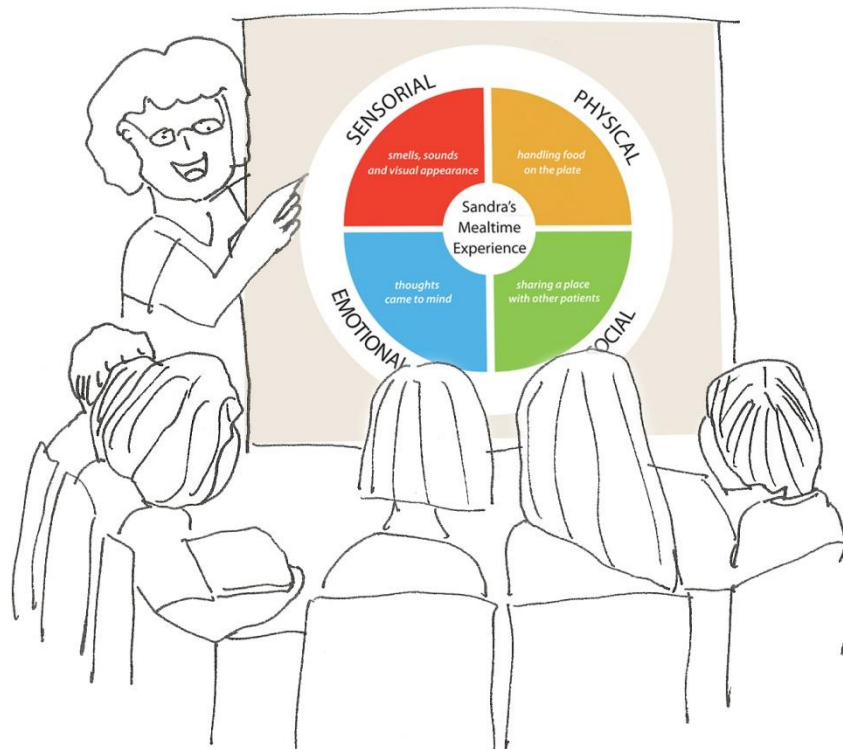
Figure 8.2 Presenting the conceptual framework for patients in the workshop.

The patients' views highlighted that the idea that "favourite" is what becomes "familiar" in our everyday lives. They said:

> *P4: My wife*

> *P1: Husband*

> *P2: Tricia [the name of his wife]*

Our dialogue proceeded into reflections of what kind of mealtime would these patients' relatives create for "Sandra" (the fictional patient character). For example, I prompted questions to get them thinking about things such as environmental conditions, food presentation, and people's interactions, such as healthcare professionals providing assistance to the patient.

While patients were expressing their views, the facilitators were simultaneously illustrating their voices on a white board on the wall (see Figure 8.3). This allowed patients to see actively what we were doing together.

Figure 8.3 Illustrating the patients' voices while playing *What if?* game at the workshop.

Environment

In discussing what kind of environment the patients' relatives would provide for "Sandra", the patients drew attention to the contextual experience in order to create a more familiar situation. They said:

> *P1: A quiet environment and maybe a little light music.*

> *P2: There's always a nice smell from a gammon steak. A unique aroma that comes from it and you know I've often thought that people could make a fortune if they had an air freshener that smelled of food.*

> *P4: Big table.*

> *P4: Everyone sitting having a meal.*

P1: Flowers on the table.

P1: A separate dining room for mealtime.

P4: I think you could give somewhere for people talk (...) then you'd get a quiet moment.

P4: Grouping them together so you can talk to each other. Would be the first thing.

P1: Have the patients sitting across from each other.

P1: To enable them to talk if they wish.

P2: A big table with them all round it and talking to each other.

P2: Well they would have to be around a table together and someone would have to initiate the conversation to one particular subject.

What is emphasised from these patients' voices is the mealtime as a well-known situation in people's lives. Although patients expressed this view of sharing a mealtime together, we understood previously in Chapter 7 that people with different health conditions might feel uncomfortable in experiencing this situation. In response to this issue, patients tend to express ideas within this view of the mealtime as "a separate room" or "somewhere for people talk". What these voices highlight here is the mealtime might offer opportunities for patients to experience different situations: both collectively, as "talking to each other"; and individually, as "you'd get a quiet moment". Another thought the voices prompt is about the aesthetic. Consider, for example, how P1 expressed views associated with the combination of components such as "flower on the table" and "a little light music".

Food

In discussing, what kind of food presentation that the patients' relatives would provide for "Sandra", the patients revealed:

P4: It looks nice.

P1: Presentation's important [the presentation is of the food].

P2: Good quality food.

P2: If you want to create (...) the food would have to be cooked on site instead of brought in, because I mean the people who are bringing it in are just, they're

serving it they're not creating anything. They're just simply serving it out to the patients. So there's no creativity involved in it.

These voices from the patients highlight their views of appreciating food. Think, for example, how P4 considered the issue that food needs to "looks nice". What seems to be demonstrated here is that patients might want to be inspired at the mealtime. In other words, they want to receive appetising food.

Staff

In discussing how the patients' relatives would interact with staff and help "Sandra" at the mealtime, the patients' voices highlight issues around promoting personalisation. They expressed:

> *P4: They'd be cleaning it up.*
>
> *P1: Assist the patient in taking food from the plate.*
>
> *P1: Ask if the patient likes the food, if they're happy with the food.*
>
> *P1: And ask if he needed to cook something else (…) if they do not like it.*
>
> *P1: You [the staff] could provide a menu for individual patients.*
>
> *P2: Cooking the food (…) it would have to be one person cooking each different thing and then somebody putting it on the plate and then they'd serve the patients.*
>
> *P2: Well if she needed assistance she could get assistance from any one of the people who were working with her, that's where good team participation that had to be.*
>
> *P4: You just see things getting passed about and everyone running around you and you get a good idea of what's coming.*
>
> *P2: If it was somebody who was cooking for you in the hospital, it's not practical but if they were you'd be sitting there looking forward to what they were creating for you (…) instead of having a plate with stuff dumped on it (…) like a dog's dinner.*

What seems to be emphasised here is the mealtime involving multi-roles. For example, patients expressed thoughts associated with staff in asking, assisting, providing, cooking and serving individual patients. This describes healthcare professionals within a focus of the mealtime itself. However, as discussed in Chapter 2, these healthcare professionals are

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doing many other non-meal oriented tasks. Patient 2 added his thoughts related to this idea of the mealtime as involving "good team participation".

This initial exercise shows unexpected findings; the patients' thoughts with family in mind (see Figure 8.4) rather than with their favourite Chefs. I found myself thinking, did it happen because they do not tend to watch TV chef programmes or eat in restaurants? What these voices seem to be demonstrating here is the significance of recognising the mealtime as a "normal" experience of life which might be important not only after, but also during the rehabilitation process. This view seems somehow connected with findings from the contextual review, as discussed in Chapter 2. Think, for example, of the rehabilitation process within a goal of getting patients back to "normality" (Perry and McLaren, 2003). Through these patients' voices this issue seems to be important during patients' recovery, which draws attention to design on how to maintain the familiarities and normalities of life during rehabilitation.
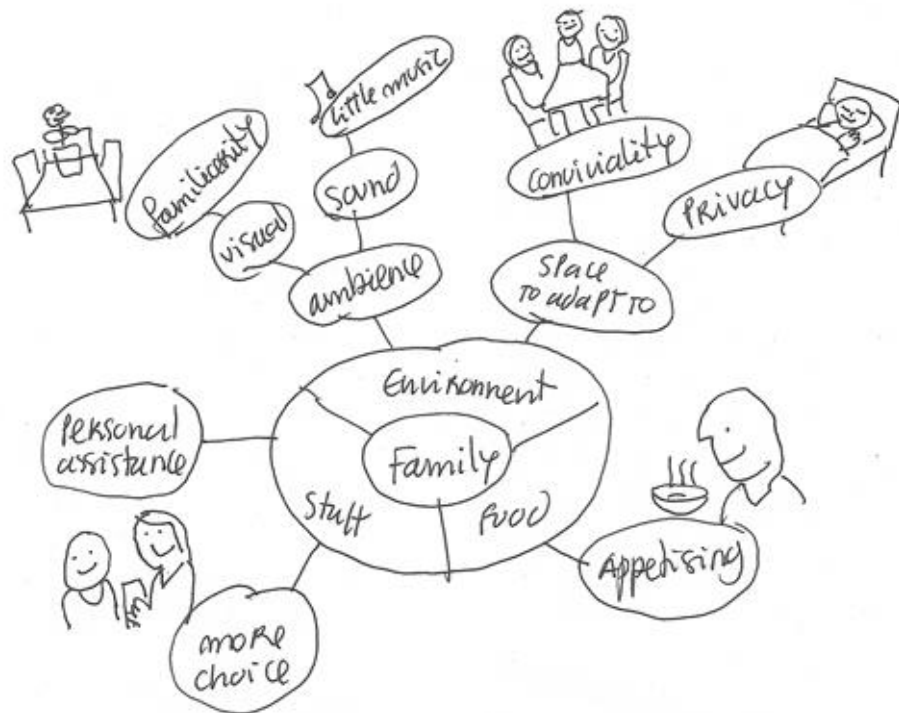
Figure 8.4 A conceptualisation of the main issues in playing *What if?* at the workshop.

8.2.3.2 Magical game

Playing the Magical game, I began by giving each patient a player piece with a number. The purpose of giving a player piece for each patient was to help the facilitators to identify the patient's voice. Simultaneously, I placed a game board on the table (see Figure 8.5).

Afterwards, I started to explain the rules of the game by introducing the game pieces, such as game boards and theme colour-cards. In doing so, I explained that patients would be invited to select a theme colour-card in order to open up a dialogue.

Figure 8.5 Explaining the game roles to play the Magical game

In selecting a theme colour-card, I aimed to trigger a moment of imagination about what would be a pleasurable experience at the mealtime. To emphasise this idea of imagination, I invited them to close their eyes in order to create a sense of dreaming. Most importantly, the game was about stimulating and encouraging them to reflect about their desires and likes. However, getting the patients to close their eyes was not always successful.

I began by saying to the patients to imagine that they had just won a prize for a magical mealtime experience, what would be a magical experience? While patients were imagining their stories about the theme colour-card, I was triggering prompt questions as a source of inspiration to open up a diversity of thinking. For example, questions such as; where are you? who is with you? what are you doing with them? and what are you thinking?

By selecting a card it involved the patients imagining for one minute, and then telling the group what they had imagined for three minutes. This active participation was performed four times. As a result of playing this game, each patient expressed individual desires and aspirations for each theme, as sensorial, physical, social and emotional, and in this way

offered three individual perspectives of what would be sensorial, physical and social qualities to promote experiential quality at the mealtime.

Expressing magical experiences was a game where patients verbally tell me what they had imagined and, simultaneously, the facilitators visually demonstrated their individual stories which were identified by theme colour-cards and player pieces (see Figure 8.6). As I mentioned earlier, it allowed patients to see actively what we were doing together. In what follows I will present each patient's view of a "magical" mealtime experience.

Figure 8.6 The patients' voices in playing the Magical game at the workshop.

Patient 4

Patient 4 expressed his thoughts, revealing a memorable rather than an imagined experience. For example, he revealed his aspirations and desires about an enjoyable experience associated with his lifestyle, which is related to this idea of going out to a restaurant with his family. He said:

> *P4: Aye, going to McDonalds with my Grand weans.*
>
> *P4: Going to the McDonalds for the afternoon.*
>
> *P4: You can smell the chicken and chips and that.*
>
> *P4: The people going about and other people talking.*
>
> *P4: It was quite good*
>
> *P4: See what's happening and going on around you (…) you can pick up what you want to on yourself, have your meal by yourself.*
>
> *P4: Well eh my daughter-in-law and son and the kids and sometimes my daughter.*
>
> *P4: You get a good tuck in.*
>
> *P4: Quite happy.*
>
> *P4: Enjoyed being there.*

What is emphasised from this patient's voice is his personal value associated with the mealtime. Consider, for example, how the patient expressed his thoughts by describing the type of environment, a bit of ritual in which he was doing things and who was with him at the time. This voice seems to demonstrate that enjoying a meal brings forth a focus on personal pleasures and goals.

Patient 1

Patient 1 showed enthusiasm while we played this game. Although she was more engaged in a sense of imagination, she also expressed her thoughts connecting more memorable experiences. Once again, these aspirations highlight attention to individual lifestyles. She revealed:

> *P1: She's anxious [the nurse describing the patient's emotion at the moment]. An Indian restaurant, the smell of curry and different smells from the kitchen, tables*

all decorated with candles which are lit with different colours and tables with placemats.

P2: Family sitting round the table and the meal brought in, in different dishes.

P1: Different food

P1: Choosing an appetising dish

P1: Socially ideally (…) would be the Grandson's playing their games and I laughing at them and helping them when required. Typical grandmother.

P1: Listening to them – listening to their wee jokes.

P1: The satisfaction of feeling full and feeling drowsy.

This view from Patient 1 also emphasised issues associated with what she values. Consider, for example, the patient's thoughts in describing the environment and food that she likes and who is with her at the time. Family seems to be an important issue for these patients. However, the view of familiarity is not only in a sense of being around family but is also about what is well-known and the value it has for the person. Think, for example, how the patient revealed expressions of being able to choose "an appetising dish". Stimulating patients in pursuing their personal goals seems to be demonstrated here as a factor in supporting their quality of life.

Patient 2

Patient 2 revealed his thoughts in a more self-referential experience. For example, he was telling parts of experiences that he had had in the past. However, he also highlights attention to individual lifestyles. He said:

> *P2: I'm going on somebody's boat, with the barbeque on the back of the boat so you're getting the smell of the smoked food and putting a couple of steaks on barbeque. And then on the plate and inside the boat it's no very comfortable but the plate on my lap and a glass of wine.*

> *P2: I was out one afternoon and I come in and I was hungry and I popped my head round in the dining room and there was a local Sheriff (…) and saw me and gestured that he wanted to talk to me. So I went and sat down at the (…) to go to the pub and get a drink and a fag.*

> *P2: I was thinking hurry up and get across to the pub (...) I was thinking (...) I*
> *wanted to be more sociable after the meal (...) interact with the other people (...)*
> *have a drink and a fag.*

Once again, what these patients are highlighting is that enjoying a meal is about stimulating patients to pursue their individual values. Think, for example, how Patient 2 showed an appreciation of issues related to sociability. What these patients' voices are highlighting here is the idea that each is a person with individuality, feelings and their own goals.

Although playing this game revealed some difficulties, in particular to get patients thinking in a sense of imagining, it showed two main issues related to what they see as significant to support aspirations of enjoying a good life at the mealtime (see Figure 8.7). Fundamentally, it revealed their thoughts highlighting their individual desires and aspirations in a diversity of ways. However, playing this game brought some challenges. While playing the second card, Patient 4 expressed, "I'm too warm in here […] it's stuffy". At this time, the active nurse suggested, "Could we open the doors?" and I also added, "You can go outside", in order to take some fresh air. The patient immediately responded by saying, "Yeah, that's what I like [going outside take some fresh air]." At this time it seemed to be important to allow the game to become flexible and it shifted into a sort of "pause" mode until the patient felt better. This "pause" lasted approximately 10 minutes. Here one of the nurses and one design student (facilitator) went along with the patient while I and another nurse made sure that the other two patients were feeling well and comfortable in the room. Afterwards, the patient came back to the room and the game returned to "play" mode.

After playing this game I invited patients to have a break to drink a coffee or tea. Afterwards, I initiated the second part of the workshop, summarising what we achieved in the first part. This opened a dialogue to allow patients to share ideas and further thoughts. Following this, I introduced the next game.
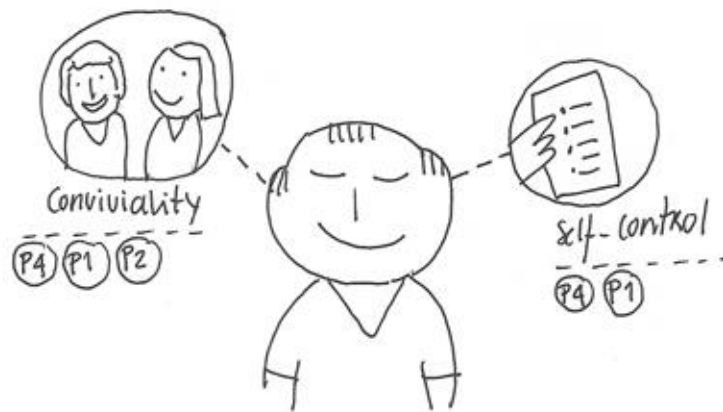
Figure 8.7 A conceptualisation of the main issues in playing the Magical game at the workshop.

8.2.3.3 Map game

To play the Map game, I started to explain the aims and rules of the game by introducing the game pieces; a game board wall and theme colour-cards (see Figure 8.8). In doing so, I explained that patients would be invited to select a theme colour-card, in the same way as their prior participation in the Magical game.
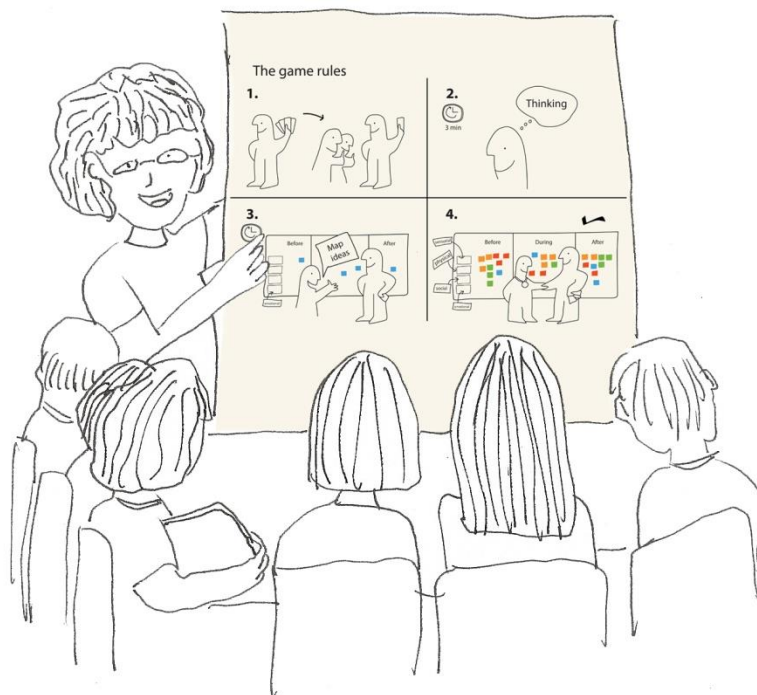
Figure 8.8 Explaining the game roles to play the Map game

Prior discussions about the mealtime aimed to understand experiential considerations to promote enjoyable experiences from the patients' thoughts. At this time, I invited patients

to help me explore opportunities to promote the quality of the patient experience at the mealtime in hospital. The purpose was using the theme colour-cards to open up a dialogue exploring different ways of thinking, such as sensorial, physical, social and emotional.

Before we started to play, I also emphasised the idea that patients were experts in this matter because they had first-hand experience of being in such a position from their experiences at the mealtime in rehabilitation in hospital. Simultaneously, I encouraged them to see this game as an opportunity for them to share their ideas and opinions on how the patient experience could be changed for the better at the mealtime. In this way, I encouraged patients back to think about "Sandra" (the fictional patient character) who is in hospital. While patients were reflecting on possibilities, I triggered prompt questions as a source of stimulation and encouragement for their expression, for example, questions such as "what would Sandra experience when she is waiting for food?", "What kind of smells and sounds would be around her?" and "Who would be with her?"

After selecting a card, the patients were asked to think about ideas to change the current patient experience at the mealtime for three minutes, and then they had seven minutes to tell the group what they thought would change the mealtime for the better. This active participation was performed four times. As a result of playing this game, the present mealtime storyboard was mapped with patients' suggestions for future possibilities.

Suggestions comprised patients telling what they considered to be valuable experiencing at the mealtime. In the same way as the previous games, the facilitators also illustrated their ideas identified by colour-card themes (see Figure 8.9). Once again, it allowed patients to see actively what we were doing together.
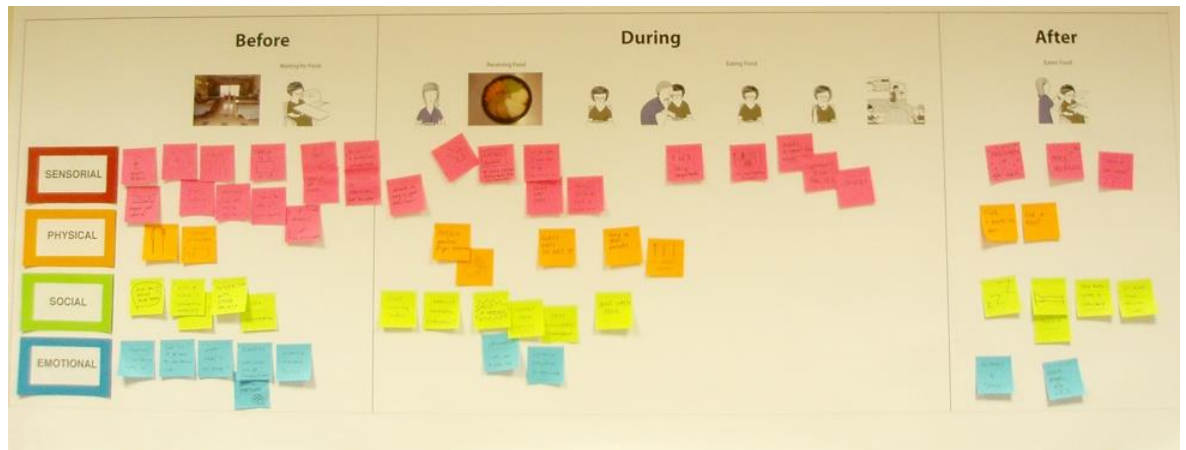
Figure 8.9 The patients' voices by playing the Map game at the workshop.

The patients' ideas were mapped throughout the mealtime stages such as before, during and after the meal. Through each stage, ways of thinking about the mealtime associated with experiential considerations such as sensorial, physical, social and emotional were explored. In what follows I will demonstrate what patients suggested for each mealtime stage.

Before

What would be considered at the mealtime to promote sensorial quality? How would it smell, sound and look like? The patients' ideas highlighted attention to issues of personal goals and quality of the environment. They expressed:

>*P2/B: The tatties and mince.*

>*P2/B: The ideal situation would be to be able to pick your main beforehand and it would be good quality food (…) you want something that's to your liking.*

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P2/B: In an ideal world your food would be cooked on the premises and not driven em … 200 miles.

P2/B: You would be able to get what you wanted, if you wanted mince and potatoes you got mince and potatoes. You would obviously have to choose what you wanted beforehand and that would be fine (...) guys cooking that food for you.

P2/B: em … just getting the smell of the food.

P1/B: It's not good to smell food when you can't eat it.

P4/B: Music might help (...) just some quiet background (...) I like country and western (...) it would be nice to listen to those.

What these voices seems to show is the idea that the mealtime involes the issue of promoting individuality. Consider, for example, how Patient 2 expressed thoughts giving significance to food smells. In contrast, Patient 1 indicated that food sensory is problematic, in particular when patients present different abilities to eat. What seems to be highlighted here is that the voices are recognising a patient with individuality, with their own feelings and own needs and how these issues require attention to promote good quality of life for the patient in the future. Another viewpoint draws attention to issues of personal pleasure. For example, Patient 4 expressed views associated with the idea of the quality of environment in promoting patients' likes. In continuing to play this game, theme colour-cards were selected, which drove our discussion to physical issues.

What would be considered at the mealtime to provide physical quality? How would it be, act and move? The patients' views revealed common thoughts within this idea of going out to eat which suggests the patient moves from the "treatment" room to a different room. According to them, the mealtime requires a physical space with environmental conditions to choose food, to socialise with others and to receive assistance. They said:

P4/B: There's no room, you need a room (...) you're in your bed every day and everybody sits and your meal's brought in (...) that doesn't change.

P4/B: I get to choose what I want.

P1/B: A table for the four patients.

P1/B: A menu so that you could choose what you wanted to eat.

P1/B: Ideally the patient should be made sure they're asked if they want to go to the toilet before mealtimes (...) because what happens is in the middle of the

mealtimes they want to go to the toilet and serving food. So the patients just sit until the end of the meal time before they get to the toilet.

P1/B: A separate room for meals would be good.

P2/B: if I could change (...) I would change the ward (...) There's nothing worse than everybody else around you is eating and you're not, you can't eat and you're not given the choice,

P2/B: A room like this where the patients could go and sit down to (...) if you could go

P2/B: Sitting at the table.

P4/B: Just sitting down.

What these patients' voices highlight here is a desire for change at the mealtime. Consider, for example, how Patient 4 demonstrates his thoughts by saying "you're in your bed every day". In addition, P2 expressed his views in this way: "there's nothing worse than everybody else around is eating and you're not". In this line of thinking, they tend to suggest ideas to allow patients, those who can do it, going out of the treatment room, or "ward", in order to have their meals and at the same time socialise. In other words, it shows their ideas to permit patients to experience a kind of ritual of going out to have a meal. In this way it might also benefit the patient who cannot eat to live a better quality of life. The theme colour-cards were again selected and this brought about a discussion about social issues.

What would be considered at the mealtime to provide social quality? What would they do? Patients 2 and 4 expressed thoughts associated with issues of sociability and personality. They reported:

P2/B: Having interaction with other patients when possible (...) having an interaction with the other patients to be about to talk to them (...) because when you're in bed you lay and didn't talk to anybody.

P4/B: One of the nurses (...) finding out what you want and how capable you are. If you are capable of eating by yourself or not.

These voices highlight attention to the idea of sociability, involving different experiences. Think, for example, how Pateint 2 expressed thoughts associated with the patient being able to socialise in and/or out of bed. According to Patient 4, socialising would support

patients' needs of living with difficulties to eat. Perhaps what these voices are demonstrating is the patients' desire for a wider sociability. In continuing to play the mapping game, a discussion based on emotional issues was stimulated.

What would be considered at the mealtime to evoke emotional quality? What would it feel like? Patients 4 and 2 shed light on the patients' expectations before the meal. They expressed:

> P4/B: She [a fictional patient character] should be thinking she's going to get a good meal (…) a freshly made meal (…) anticipation of a good meal.

> P2/B: Looking forward to her meal [the fictional patient].

These voices demonstrate the importance of the mealtime in having a role to stimulate an anticipation which brings forth positive emotional response. Consider, for example, how patients expressed thoughts demonstrating that they hold expectations about food. What seems to be highlighted here is that if these patients' expectations are confirmed when they are receiving food they can feel satisfied (Hassenzahl, 2004).

During

In discussing sensorial issues during the mealtime, when patients are receiving their meals, all patients expressed similar thoughts associated with promoting the quality of food presentation. They reported:

> P4/D: Keep the skins on anyway.

> P4/D: Freshly cooked there (…) chicken curry (…) fried rice

> P1/D: Meat to look like meat, in a separate dish, potatoes in a separate dish, also Vegetables (…) to have sauces.

> P2/D: Something that looks nice (...) not the plate of muck you get (...) let's say potatoes, keep them separate don't be on top of each other.

From these patients' voices we can see that good quality of food leads to ideas of promoting visual appearence, as demonstrated in Chapter 3, section 3.4. But it also draws attention to the combination of components in order to present food. There is this view that different food requires different tableware. Think, for example, how Patient 1 expressed

her views by saying "potatoes in a separate dish". Perhaps most interesting here is the idea of promoting a more familiar rather than unfamiliar situation at the mealtime.

In discussing physical issues during the mealtime, Patients 4 and 1 highlighted suggestions related to promoting friendliness. For example, packets that are "quick open" and glasses that are "easy to reach".

> *P4/D: She would need physical therapy to help her move her fingers (...) you need to keep moving at the table, keep your hands moving like I do just now.*
>
> *P4/D: Sometimes you get terrible packets and you can't open them (...) a wee pair of scissors to cut it (...) because it's very difficult when you've had a stroke, you find it really hard to start a sealed pack and you feel thick.*
>
> *P1/D: Placing my glass handy beside where you're sitting, next to your cutlery so that's it's easy to get.*
>
> *P4/D: The nurses should be there. If they've given their meals they should check they can eat.*

These patients' voices are showing ideas about how to promote autonomy and self-control at the mealtime. Consider, for example, how Patient 4 expressed views associated with difficulties to open packets. Another comment reveals the patient's goals at the mealtime. For example, P4 indicated his views associated with the mealtime as being a kind of therapy by saying "you need to keep moving". What seems to be emphasised here is the view of the mealtime in supporting a faster, better and more enjoyable patient recovery.

In discussing social issues during the mealtime, patients expressed, once more, thoughts associated with a wider view of sociability. They said:

> *P4/D: Telling you jokes and this and that.*
>
> *P1/D: To ask the patient if she needs assistance to eat with her meal.*

Once again, the patients' voices bring two views of sociability: on one hand, in providing an enjoyable and convivial moment; and on the other hand, in supporting individual needs to eat. For example, P4 saw it happen in ways that promote entertainment. According to P1, being entertained can help with eating. It is interesting to think about how exploring issues of sociability can support patients' aspirations in many ways.

In discussing emotional issues during the mealtime, all patients shared similar thoughts associated with the patients' expectations about the food. They said:

> *P4/D: Is she eating it? That's a good meal (...) oh, I'm enjoying it, it's good.*
>
> *P1/D: Enjoying the meal.*
>
> *P2/D: Waiting for more for her next meal (...) that was good*
>
> *P1/D: Feeling of satisfaction.*

From these patients' voices we can see how promoting quality of food can evoke positive feelings. Think, for example, how Patient 4 expressed thoughts considering that the act of "eating" demonstrates a positive feeling as "enjoying". This issue of the quality of the food shows connections with issues around good emotional quality.

After

The patients' thoughts, while discussing sensorial issues after the meal, revealed ideas related to personal pleasures. They reported:

> *P1/A: She [the fictional patient] should get freshened up after mealtimes (...) hands washed.*
>
> *P2/A: Peace and quiet to go to sleep.*
>
> *P4/A: I think it should be relaxing or a good sleep, peace and quiet.*

There is a common sense in these patients' voices about suggesting ideas to promote relaxation after the meal. Consider, for example, how Patients 2 and 4 revealed thoughts associated with the environment, involving a calm atmosphere, which provides opportunities for patients to relax and/or sleep. In other words, their comments seem to demonstrate that after the meal, when they are relaxing, they have returned to their "treatment" room.

In discussing physical issues after the meal, the patients indicated this view of the patients returning to their rooms. As they suggested before, the mealtime would provide patients with an experience similar to going out; experiencing a bit of a ritual or event out of the mealtime. They expressed:

> *P2/A: I just think that when she's finished her meal she would be going back to her bed [the fictional patient].*

P4/A: Maybe tidy up the wee table, tidy it up a wee bit.

P1/A: Moving back to beside her bed or put in bed for a rest.

P2/A: Go for a sleep.

P2/A: After your meal I would have said to somebody can they take me back to my bed.

P4/A: To put you back into your bed and tuck you in.

P1/A: Take the dishes away and clean the area.

What seems to be highlighted in these patients' views is the way of living and reliving experience. Consider, for example, how patients' suggestions for before the meal highlighted opportunities for going out of their treatment room, which seems to be associated with this idea of lifestyle, but also of "normality". At this stage, they present suggestions of going back to recovery and treatment, perhaps linking this idea of the patient enjoying his/her life during his/her temporary recovery process in hospital.

In discussing social issues after the meal, Patient 1 expressed thoughts revealing her ideas in this way:

P1/A: Patients would like to sit beside another patient so as to be able to speak to and not shout.

What seems to be highlighted here is the idea of the mealtime in supporting individual pleasure. Think, for example, how Patient 1 expressed views to open possibilities for patients to socialise, if they wished to, after the meal.

All patients shared similar thoughts when we were discussing emotional issues after the mealtime. They said:

P4/D: She'll starting sleepy [the fictional patient], if she's had a good meal she'll start to go yawn and stretch.

P2/D: I agree with that, aye.

P1/D: Relaxed and then tired.

P4/A: I'd like to relax.

P4/A: If you've really enjoyed it then maybe a wee snooze.

From these patients' voices we can see that an enjoyable experience might require a moment of relaxation after a meal. This view of the mealtime might show that promoting a good quality of life in hospital is about supporting patients to have pleasurable, enjoyable and relaxing experiences.

From such a perspective, the patients' ideas seem to present a picture in a way (see Figure 8.10) that draws attention to a new patient experience. Illustrating the patients' ideas using a storyboard technique (Martin and Hanington, 2012) helped me to reflect and see the emerging issues visually. This understanding revealed possibilities throughout the three stages: before (the patient waits for his/her food), during (the patient receives his/her food and eats) and after (the patient has eaten his/her food). Through these patients' ideas, I was able to view the mealtime from the perspective of facilitating personalisation and revealed these emerging issues, revealing a focus on creating moments for patients to experience the normalities of life. Although patients revealed aspects of the possibility of the future mealtime to provide "normality", for example, spaces that are decorated with familiar tastes, these patients' ideas revealed that the mealtime must recognise the person behind the patient; one who has individual needs, likes and goals towards living a good life. In what follows, I will underline in more detail these different issues in relation to the patient experience.
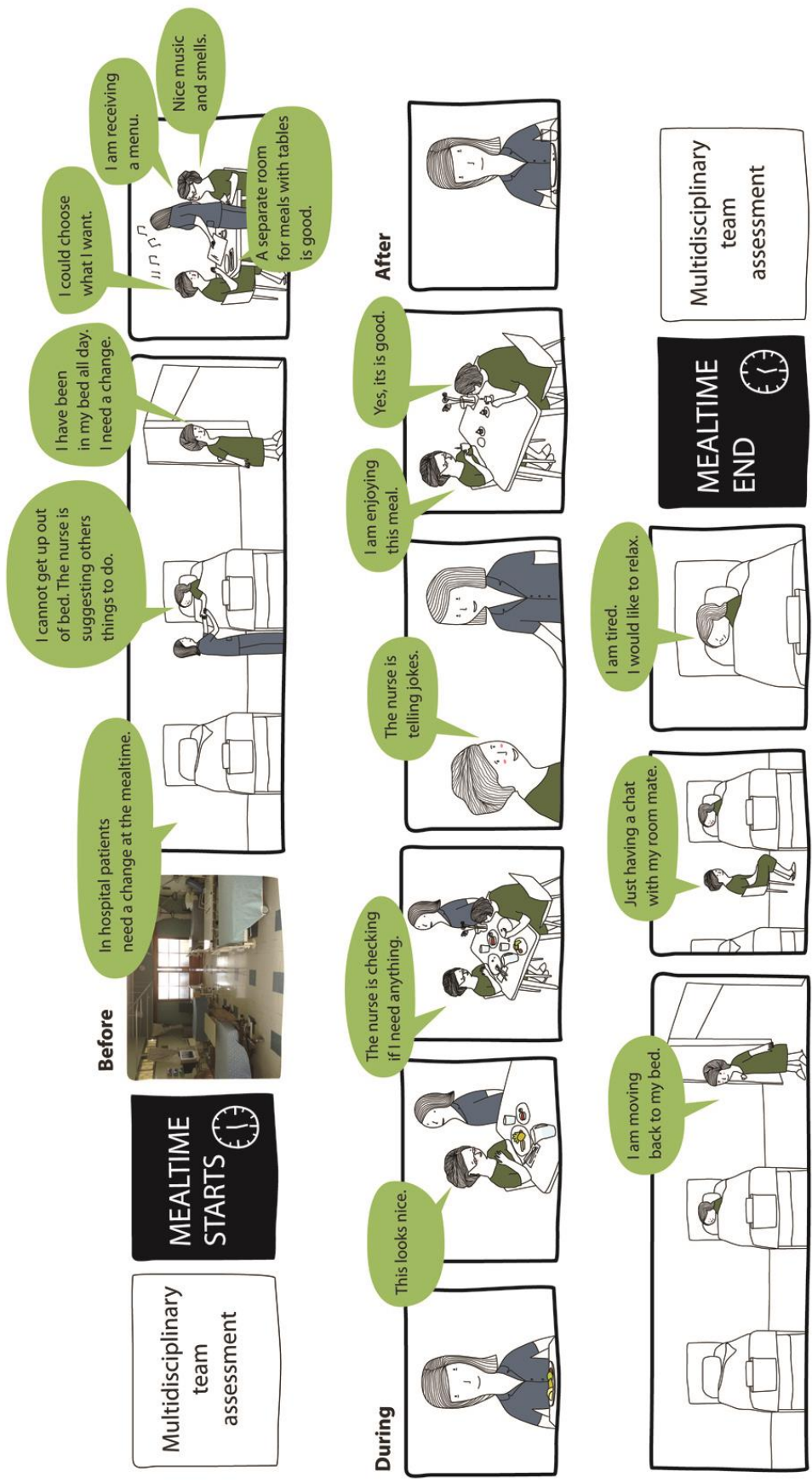
Figure 8.10 The mealtime storyboard based on the patients' ideas for future experiences in stroke rehabilitation in hospital.

8.2.4 Giving patients a voice

In this third phase of the research, as outlined earlier in this chapter, I aimed to explore and elicit what could make a significant difference at the mealtime in stroke rehabilitation for the patient experience. Fundamentally, this exploration allowed me to identify a number of issues (see Table 8.3 and Figure 8.11), demonstrating the need to support personalisation at the mealtime to enhance the patient experience (see Figure 8.12)

Table 8.3 The kind of issues that have emerged from the patients' ideas "voices".

KEY ISSUES		P'S VOICES
Personal needs	Space	You need a room, a separate room for meals where patients could go and sit down. You are in your bed everyday. There is nothing worse than everybody else around is eating and you are not.
	Personal (assistance)	Assist the patient
	Personal (care)	Cheeking if the patient can eat
	Personal (service)	Asking the patient if she/he need assistance
	Tableware (friendly)	Cutlery easy to get Packets easy to open
Personal likes	Ambient (sound)	Quiet background, light music Relaxing Piece and quiet
	Ambient (visual)	Flowers on the table Tables decorated with candles
	Space	A big table
	Social setting	Sitting beside another patient Having interactions with patients Everyone sitting having a meal Grouping together Patients sitting across from each other
	Sociability	Having fun People talking
	Food (process)	Freshly cooked

	Food (presentation)	Meat to look like meat Something that looks nice in separate dishes To have sauces
	Personal care	Get freshened up Hands washed
Personal goals	Ambience (smells)	Receive assistance if you need Getting the smells of the food Not getting the smells of the food when you cannot eat
	Space	Sitting at the table Going back to bed
	Social setting	To be around a table together
	Sociability	Someone would have to initiate the conversation
	Food (more choice)	You would be able to get what you want To choose what you want To get to choose what I want Different food
	Food (likes)	The tatties and mince Chicken curry Fried rice
	Food (more self-control)	Be able to pick your main beforehand
	Personal (service)	Tidy up Take the dishes away Clean area

Figure 8.11 A conceptualisation of the main issues at the mealtime that have emerged from the patients' voices.
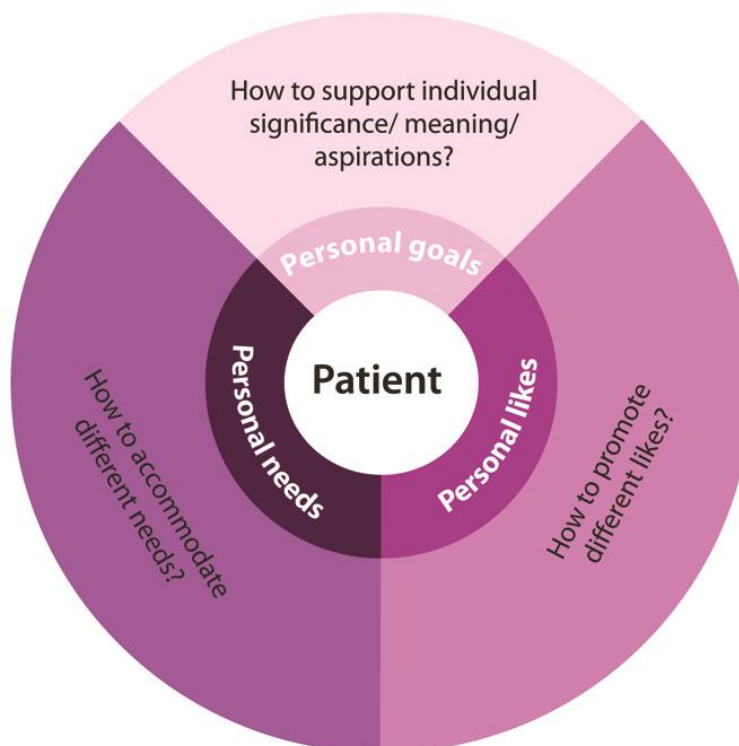
Figure 8.12 An overview of the key issues and insights.

In Figure 8.12 above, it becomes apparent that the patients' voices are bringing forth issues of personhood: recognising the person behind the patient, with individuality, feelings and his/her own agency in his/her recovery. Consider, for example, how patients draw attention to the context of their lifestyle, family, personal capabilities and aspirations in the workshop. In fact, patients express their ideas, demonstrating that the mealtime might benefit from the integration of patient-personhood. Although this notion of personhood at the mealtime offers exciting opportunities for exploring the patient experience, it poses here an issue within this context of stroke rehabilitation: how do we "mass personalise" rehabilitation? Think, for example, the implications that stroke incidence has in the organisations that provide the health services and the cost involved in the logistics of those services (Stroke Association, 2013). However, to facilitate personalisation at the mealtime might be of benefit by contributing to patients' recovery and well-being. In rehabilitation in hospital, patients present a number of eating difficulties (Westegren et al., 2002a). As demonstrated in Chapter 7, patients recalled the mealtime upon two *types* of experiences; those patients who can and those who cannot eat in a traditional sense. In participating in this workshop, patients explained that this idea of adapting the mealtime space to accommodate individual needs might make a significant difference for the patient experience. In doing so, it could promote little pleasures of life and support well-being, for example, creating a comforting ambience (convivial and privacy). Exploring possibilities

brings forth another issue; recognising that patients have individual likes. Patients indicated this idea of how experiencing little pleasures at the mealtime, for example, relaxing, getting freshened up, receiving food that they like, having fun and socialising with each other, could promote enjoyable and satisfying moments for their lives during recovery in hospital. As discussed in Chapters 6 and 7, there is a lack of social dimension at the present mealtime. Although feelings of embarrassment have been identified when patients reveal their conditions in public (Perry and McLaren, 2003), these feelings might surface because of a lack of environmental factors. The issues emerging related to watching other patients eating when you cannot and vice versa might be relatively simple to fix. However, it does not mean that patients do not want to socialise. Think, for example, how the patients placed a strong emphasis on social issues when discussing their ideas when compared to recounting their lived experience. This social dimension seems to be a significant element when considering the patient experience in the future. Patients' voices are emphasising a need for socialisation through the games by saying "grouping them together", "to be around a table together" and/or "having interactions with patients". In other words, patients see the mealtime as a moment to experience a shift out of their "mechanistic" clinical routine, perhaps, a moment in which they see themselves celebrating life in a more social, familiar and comforting environment. Personal goals are also demonstrated in these patients' voices. They reveal a view of their desire to experience a sense of control "to choose what you want", or, in other words, to make decisions in order to achieve their aspirations of enjoying life.

What this research study emphasises here is the need to explore how these patients' suggestions and "ideas" can be considered to explore opportunities to redesign a new mealtime scenario. Could looking at this notion of personalisation, socialisation and familiarity enable the identification of further issues on how to enhance the patient experience at the mealtime in stroke rehabilitation in hospital? It is relevant not only to explore the patients but also the healthcare professionals' ideas. What seems to be significant here is to understand, from the healthcare professionals' voices, what can be done to explore these issues highlighted by the patients. In doing so, it can bring new insights. In fact, it can turn ideas into concepts to develop a new scenario in order to make them accessible to explore their design for desirable futures (Krippendorff, 2006). In what follows, I will present the findings from the workshop conducted with healthcare professionals.

8.3 The workshop with healthcare professionals

This chapter proceeds by describing the second workshop; the one held with healthcare professionals. I will also begin by presenting who participated in this study. Furthermore, I show how the study was conducted by playing two games (see Figure 5.29). The main focus was to explore what can be taken forward from the patients' ideas in order to turn them into concepts. In this way, the workshop involved two rather than three games. By presenting the findings from the study, I will illuminate the healthcare professionals' voices related to these two design games: i) *What if?*; and ii) the Roller Coaster game, as I discussed in Chapter 5, section 5.3.3.2. In exploring What if?, I found that the healthcare professionals' voices referred to their favourite chefs in contrast to the results for the patient workshop. Does this finding reveal that patients were more creative because they did not answer in the way that I expected? Or does it reveal the socio-cultural differences between the two groups, highlighting their different perspectives? By playing this game, the healthcare professionals' voices revealed this idea of bringing "personality" to the mealtime experience. "Personality" was related to this view of the professional role, revealing passion, knowledge and empathy as important characteristics to create moments for people enjoy their mealtimes. With the Roller Coaster game, I found the healthcare professionals' voices brought forth this issue of creating empathy at the mealtime for patients, which was focused on three elements: the environment, food and personality. To conclude this part of the discussion, I will demonstrate how these healthcare professionals' voices made an important contribution to transform the patients' ideas into concepts.

8.3.1   Who participated?

Initially I intended to develop this research study with the four healthcare professionals who participated in Phase 1. However, as I mentioned in Chapter 5, healthcare professionals tend to have busy schedules and it was difficult to find a time to bring all of them together. Therefore, participants in this study were three healthcare professionals, all clinical practitioners in the Stroke Rehabilitation Unit, as described in Chapter 5 (see Table 8.4). However, the group of healthcare professionals represent different roles, and, as such, these healthcare professionals are considered to be relevant participants. These healthcare professionals were a nurse who also participated in Phase 1 of the research, a speech therapist, and an occupational therapist.

Table 8.4 The healthcare professionals who participated in the interviews

Healthcare professionals	Specialism	Work experience (in years)	Gender
HP1	Nurse	6	Woman
HP5	Occupational Therapist	-	Woman
HP6	Speech Therapist	-	Woman

The table illustrates the characteristics of the healthcare professionals in relation to their unique identifier code, specialism, work experience and gender. By illustrating the healthcare professionals' characteristics, I have introduced those who participated in this research study. The following section will focus on describing how the workshop was conducted.

8.3.2   Conducting the workshop with healthcare professionals

Previously, in previous Chapter 5, section 5.3.3.2, I discussed how I conceived this workshop. Here I will demonstrate how the design games were conducted (see Table 8.5) and what findings were gathered from them.

Table 8.5 Conducting a workshop, as a game, connected by thinking and suggesting

Playing	
Thinking	*Suggesting*
Collectively	Collectively
15 minutes	45 minutes
Room – Hospital – Stroke Unit	

The table above illustrates each game, revealing the way of playing it, and time involved, and where it took place. Before I start to describe how this workshop was conducted, it is important to explain first how this socialised and materialised situation was created in order to promote a collective dialogue (see Figure 8.13).
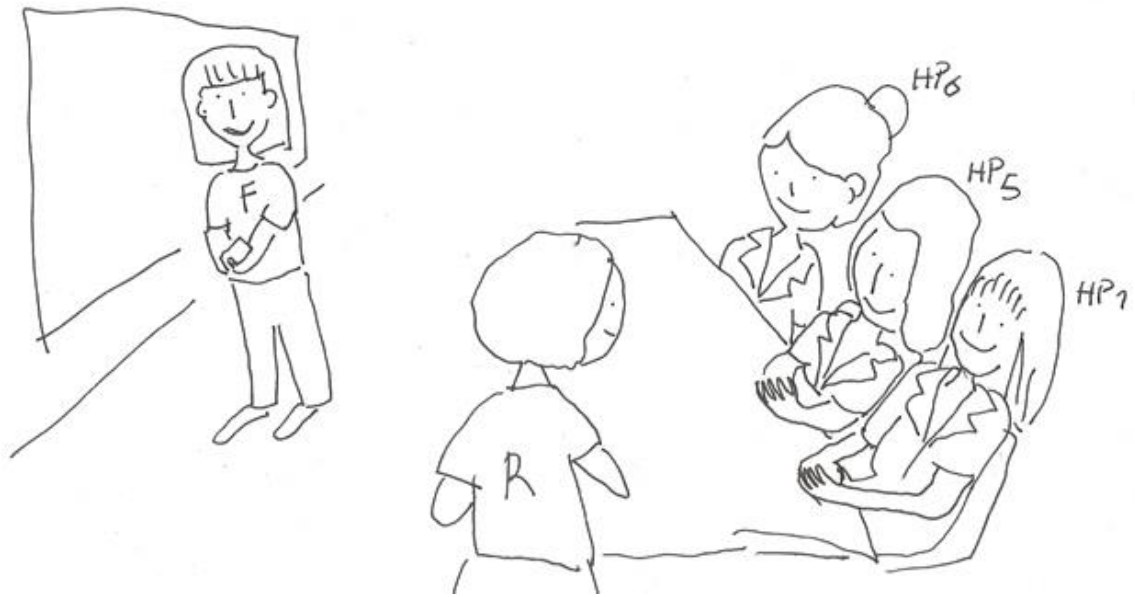
Figure 8.13 The environmental overview of the workshop with healthcare professionals, involving the researcher (R), three healthcare professinals (HP) and a PhD student as facilitator (F).

A PhD student at the Glasgow School of Art attended this workshop to help in illustrating the healthcare professionals' voices throughout the workshop while we were playing the games. The workshop started with me introducing the aims of the workshop to the healthcare professionals. In other words, I told them what we were going to do and why. Afterwards, I invited healthcare professionals to play two games. The aim of the first game was to get the healthcare professionals thinking about the mealtime from a chef's perspective in order to open up different ways of thinking about the mealtime. Afterwards, the healthcare professionals were asked to suggest possibilities to promote the quality of the patient experience at the mealtime based on the patients' expectations, as demonstrated in Chapter 8.

In this workshop, I began by thanking the healthcare professionals for their participation and recapitulating the initial information given to them in order to clarify any issues. Simultaneously, I invited them to imagine that they were going to exchange their National Health Service (NHS) uniform for a Glasgow School of Art (GSA) uniform because they were in now placing themselves in a different role, exploring opportunities to promote the quality of the patient experience. Furthermore, I also emphasised the importance of the healthcare professionals' participation, encouraging them to be open and honest about their suggestions and ideas because their views would be valuable to this study. Following this, they signed a consent form (see Appendix D). In what follows I will illustrate the healthcare professionals' voices from their participation in this workshop.

8.3.3 Findings

8.3.3.1 *What if?*

Playing *What if?*, I began by showing to the healthcare professionals the mealtime as a day-to-day activity in people's lives, an activity which becomes "familiar", but also an activity where people expect to experience certain things due to prior experiences. Here I used a PowerPoint presentation to show the mealtime stages such as before, during and after, and a conceptualisation of experiencing the mealtime which brings different "levels" of experiencing (see Figure 8.14). Fundamentally, this presentation can emphasise how these levels of experiencing, which have a temporal dimension (relating to time), can reveal an anticipation, encounter and reflection to evoke emotional quality. In doing so, I used a fictional character called "Julia". The purpose of initiating this workshop with this presentation was to stimulate the healthcare professionals' reflections about design for experiencing. Following this, I aimed to get healthcare professionals thinking about the designing of the mealtime in this way: *What if it was redesigned by your favourite chef?*
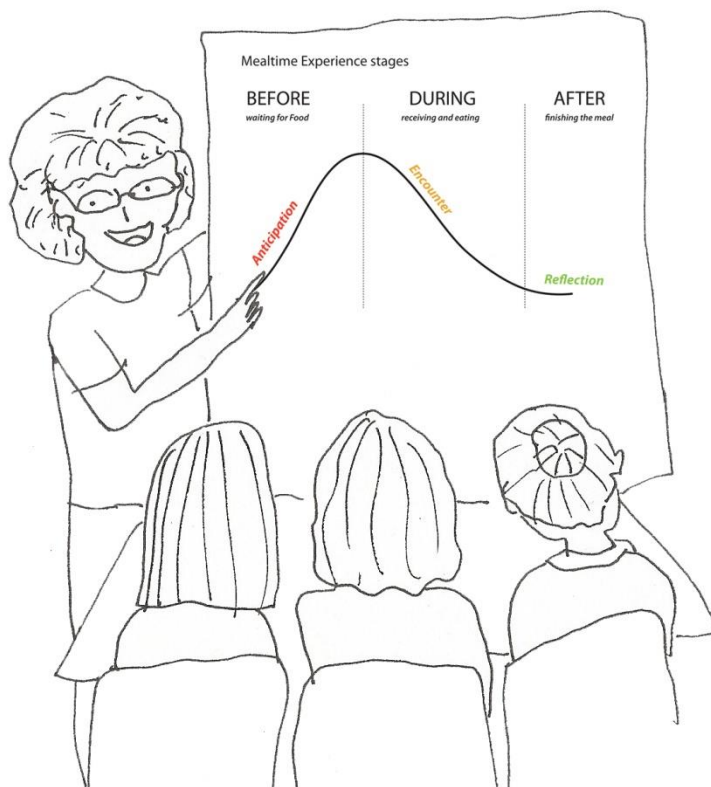
Figure 8.14 Presenting a conceptualisation of experiencing the mealtime for healthcare professionals in the workshop.

The healthcare professionals' views presented contrasting views when compared with the patients' views, as demonstrated in Chapter 8, section 8.2.3.1. In other words, their views, when compared to those of the patients, showed that socio-cultural differences highlight different perspectives. These healthcare professionals drew attention to the notion that "favourite" is what becomes "admired". They said:

> *HP1_Nurse: Jamie Oliver.*
>
> *HP5_Occupational therapist: I say Gino D'Acampo.*
>
> *HP6_Speech therapist: I like Michel Roux.*

In discussing their favourite chefs, the healthcare professionals also expressed preferences associated with the chef's personality, and, by saying so, demonstrated that designing the mealtime can possibly reveal an act of personality and a sense of identity.

Our dialogue proceed into reflections about what kind of mealtime would these "admired" chefs create for "Julia's" (the fictional character) experiencing. For example, I prompted questions to get the healthcare professionals thinking about "levels" of experiencing, such as anticipation, encounter and reflection.

While the healthcare professionals were expressing their views, the facilitator was simultaneously visually representing their voices on a whiteboard on the wall (see Figure 8.15). This allowed the healthcare professionals to see actively what we were doing together.

Figure 8.15 Illustrating the healthcare professionals' voices while playing What if? at the workshop.

Before, as anticipation

In discussing what kind of anticipation "level" the famous chefs would create to make "Julia" look forward to the meal, the healthcare professionals' voices highlighted attention to issues of subjective well-being. They said:

> *HP6_Speech therapist/B: Like the smells of the food, you know you get the smells wafting through from the kitchen.*
>
> *HP1_Nurse/B: Something nice to look at.*
>
> *HP5_Occupational therapist/B: I suppose good food, it doesn't make a difference really when it's good quality.*
>
> *HP1_Nurse/B: They take in what they person that they're cooking for, what they like.*
>
> *HP5_Occupational therapist/B: You'd be hoping that he [Gino D'Acampo] was going to come out and say hello to you.*
>
> *HP1/B: He makes everything a joke, he [Jamie Oliver] makes things funny by the comments that he makes when he's doing the cooking. He involves people as well.*
>
> *HP6_Speech therapist/B: And yeah, he can be quite amusing and he's so enthusiastic about the food that he talks about it's not as much about making jokes for him it's about "Wow! Look at this".*
>
> *HP5_Occupational therapist/B: He's very enthusiastic isn't he? He's very enthusiastic about what he's cooking.*
>
> *HP1_Nurse/B: He's very passionate about what he put's in his food, he loves his spices and all things like that and he's very passionate about his taste. Everything has to taste good not just look good but taste.*
>
> *HP6_Speech therapist/B: I guess you've got that expectation because it's him [Michel Roux], you know it's going to be something that's going to be tasty at the end.*
>
> *HP5_Occupational therapist/B: Well he's an Italian chef so he would, you would look forward to having an Italian meal which would maybe be a bit different from what you would Cook yourself at home. Maybe. He's good fun as well so ...*

HP5_Occupational therapist/B: He's got a good sense of humour too though, hasn't he?

HP1_Nurse/B: It's his personality.

HP6_Speech therapist/B: It's that, just that knowledge and the fact that they even care.

The views from the healthcare professionals revealed thoughts related to a combination of points that "Julia" would be in contact with. Consider, for example, how HP1 expressed views related to senses as "something nice to look at". Another point is their view of social contact, or in other words, a professional role. Think, for example, how the healthcare professionals emphasised that the professional would cook the food taking into consideration what "Julia" likes. This clearly shows the importance of addressing personal goals at the mealtime, as the patients' voices highlighted previously in Chapter 8. Perhaps more interesting is this view of the professional "chef" as being "enthusiastic" and "passionate" and how this professional emotional state can add value to the food but also to the social interaction. For example, HP5 expressed that "Julia" would be hoping to receive an emotional trigger from the professional by saying "hello" and having "a good sense of humour". What HP6 added here is the significance of these professionals' knowledge and "the fact that they even care".

During, as encounter

In discussing what kind of encounter "level" the chefs would create to ensure "Julia" has a nice, fun and friendly time while eating, the healthcare professionals' views draw attention to issues of the quality of the food, environment and professional personality. They expressed:

HP6_Speech therapist/D: It's that's thing that when you eat there is so much happens before you put that first bite in your mouth it's about the smells and it's about if something comes down and it's on your plate and it's just presented really nicely. It's laid out really well.

HP1_Nurse/D: If those stages have already happened, the smell, the presentation, then you're psyched up to enjoy that food. If you don't, something smells rotten or rank and then you see it in front of you and you think that looks even worse you're not going to enjoy it no matter what.

HP1_Nurse/D: So it's all about visual and smell to start of with.

HP1_Nurse/D: If you know where it's been prepared is very clean and it's good then you will enjoy it better.

HP1_Nurse/D: It would be like a nice environment, a comfortable environment.

HP5_Occupational therapist/D: Calm.

HP6_Speech therapist/D: A comfy chair, I hate it when you go to a restaurant and kind of half way through the meal you're like, back's killing you.

HP5_Occupational therapist/D: I think the way it's served to the person who's serving it to you as well has a big impact on how well ...

HP6_Speech therapist/D: The waiter brings it over and kind of puts it down nicely.

HP1_Nurse/D: That I don't expect to ask for something and then get something different.

HP5_Occupational therapist/D: I think to be knowledgeable about what they're serving you, to be happy.

HP1_Nurse/D: It's their personalities makes it pleasurable as well and the way they're dressed as well.

HP1_Nurse/D: You enjoy it more.

HP6_Speech therapist/D: You kind of go, "Oh, wow."

What seems to be highlighted in these voices is the importance of "Julia" receiving a good quality of food, environment and presentation at this stage. Consider, for example, how the healthcare professionals expressed their thoughts related mainly with the senses related to "visual" and "smell". Environmental issues were related with comfort and well-being. On the other hand, these healthcare professionals seem to continuously draw attention to the professional's role and his/her personality. Think, for example, how HP5 demonstrated attention to "the person who's serving" the food and emphasised that the professional's emotions would be "happy". Additional thoughts showed attention to the way the professional would place food on the table with views that it would be placed on the table "nicely". What these voices seem to highlight here is this link: how a positive emotional state might influence positive emotional responses, such as "Oh, wow", and, consequently, promote pleasurable experiences. This is an interesting point to reflect upon in the context of the mealtime in stroke rehabilitation.

After, as reflection

In discussing what kind of reflective "level" the chefs would provide to make "Julia" relax, the healthcare professionals' views drew attention to experiential considerations such as the physical and social. For physical qualities, the healthcare professionals revealed thoughts of providing environmental conditions to respond to lifestyles such as having a cup of tea. Simultaneously, for social qualities, they indicated views of promoting a sense of conviviality. They stated:

> *HP6_Speech therapist/A: Just having the time to have enjoyed your meal without feeling like you're being rushed to have it, so that by the time you've got to that final stage you're not suffering from indigestion because you've had to eat so fast.*
>
> *HP6_Speech therapist/A: You can sit and have a cup of tea or whatever afterwards, you know, at your leisure, you know.*
>
> *HP5_Occupational therapist/A: For me, if I've got a meal sitting in front of me and I've not eaten it all because I can't eat anymore, I'd like it to be taken away quickly rather than it sitting in front of me for a while. 'Cause you'll just pick because once I've eaten and I'm full, that's me I've had enough.*
>
> *HP1_Nurse/A: But it's taking it away at the right time though, if you've only sat for a break like I have to and they take it away then you're like, "Hey!"*
>
> *HP1_Nurse/A: So given time to appreciate your food and feedback.*
>
> *HP6_Speech therapist/A: You won't feel under pressure to have more.*
>
> *HP5_Occupational therapist/A: I suppose some people after they've had a meal like to maybe have a something to wash it down, a drink or like a hot or cold drink.*
>
> *HP1_Nurse/A: I would like a cup of tea with mine, so it's about asking them, "Do you like tea?"*
>
> *HP1_Nurse/A: If they ask if you enjoyed it then, feedback.*
>
> *HP5_Occupational therapist/A: I suppose you'd be chatting about, "Oh, yours looked nice and how did you enjoy it?" HP1_Nurse/A: "Gi's a bit."*
>
> *HP1_Nurse/A: Chat to Jamie about what he's doing at the weekend, a wee chocolate.*

These voices from the healthcare professionals demonstrate views within this idea of lifestyle, which requires time to appreciate and enjoy things. Think, for example, how HP6 expressed that this can be the time when "Julia" can have a cup of tea. Having a cup of tea is seen as a moment of "leisure". What seems to be highlighted here is this view of relaxing, similar to what the patients' voices considered to be important to promote at mealtime in hospital. Another thought that healthcare professionals also highlighted here is the professional's role in receiving and providing "feedback". For example, HP1 expressed her views related with the professional's role in asking questions such as "have you enjoyed it?" and/or just coming along and having a little chat with "Julia" about little things in life. Once again, the professional's role (see Figure 8.16) at the mealtime seems to emerge as an important issue from these healthcare professionals' voices.
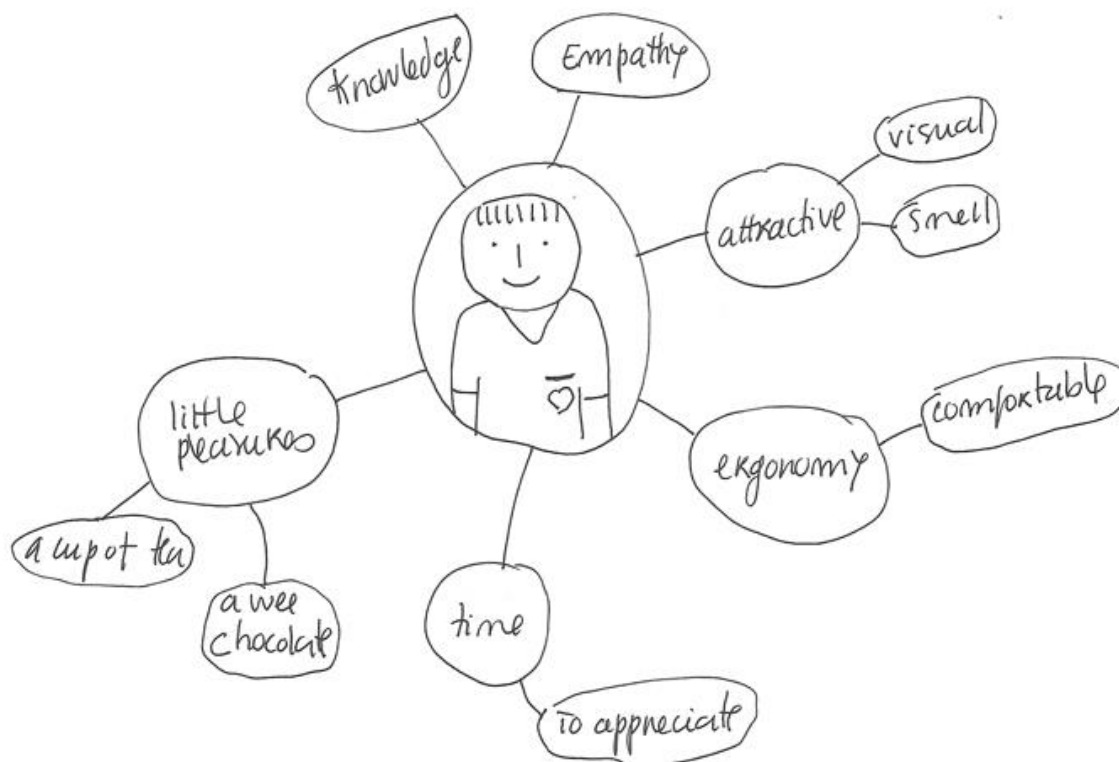
Figure 8.16 A conceptualisation of the issues emerging in playing *What if?* at the workshop.

What I found by playing this game was that the healthcare professionals' reflections highlight attention to the designing of the mealtime to promote a sort of enchantment through each stage for those who are going to live the experience. Although the game revealed a focus on thinking from a chef's perspective to create good food and a pleasing environment, it also revealed that expressing empathy "personality" might support positive emotional states as well as enhance positive emotional responses. In other words,

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professionals who have pleasant personalities might influence experiencers in experiencing the pleasure and enjoyment of living a good mealtime.

After this game I invited the healthcare professionals for a coffee and tea break. I began the second part of this workshop summarising what we have done on the first part and opening up a dialogue to allow healthcare professionals to add further thoughts about it. Afterwards, I introduced the next game. In the following section I will illustrate the healthcare professionals' voices in playing the Roller Coaster game.

8.3.3.2 Roller Coaster game

In playing the Roller Coaster game, I started to explain the aims and rules of the game by introducing the game pieces; a game board wall and the passenger and questions cards (see Figure 8.17). In doing so, I explained that the healthcare professionals would be invited to suggest opportunities to explore "levels" for experiencing throughout the mealtime, involving moving the passenger on the track in order to elicit questions.

Figure 8.17 Explaining the game rules to play the Roller Coaster game

Prior discussions about the mealtime aimed to get healthcare professionals thinking about the redesigning of the mealtime. The purpose of these discussions was to encourage them to reflect about the mealtime as a familiar experience, perhaps responding to people's

lifestyles. At the same time, I invited healthcare professionals to express their ideas to explore "levels" of experiencing, such as anticipation, encounter and reflection, thinking from a chef's perspective. The purpose was to stimulate their reflections to think of ways of how to promote enjoyable and pleasurable experiences at the mealtime. At this moment, I invited healthcare professionals to think about the patient experience. Simultaneously, I emphasised that they are experts in providing and delivering the mealtime every day for patients, and, in saying this, I encourage them to see this game as an opportunity for them to share their views and opinions of how the patient experience could be changed for the better at the mealtime in hospital. In this way, I invited them to think about "Julia", the fictional character, who is now in hospital in her bed, expecting to have a pleasant and enjoyable experience at the mealtime. What can we do to promote this? While the healthcare professionals were reflecting about this, I placed the patient "on a customer journey" on the track to start to play.

For suggesting possibilities, this game involved me moving the patient "passenger" on the track to each point and then prompting a question card for the healthcare professionals to reflect on their ideas for five minutes, and then moving the patient "passenger" to the next point. This active participation was performed ten times. The themes emerged from the prompt question cards were based on the patients' ideas. The aim was to get the healthcare professionals to think "invisibly" from a patient's perspective. As a result of playing this game, the healthcare professionals' ideas were mapped in accordance with the thinking generated from the patients' ideas.

Suggestions included healthcare professionals telling what they considered to be valuable for patients' experiences at the mealtime in hospital. In the same way as the previous game, the facilitator also illustrated their ideas as identified by the coloured question card "level" (see Figure 8.18). This allowed healthcare professionals to see actively what we were doing together.
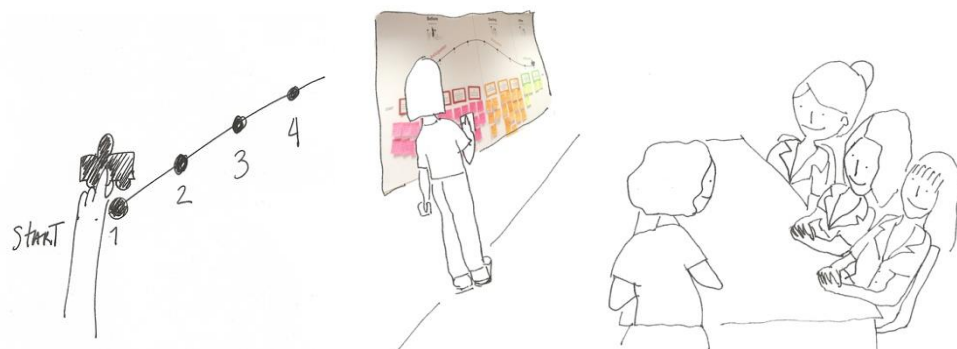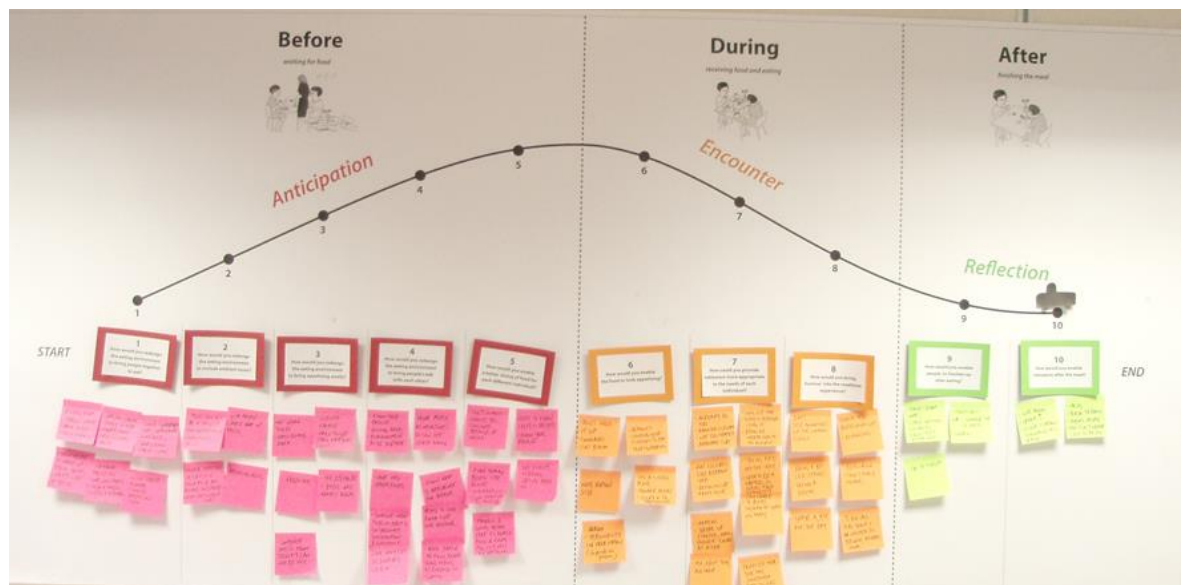
Figure 8.18 The healthcare professionals' voices by playing the Roller Coaster game at the workshop

The healthcare professionals' voices were mapped throughout the mealtime stages, for before, during and after, also involving levels for experiencing anticipation, encounter and reflection. Through each stage, ways of thinking about the patient experience were explored based on the patients' ideas, as demonstrated in Chapter 8. In what follows I will demonstrate what the healthcare professionals suggested for each mealtime stage "level".

Before, as anticipation

Placing the patient "passenger" at the first point, I prompted the first question card; *how would you redesign the eating environment to bring people together to eat?* The healthcare professionals revealed similar thoughts to those of the patients, as demonstrated in Chapter 8, which recognise the need for an appropriate space to eat in order to provide patients' well-being. They said:

> *HP1_Nurse/1: Create a dining room.*

HP1_Nurse/1: Tables and comfortable tables and chairs, decent sizes, space to eat, calm environment,

HP6_Speech therapist/1: Natural light

HP1_Nurse/1: Aye, natural light, aye. Decent cutlery, decent plates,

HP5_Occupational therapist/1: Choice of food,

HP1_Nurse/1: Something that you can sit in without getting a sore bum, comfortable, soft.

HP6_Speech therapist/1: Space to bring in wheelchairs.

HP6_Speech therapist/1: Washable chairs.

HP6_Speech therapist/1: Make sure they're not hitting off the edges, Wipe clean tablecloths.

HP5_Occupational therapist/1: They could maybe choose where they sit.

HP1_Nurse/1: I would maybe match the people, it maybe sounds daft but I'd match the couple of people who maybe sit in silence at the same table if they chat they'd have a chatting table.

HP1_Nurse/1: Uh huh, you'd like to ask them do you want to sit with a bletherer or do you want to sit in quietness? It's giving them a choice.

HP1_Nurse/1: It depends on the person (…) if they had swallowing difficulties they'd feel uncomfortable sitting so they'd have their own table as well.

HP6_Speech therapist/1: They need to concentrate on eating.

HP1_Nurse/1: It would be small section tables.

HP1_Nurse/1: Maximum four (…) like in a restaurant.

HP5_Occupational therapist/1: Round tables because they're quite good for chatting.

HP1_Nurse/1: Nice wee flowers on the table or a nice candle or something.

HP6_Speech therapist/1: Like a little café.

HP1_Nurse/1: The music.

HP5_Occupational therapist/1: It might be nice to have some chatty people.

HP5_Occupational therapist/1: You could maybe give them a subject and they'd maybe all start discussing it.

HP5_Occupational therapist/1: Happy staff,

HP6_Speech therapist/1: Relaxed.

This idea of providing a space to eat shows that healthcare professionals' voices emphasise the perspective of promoting familiarity during patients' recovery in hospital. Consider, for example, the healthcare professionals' expressions associated with familiar spaces such as "a restaurant" and/or "a café". What seems to be highlighted from these voices is the recognition that the mealtime needs to address subjective well-being. Think, for example, how HP6 expressed ideas to accommodate patients who need wheelchairs. Additionally, HP1 demonstrated thoughts about the patients' socialising, creating a group of patients by paying attention to their individual preferences in order to match those who are more and less talkative. However, they also expressed ideas for those who present swallowing difficulties in requiring more individual space in order to promote comfort and well-being. Another thought they raised is related to the professional's role which is not only seen as an assistant or facilitator but also as a entertainer, in other words, someone who is promoting sociability, as patients suggested in previous workshop demonstrated in Chapter 8. However, these voices also highlighted attention to the emotional state of these professionals' personalities to express happiness.

Prompting the second question card, *how would you design the eating environment to include ambient music?*, the healthcare professionals highlighted thoughts about promoting personal pleasure. They expressed:

HP5_Occupational therapist/2: A lot of older people would hear music.

HP1_Nurse/2: It's appropriate music, none of your pop stuff.

HP5_Occupational therapist/2: It gives them something to chat about.

HP1_Nurse/2: It's something to soothe.

HP1_Nurse/2: It's about the age, it's appropriate to the people, everyone likes Westlife (laughs) put some Westlife on, some Daniel O'Donnell. It's appropriate music to appropriate people.

HP6_Speech therapist/2: Or you know, you could have a guitar, whether it was the radio station you pick or you could have I don't know a few CDs and then do

you know you give them a choice to a person each day. Someone chooses something.

HP1_Nurse/2: A selection of CDs and it was asking them what they would like.

HP6_Speech therapist/2: Just played in the dining room

HP5_Occupational therapist/2: A wee Hi Fi, it works actually just taking in turns to choose.

HP6_Speech therapist/2: A wireless sound system, get something different.

HP5_Occupational therapist/3: Relaxing music.

These voices are highlighting two issues about sensory environment: on the one hand, they show how they are making sense; and on the other, how they are seeing it happen. The healthcare professionals' ideas recognised the need to promote appropriate sensory experiences, by respecting that each person has individuality and their own likes and dislikes about things such as music. For example, HP1 expressed views about what patients might like to hear. Additionally, their ideas demonstrated a diversity of possibilities on how the sensory environment could be constructed. Consider, for example, the number of alternatives listed by healthcare professionals to allow patients to select what they would like to hear. I find myself thinking how interesting it is to see these healthcare professionals' thoughts revealing empathy for what the patients would like to experience at the mealtime.

Moving the patient "passenger" to the next point, I prompted the third question card; *how would you redesign the eating environment to bring appetising smells?* The healthcare professionals expressed thoughts associated with promoting freshness. According to them, reducing food smells can influence a more pleasant experience.

HP1_Nurse/3: Just away from the toilet.

HP1_Nurse/3: You just take them to (...) a dining room.

HP1_Nurse/3: Whether you've had an Indian the day before.

HP5_Occupational therapist/3: Reversing (...) a sort of like candle like a scented one in the area where they were eating.

HP_Speech therapist6/3: Although I think it would be quite hard to get the smells of the food that everyone liked.

HP5_Occupational therapist/3: Fresh air maybe even, plenty of fresh air if it's not too cold to open the window.

HP1_Nurse/3: The trolley itself's not always appetising?

HP5_Occupational therapist/3: The smells coming from it.

HP1_Nurse/3: The combined smells …

HP1_Nurse/3: if there was one meal it would be fine, but they're so different there's four hot choices, so it can be chilli, it can be curry, it can be mince. It's all the smells mingled together.

HP6_Speech therapist/3: It might not necessarily be about smells coming off the trolley.

HP6_Speech therapist/3: Maybe reducing the smell of the trolley would be better.

What is emphasised from these healthcare professionals' voices is the significance of having an appropriate space in which to eat. The combination of smells might influence them to have unpleasant rather then pleasant experiences. In this way, the healthcare professionals considered it to be important to reduce instead of promote smells. According to HP6, promoting a common sensory environment can be difficult due to people presenting different likes and dislikes. What these voices suggest is promoting "fresh air". Perhaps more interesting is that these healthcare professionals are recognising issues that can make a difference to promote a better quality of life for those patients.

Prompting the fourth question card, *how would you design the eating environment to bring people with stroke with each other?,* the healthcare professionals revealed thoughts to promote conviviality. Patients experiencing convivial situations highlighted attention to the healthcare professionals' roles at the mealtime. They said:

HP1_Nurse/4: Knowing your patient (...) dining area.

HP1_Nurse/4: It's having an environment where they can be together.

HP5_Occupational therapist/4: Socialise.

HP1_Nurse/4: Moved a patient (...) so they can look this way and see what's happening.

HP6_Speech therapist/4: Move people a bit,

HP1_Nurse/4: If someone likes a blether, we've moved them rooms to someone else if we have got somebody young if amongst the older people and they're really sick I've moved that person to another environment so they could have that enjoyment of conversation.

HP6_Speech therapist/4: It's just about knowing your patients and knowing what's appropriate for them,

HP5_Occupational therapist/4: I think you would need to have someone in the room that they were in as well trying to get them.

HP6_Speech therapist/4: To talk.

HP1_Nurse/4: Conversation co-ordinate.

HP1_Nurse/4: I think a dining room if you sat people together that could talk, that could see each other.

HP6_Speech therapist/4: Someone with communication difficulty (...) sometimes it's not always appropriate that the person's engaging in a big conversation.

HP5_Occupational therapist/4: Some people might just enjoy the opportunity to it and listen.

HP6_Speech therapist/4: Listen, yes, totally.

Once again, these voices are emphasising issues associated with personal goals, needs and pleasure. Consider, for example, how HP1 expressed thoughts associated with the patients' age and capabilities at the time. These voices also highlight the healthcare professional as an expert in patients, or in other words, that they have the knowledge to know how to promote sociability to better accommodate patients' needs and, consequently, to allow them to socialise. Think, for example, how the healthcare professionals expressed views which see the professionals' roles at the mealtime in facilitating the patient socialisation. It might be in coordinating conversations and/or promoting opportunities for patients with communication difficulties to enjoy listening.

Prompting the fifth question, *how would you enable a better choice of food for each different individual?,* the healthcare professionals indicated thoughts revealing an emphasis on the quality of the patient experience in promoting what patients like. In other words, these healthcare professionals are acknowledging, once more, the meaning of the mealtime in promoting what patients appreciate as a positive and pleasurable experience at this time. They reported:

HP1_Nurse/5: There's only so much choice you can give, with the menus.

HP5_Occupational therapist/5: Know their likes and dislikes.

HP1_Nurse/5: Ask your patient.

HP6_Occupational therapist/5: What they would like.

HP1_Nurse/5: Include your patient in their choices.

HP6_Speech therapist/5: kind of giving them that option of your not hungry right now, well we'll hold something back for you.

HP6_Speech therapist/5: Like speaking to the person's family.

What seems to be highlighted here is the significance of giving patients a voice to make their own choices about food. Consider, for example, how HP1 expressed her views by saying, "ask your patient", or how HP3 also suggested including "the person's family". However, these healthcare professionals' voices share similar views with those of the patients, as demonstrated in Chapter 8, in this idea of giving patients a choice through providing a menu. Another thought expressed here is the attention to the patients' emotions which can require reconsideration in terms of the appropriate time to eat. For example, HP6 expressed that patients cannot be "hungry right now". What is emerging from these voices is a complexity of issues that require a more personal rather than standard service in order to promote a good quality of life for those patients.

During, as encounter

Moving the patient to the next point on the track, I prompted the sixth question card, *how would you enable the food to look appetising?* The healthcare professionals revealed views on how to promote good quality of food presentation. They said:

HP5_Occupational therapist/6: Not bland, colourful

HP1_Nurse/6: Seasoned well, looking nice. Aye they like it seasoned.

HP5_Occupational therapist/6: Presented nice.

HP5_Occupational therapist/6: Something that you're going to look at (...) and you think I can't wait to eat this.

HP6_Speech therapist/6: Just a nice kind of size, nice portion size.

HP5_Occupational therapist/6: I suppose being on a nice clean plate (...) Not one that looks as if it's been through too many dishwashers (...) Clean cutlery.

HP1_Nurse/6: To create a happy face.

HP5_Occupational therapist/6: Don't put it on the plate with a sad face put it on with a happy face.

HP1_Nurse/6: Put I love you on the plate.

HP1_Nurse/6: Personality.

From these healthcare professionals' voices we can see that this idea of good quality of food presentation leads to considerations that the colour and shape of food as being relevant attributes to promote visual appearance, as discussed in Chapter 3, section 3.4. Another thought is the attention expressed to the combination of components such as food and tableware. There is this idea that tableware might require be replaced after a period of time in order to promote good quality presentation. For example, HP5 expressed that "too many dishwashers" can affect the quality of tableware presentation. What these voices seem to highlight here is the importance of creating the visual presentation. In doing so, HP1 highlighted attention to the professional's role and personality in influencing emotional quality at this time. Consider, for example, how HP1 expressed her thoughts by saying that the healthcare professional would bring a positive emotional state, such as "a happy face", and create food that expresses messages such as "I love you". I find myself thinking about the importance of these voices and how these dialogues reveal interesting issues about the mealtime. However, these voices also emphasise reflections about thinking why these issues have not been addressed yet.

Prompting the seventh question card, *how would you provide tableware where appropriate to the needs of each individual?*, the healthcare professionals indicated thoughts of promoting familiarity and personality. They expressed:

HP1_Nurse/7: If there's some patients who can't use the ordinary cutlery we've adapted cutlery (...) to suit the patients needs (...) the Toby cups.

HP6_Speech therapist/7: It's about totally personalising it for that person,

HP5_Occupational therapist/7: Just ensuring that they can be as independent as they would like to be.

HP6_Speech therapist/7: I suppose it would be quite nice if you could maybe have(...)like a mat that went on every table that was nice and colourful (...) a bit more like that kind of restaurant type idea.

HP5_Occupational therapist/7: some people like to eat and drink, eat their food and drink their drinks from specific cups, maybe they could bring in something from home that they'd prefer to use themselves.

HP6_Speech therapist/7: Taking the plates off the tray do you know.

HP1_Nurse/7:Half the time it is.

HP5_Occupational therapist/7: Something that's aesthetically pleasing.

HP6_Speech therapist/7: They should just get little vases with little plastic flowers in them.

HP1_Nurse/7: Tucking in the napkin.

HP_Nurse1/7: a course at a time (...) all about time.

HP6_Speech therapist/7: Half an hour's not long (...) to eat.

HP1_Nurse/7: it'd ideally be about giving them the time, about an hour.

What seems to be emphasised from these voices is the importance of promoting a good quality of life by accommodating personal needs, similar to what the patients' voices also demonstrated earlier in this chapter. For example, HP1 expressed her views revealing that tableware can require adaptations. However, healthcare professionals also suggested ideas to promote familiarity. Consider, for example, if tableware was presented in similar ways as in a "restaurant". According to HP6, it could be "taking the plates off the tray" and promoting tables with decoration, such as "little vases with plastic flowers". Another issue emerging here is the importance of giving patients time. What these voices are continuously showing is how the present mealtime does not "fit" with those patients'needs and how future design needs to take the future mealtime into consideration in regards to issues of subjective well-being.

Moving the patient "passenger" again, I prompted the eighth question card; *how would you bring humour into the mealtime experience?* Prompting this question evoked great enthusiasm among the group. Healthcare professionals were continuously laughing while expressing their voices. What seem to be emerging here is the idea of the mealtime in the

future in promoting both patients and healthcare professionals as having a good time together. They expressed:

> *HP1_Nurse/8: Stories, funny stories.*
>
> *HP6_Speech therapist/8: Yeah just stop kind of being a nurse or a speech therapist.*
>
> *HP5_Occupational therapist/8: You take that hat off.*
>
> *HP1_Nurse/8: Be a normal person.*
>
> *HP6_Speech therapist/8: Yep, you know see like stories about the family…*
>
> *HP1_Nurse/8: Remove all professionalism (laughs) that's it jacket's off let's get real. Stripping (laughs) that would make them laugh.*
>
> *HP1_Nurse/8: Reminiscing.*
>
> *HP5_Occupational therapist/8: Something a bit less serious.*
>
> *HP5_Occupational therapist/8: Just making it as relaxed as possible.*
>
> *HP6_Speech therapist/8: it, it's just about switching off from everything else.*
>
> *HP1_Nurse/8: Relaxation.*
>
> *HP6_Speech therapist/8: And humour,*
>
> *HP1_Nurse/8: You could Google it (…) Joke for the day (…) On their iPhones aye (…) There's a joke of the day everyone's fine, that would getting them looking forward to mealtimes. Today's joke is*
>
> *HP6_Speech therapist/8: I think that would be a great idea (…) Choose a joke (…) Getting staff to dress up*
>
> *HP6_Speech therapist/8: Get the clown shoes on (…) the red noise honk honk.*
>
> *HP1_Nurse/8: Yeah a wee white hat, a wee dance, I could do Gangnam style.*

What these voices seem to demonstrate here is this idea of how the medical is fundamental but that the mealtime needs to become more than medical. In other words, it requires treatment, but these voices also suggest that it means being able to support patients and healthcare professionals to live a good life in hospital. Consider, for example, how these healthcare professionals make sense of the mealtime. Fundamentally, what these voices seem to be highlighting is that not only patients, as demonstrated in Chapter 8, but also

healthcare professionals desire to experience a change at the mealtime in order to allow them to enjoy a good time together. What is interesting to see is that although patients and healthcare professionals have different roles, experiences, views and ideas about the mealtime, they also demonstrate that they have complementary concerns and desires.

After, as reflection

Prompting the ninth question card, *how would you enable people to freshen up after eating?*, the healthcare professionals revealed thoughts to promote personal care.

> *HP1_Nurse/9: Hand-washing*
>
> *HP5_Occupational therapist/9: To give (...) the opportunity to clean their face and maybe their mouths and things.*
>
> *HP6_Speech therapist/9: Check there's nothing at the back of their mouth.*
>
> *HP1_Nurse/9: Brush their teeth (...) So it's hand washing, teeth, mouth wash.*
>
> *HP5_Occupational therapist/9: I suppose if they've had a few spillages.*
>
> *HP1_Nurse/9: Changing their tops, aye.*
>
> *HP5_Occupational therapist/9: Some people like to go to the toilet even after they've had something to eat.*
>
> *HP1_Nurse/9: After their finished we make sure they're clean, we toilet them and they have a lie down after.*

These voices are highlighting healthcare professionals' roles in promoting personal care. For example, HP1 expressed her views associated with healthcare professionals helping patients to "brush their teeth". What seems to be emphasised here is that this view of promoting personal care brings patients to back to their rooms. For example, HP1 expressed these thoughts by saying that the patients might "have a lie down after".

Moving the patient "passenger" to the end point, I prompted the last question card, *how would you enable relaxation after the meal?* The healthcare professionals revealed, once again, views which recognise the importance of promoting what the patient would desire. They said:

HP1_Nurse/10: Lie down (...) Have a lie down.

HP1_Nurse/10: Offer (...) they sit in their chair, so offer them do you want a lie down.

HP1_Nurse/10: Even just close the curtains we just create that relaxation environment (...) you encourage that rest period.

HP5_Occupational therapist/10: Music again.

HP5_Occupational therapist/10: Nice relaxing music.

HP6_Speech therapist/10: If someone's got one of their TV's blaring just kind of turn it (...) see if you can turn it down a bit.

HP5_Occupational therapist/10: asking them (...) "What do you want?" What they would like to do after their meal. "Do you want to relax, how, what, how would you relax, what would help you to relax?"

HP6_Speech therapist/10: If they've got a magazine.

What is emphasised from these healthcare professionals' views is the professional's role in promoting personal service in order to accommodate patients in ways that they desire. For example, HP1 expressed thoughts associated with healthcare professionals in offering possibilities for patients, such as sitting or lying down. According to HP5, it would be asking the patient what he/she would like to do and how they would like to do it. What is most interesting here is this view of asking not only what but also how. These issues are demonstrating that healthcare professionals want to develop some empathy with patients in order to promote their likes. This seems quite an interesting point to think about, for example, does that empathy not exist at the present? If not, why not? Another point is the environment, which healthcare professionals see as promoting relaxation through the sensory. For example, HP5 indicated that the environment at this stage would promote relaxing music.

From such a view, the healthcare professionals' ideas seems to further develop the patients' ideas in a way (see Figure 8.19) that draws attention to the mealtime upon three main themes: environmental factors, food presentation and personalisation. This understanding indicates opportunities to promote different patients' needs, likes and goals throughout the three stages: before (patient waits for his/her food), during (patient receives his/her food and eats) and after (patient has eaten food). Through these healthcare professionals' ideas, I found the mealtime under a conceptualisation to create empathy.

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The healthcare professionals showed attention to create "what they [patients] would like", for example, providing more choice and personal care in such ways that would express "I love you". By suggesting these ideas, they are highlighting the significance of thinking with patients in mind because they are "the real virtuosos" (Sanders, 2001) of the mealtime experience in stroke rehabilitation and their ideas inspired healthcare professionals' ideas. In what follows, I will underline in more detail this new conceptualisation of the mealtime.
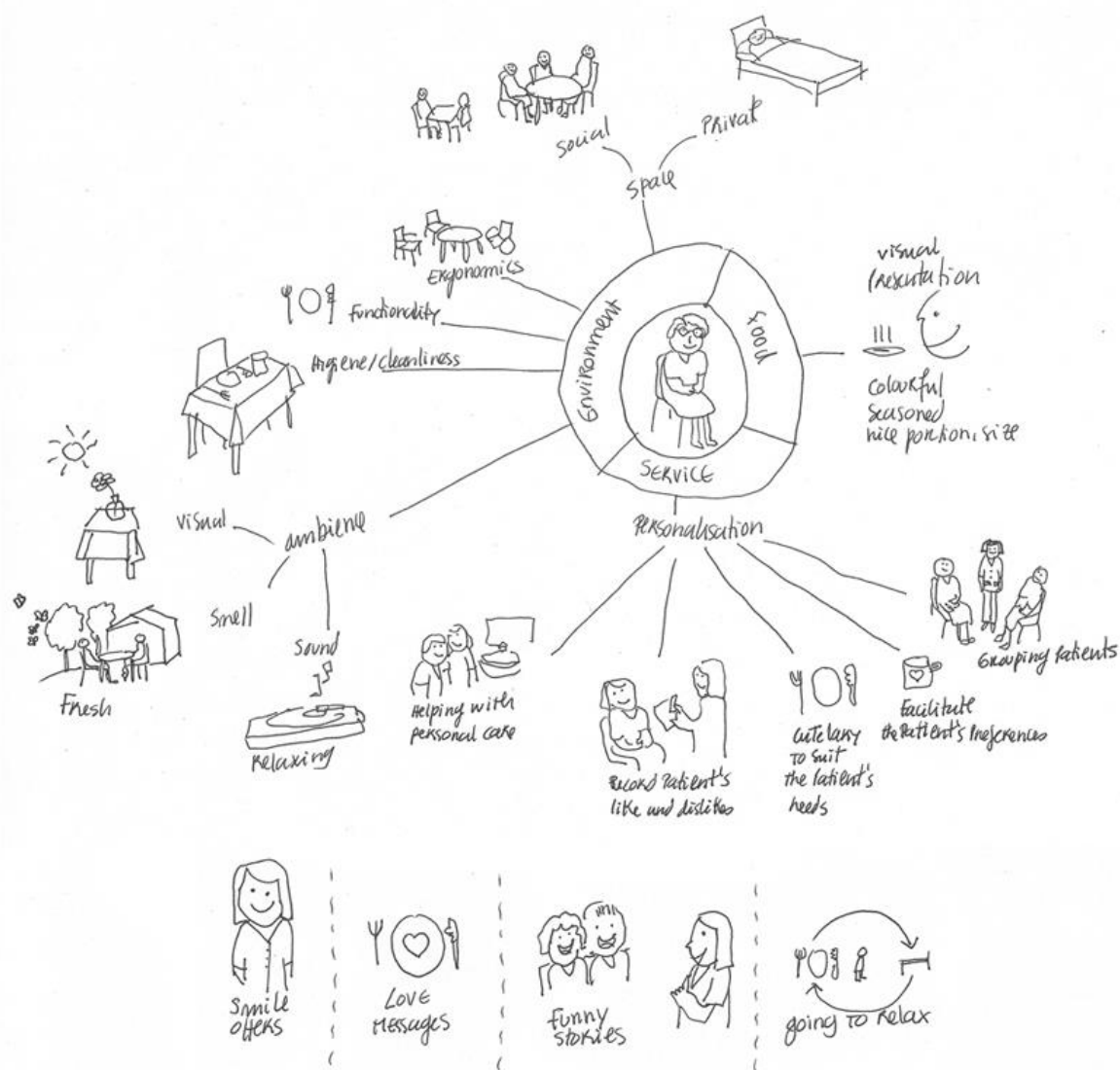
Figure 8.19 A conceptualisation of the main issues that have emerged from the healthcare professionals' voices in playing the Roller Coaster game.

8.3.4 Giving healthcare professionals a voice

In this third phase of the research, as outlined earlier in this chapter, I aimed to elicit the healthcare professionals' voices to explore what can be done with the patients' ideas in order to develop them into concepts. Fundamentally, this exploration allowed me to

identify a number of opportunities (see Table 8.6 and Figure 8.19) demonstrating directions on how to redesign the mealtime for the future (see Figure 8.20)

Table 8.6 The kinds of ideas that have emerged from the healthcare professionals' voices.

OPPORTUNITIES			HP'S VOICES
Environment	Ambience	visual	Flowers on the table
			Little vases with plastic flowers, nice candle
			Natural light
			Napkin
			Something that aesthetically pleasing
		smell	Fresh air, plenty of fresh air
		sound	Relaxing music, calm
	Functionality		Cutlery to suit the patients' needs
	Hygiene/cleanliness		Clean plate
			Clean tablecloths
			Clean cutlery
	Ergonomics		To bring wheelchairs
			Comfortable tables and chairs
			Decent sizes
	Space	Social	Patients can be together
			Patients talk and see each other
		Private	Patient is lie down
Food	Visual presentation		Colourful
			Seasoned well
			Nice size, portion
Service	Personalisation		Facilitate the patient choosing
			Knowing the patient's likes and dislikes
			Facilitate the patient's preferences
			Knowing what is appropriate
			Helping with personal hygiene/cleanliness
			Moving/grouping patients
			Facilitate opportunities to the patient's listen
			Facilitating conversation
			Asking the patient what they want
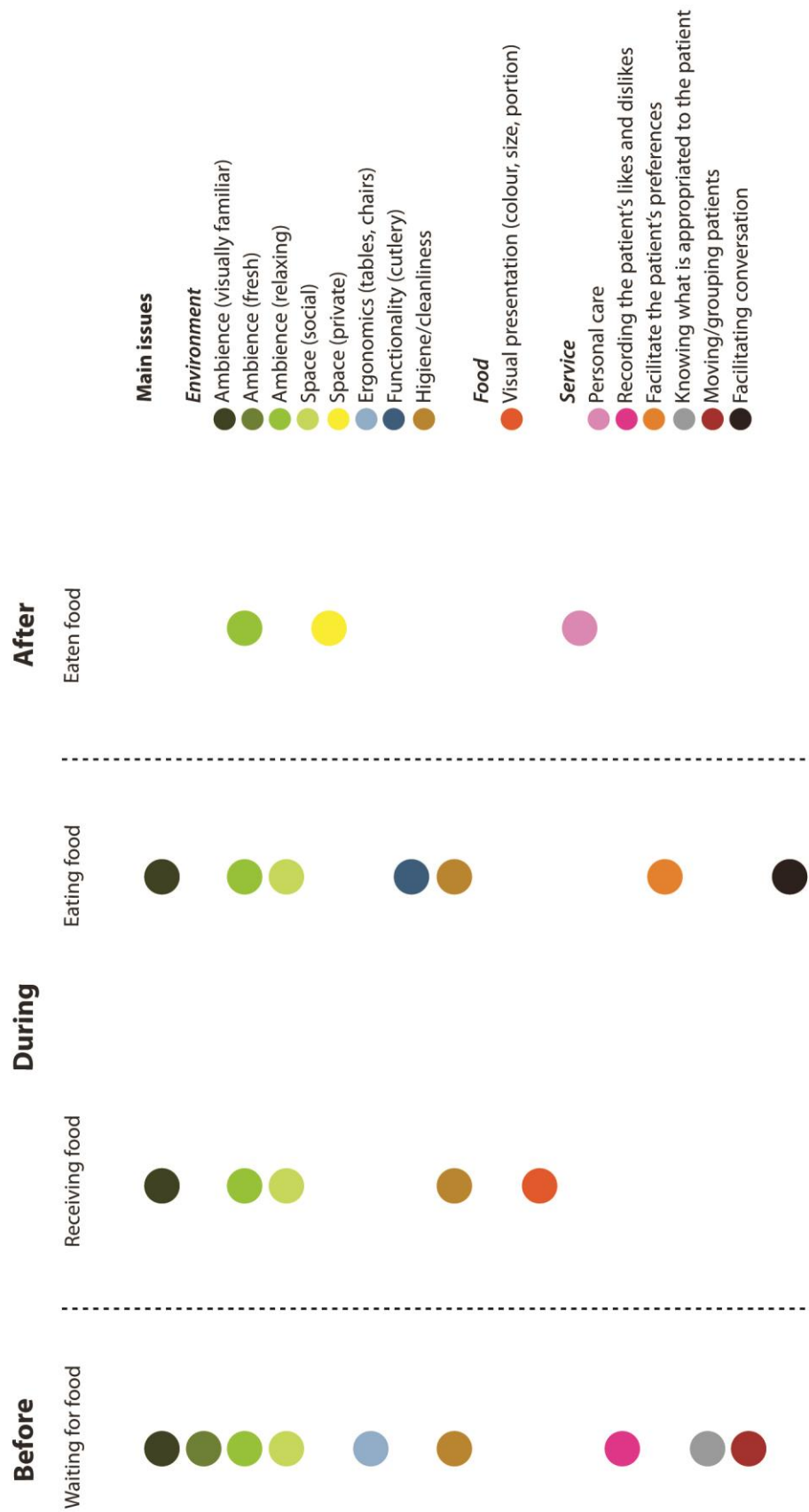
Figure 8.20 A conceptualisation of the main issues that have emerged from the healthcare professionals' voices.
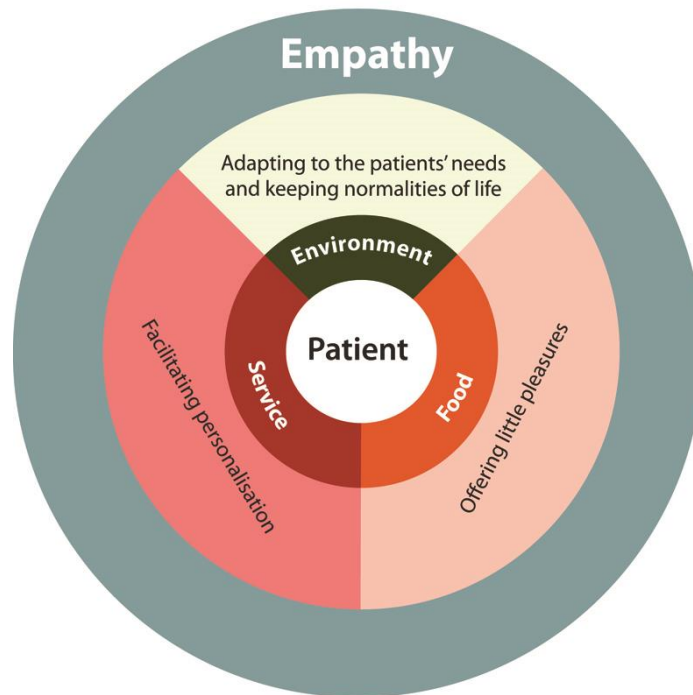
Figure 8.21 An overview of the key issues and insights.

From the diagram above (8.21), it seems that mealtime in the future is supported by this view of creating empathy through the environment, eating and providing service in such ways that accommodate patients' needs, likes and preferences. From the patients' voices, the present mealtime in hospital lacks an element of personalisation, an issue which patients' ideas demonstrated that there is a need to place a focus on the facilitation of personalisation with the view of providing space for the "normalities" of life. These were considered possibilities that could make a significant difference to the patient experience. However, it poses the issue of how do we provide "mass personalisation" in stroke rehabilitation in hospital? Based on these patients' ideas, the healthcare professionals suggested the need to create empathy within this view of supporting personalisation. Think, for example, how healthcare professionals revealed their ideas to provide more choice, personal care, better visual appearance of food, conviviality and ambience. What is emerging here is the significance of redesigning the mealtime to allow patients to pursue their personal likes and goals while at the same time supporting their personal needs.

8.4 A new mealtime Scenario

Eliciting the patients' and healthcare professionals' voices helped in envisioning a new mealtime scenario, revealing both the patients' and healthcare professionals' ideas (see

Figure 8.22). Building the "scenario" shows a summary of the main issues emerged by both patients and healthcare professionals. Overlapping these voices allowed me to see opportunities and ways to enhance the patient experience at the mealtime in the future. Fundamentally, listening to the voices in this way highlighted concepts which helped me to reflect on how to redesign the mealtime for tomorrow to improve the patients' and healthcare professionals' experiences. However, this visual narrative form shows the limitations in summarising what is actually a very complex and multi-dimensional situation.
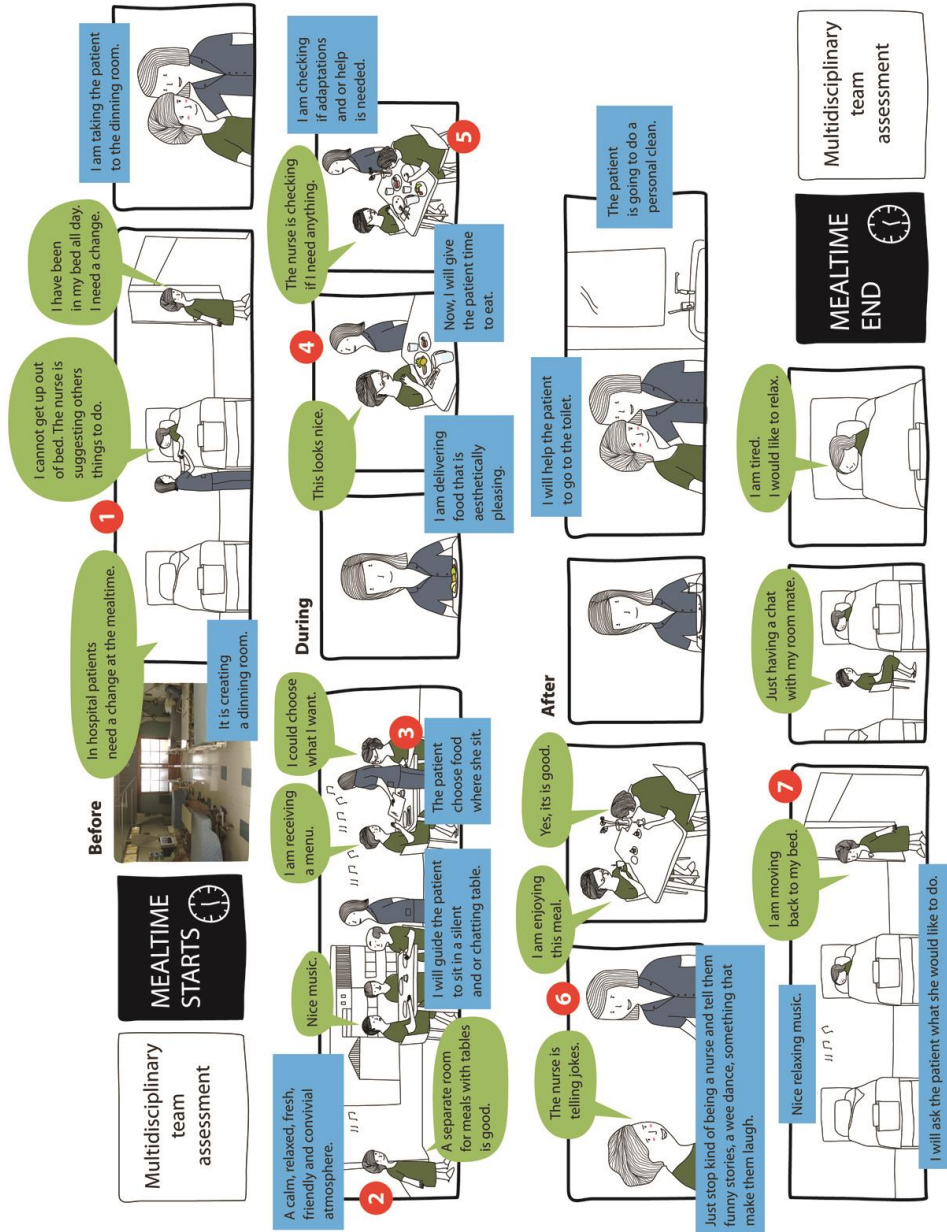
Figure 8.22 A generic example of the new mealtime scenario in stroke rehabilitation in hospital. Multiple scenarios could be possible from the findings of this workshop with healthcare professionals.

In this visual narrative, the quality of the patient experience at the mealtime in the future requires design for social and subjective well-being. If we look at the "scenario" we can see that although patients' ideas highlight priorities for change, it also shows how healthcare professionals' ideas recognise things that can make a significant difference in the future. Consider, for example, before the meal, how both patients and healthcare professionals revealed similar views about how spaces would adapt to the patients' needs. How do we create an adapted environment to promote a better experience? This situation highlights different possibilities; by promoting privacy and sociability. In this way, the mealtime might offer opportunities for patients, those who can or cannot eat, to experience well-being and enjoy life. Think, for example, how the patients described how they wanted to experience a change from their medical routine at the mealtime. In doing so, it might benefit the quality of life for those patients who cannot eat. For example, they would be in their rooms without experiencing the food sensory around them or sitting face-to-face with other patients while eating. As we understood in Chapter 7, these are problematic issues in the present mealtime scenario. I found myself thinking, how can these patients' and healthcare professionals' ideas provide concepts to promote a better mealtime in hospital? Regarding the context of stroke rehabilitation in hospital, it seems that both patients and healthcare professionals share common views about what it might be like. For example, patients expect to be able to socialise with other patients while also being able to choose food that they like. What the healthcare professionals see is the importance of personalising the service in order to provide what patients like. However, they highlight that personalisation requires "coordination", that this view involves knowing the personal needs and aspirations of each individual patient. According to the healthcare professionals, for example, patients with swallowing difficulties might benefit from experiencing individual space to allow them to feel comfortable rather than embarrassed. As the mealtime progresses, patients should experience a good quality of food presentation, a situation, which both patients and healthcare professionals see as evoking positive feelings. Another point is about facilitating autonomy through friendly tableware in order to provide a sense of control. Finishing the meal would provide social entertainment among patients and healthcare professionals in order to create moments for patients and healthcare professionals celebrate life, perhaps having the opportunity to enjoy and living a good time together. For example, patients see healthcare professionals telling "jokes" and healthcare professionals see this idea of being entertainers as an opportunity to relate to patients as an individual rather than as as professional. What I find interesting here is this idea of the desirable mealtime in promoting social accomplishment. In looking at the scenario, we can

see that these voices are revealing a kind of non-medical type of intervention. This is an interesting issue to explore in more detail in the future. As a result of experiencing enjoyment, healthcare professionals also see patients relaxing afterwards.

Illustrating these patients' and healthcare professionals' voices was a valuable way to highlight these insights, which requires our attention to promote the future. Involving these voices in collective creativity demonstrated their value, not only to represent what is desirable, but also to show how the virtuosos of experience provide a valuable contribution in the design process. Fundamentally, this study has demonstrated how creating opportunities for patients and healthcare professionals to share ideas can, consequently, open new ways to conceptualise how to promote their expectations. In other words, it has demonstrated how design can help to promote envisioned experiences.

8.5 Summary

In summary, I have presented the findings from Phase 3 of this research, which involved two separate workshops: the first workshop with patients, and the second with healthcare professionals. The first workshop demonstrated the outcomes of three games. In describing the findings of the *What if?* game, I found that patients' voices related to thinking about sharing meals with family rather than having their favourite chefs in mind. In doing so, they highlighted attention to this idea of "familiarity" or "normality" at the mealtime in hospital. I have illustrated the patients' views, revealing the possibilities associated with the designing of the environment, food appearance and people's interactions. By playing the Magical game, I found that patients expressed memorable rather than imagined experiences. However, I found the patients' views connected the desires and dreams of what they considered to be important to promote an enjoyable experience at the mealtime. By playing the Map game, I found patients' ideas continuously emphasised this idea of change at the mealtime in hospital in ways that address personal needs, likes and goals. Fundamentally, this game highlighted issues of personhood, which demonstrated how the mealtime in the future might benefit by integrating patient-personhood, or, in other words, recognising the person behind the patient. In this chapter, I have demonstrated the key issues that have emerged from the patients' ideas and the importance of reflecting about how future investigations about the improvement of the patient experience for people recovering from stroke in hospital must take the patients' perspectives into consideration. In this way, the second workshop presented the outcomes of playing two games based on the previously elucidated ideas of the patient. In describing the findings from the *What if?*

game, I found that healthcare professionals' voices highlighted attention to this idea of "personality". I have illustrated the healthcare professionals' views, revealing possibilities associated with the redesigning of levels of experiencing such as anticipation, encounter and reflection. By playing the Roller Coaster game, I found that the healthcare professionals' views continuously emphasised issues around creating empathy at the mealtime in ways that promote and support patient-centred needs, goals and desires. I concluded this chapter by demonstrating how the mealtime scenario is envisioned for the future based on the patients' and healthcare professionals' ideas that illuminated reflections to proceed in future investigations. In the following chapter, I will highlight the achievements and limitations of this research study in order to bring forth a discussion of the relevant issues.

9

Discussion

9.1 Introduction

In this thesis, a research study was developed to gain an understanding of stroke, rehabilitation and the mealtime in rehabilitation and to explore what value Participatory Design (PD) approaches might have in this context of stroke. Adapting and applying the theory, tools and methods of PD in this kind of setting were quite different in nature from other work, as discussed in Chapter 3, section 3.3.1. In the initial research, when looking at the impacts of stroke on people (Stroke Association, 2008b), it became clear to me that the design of the methods and tools for this research would require particular attention because of the conditions and vulnerability of the kinds of people with whom I would be working and the setting in which they are located. Thus, these PD methods and tools were adapted in ways that would support personal needs. In other words, I would adapt and employ tools and techniques that were able to support the particular nature of these individuals' capabilities to enable the engagement of these patients in the research so as to include all potential participants, "not just those who are already more able, articulate and socially advantaged" (Boyle and Harris, 2009). Fundamentally, involving this particular group in PD would require new ways of thinking about socio-material situations in order to support patients' well-being rather than influencing feelings of embarrassment (Perry and McLaren, 2003). As discussed in Chapter 2, early field work in my research about the treatment of stroke has demonstrated a pre-occupation, in existing rehabilitation practice, with functional restoration. This was mainly reflected in how food, more specifically Texture Modified Food (TMF), and the mealtime was approached but seemed not to give much value to other important non-functional aspects of the patient experience which might be important to their subjective well-being (SWB) and recovery. Initial questions emerged about the possibility of evaluating the way the International Classification of Functioning (ICF) model is currently being applied in this stroke rehabilitation context by using PD as an audit method. Although stroke rehabilitation is currently guided by the ICF model, would there be any value in PD being used to reveal to what extent it deals with the non-functional aspects of the ICF framework? In this way, this was a research study

focused on how to elicit multi-voices so as to allow me to obtain valuable insights about the patient experience at the mealtime.

This chapter begins by discussing PD as a valuable approach and much of this strength lies in its potential to design for change and to give a democratic voice to stakeholders. However, this research will suggest how this participative space is situated within the notion of "experience-making" (Bate and Robert, 2007) rather than decision-making. Firstly, I will explain how the method of PD was adopted to involve direct participation, in particular, patients. This discussion will address how reflections on adapting participatory tools and techniques can be both appropriate and valuable to inspire, facilitate and support patients' participation. Secondly, I will suggest a model for design connectedness, where I discuss how the relationship between tools, techniques and people can offer the possibility for voices to emerge. This will illustrate how tools and techniques can be made flexible and adapted to better accommodate patients, those who present physical and verbal difficulties, in different situations of experiencing.

The second part of this chapter will discuss how using a framework method of analysis helped to demonstrate multi-voicedness and provide deep and rich information about the mealtime in the context of a hospital Stroke Rehabilitation Unit. In doing so, it revealed an understanding of two temporary contextual and experiential situations: the mealtime of today and the desirable mealtime of tomorrow. This discussion will bring forth an illustration of what I found by eliciting the patients' and healthcare professionals' voices. The chapter ends by discussing this multi-voiced process, illuminating the significance of these voices to generate valuable forms of evidence. Essentially, I will discuss on one hand that PD has a role to play in supporting multi-voicedness in this context of stroke and healthcare, and on the other hand that stroke rehabilitation might benefit from PD approaches in order to rebalance the ICF model. This chapter will also discuss the achievements and limitations of the research.

9.2   Participatory design and the patient experience

Participatory design has become increasingly engaged in working with multiple stakeholders in these "socio-material assemblies" to deal with matters of real life concerns. In this conceptual and "political" view, this research considered "infrastructuring" as a methodological strategy to establish relations based on the participation of patients and healthcare professionals. Following this line, I adapted a framework to organise a set of participative design activities as "design games" (Ehn, 2008) (see Figure 5.1). In other

words, the method was about logistically planning a set of design situations to obtain an understanding of the patient experience at the mealtime. Although PD reveals reflections within this view of decision-making where spaces are created for negotiation among participants, this research adopted PD within reflections of "experience-making" (Bate and Robert, 2007). This notion of experience-making is based on the view of a process of inquiry which would bring together the healthcare professionals' and patients' experiences to obtain an understanding of the emerging issues within the present experience. In doing so, it would identify issues or priorities for change that consequently would help to explore new possibilities for future experiences. In other words, it would be a process which reveals past/present and to re-imagines future experiences (see Figure 3.6). Instead of following a process for negotiation, I placed a focus on a process for expression and ideation among participants. In other words, this would be a process of inquiry, involving patients' and healthcare professionals' voices where their experience and ideas would allow the building of a knowledge of new possibilities for experiencing. In this way, PD seemed a valuable approach for eliciting the kinds of information that appeared to be missing at the mealtime from the medical literature, as discussed in Chapter 2. In turn, this information might be useful for the medical community to see. The assumption was on how these PD methods might bring forth information, which might be different from the way the mealtime has been approached, but that addresses the interests and extends the knowledge of the healthcare community.

When looking at the impacts of stroke on people, a series of challenges for the design methodology and designing the study become evident in order to engage patients rather than their representatives (Macdonald et al., 2010; Bowen et al., 2010a). Work of this nature would not be permitted in this context of stroke without ethical approval, as demonstrated in Chapter 5, section 5.1.2. In applying for ethical approval, this research demonstrates the desire for legitimate participation of the patients (those affected by stroke) and the healthcare professionals (those clinical practitioners in stroke rehabilitation in hospital). One of the hypotheses here was how involving "the real virtuosos of experience" (Sanders, 2001) would generate valuable forms of evidence about the patient experience at the mealtime. Another challenge was about the nature of experiencing post-stroke, which is different for each individual patient. Patients experience a number of difficulties depending of the impacts of stroke. Consider, for example, how stroke rehabilitation care guidelines describe a patient-centric care practice approach to address recovery according to individual patients' needs (Scobbie et al., 2011; Monaghan et al.,

2005). Viewing stroke rehabilitation care through this lens, I suggested that there is a necessity to acknowledge the need for adapting tools and techniques in order to support individual capabilities through participation in design. This involves supporting those patients' capabilities, not only when they would individually participate, but also collectively in such ways that stimulate, facilitate and motivate patients' expression and ideation rather than revealing patients as active participants in recounting their experiences in research (Tsianakas et al., 2012). Consider, for example, how this research brought a group of patients together in a co-design situation to share ideas and aspirations together and to suggest possibilities for change. One of the concerns of this process was on how to involve patients in collective creativity in such ways that their participation would benefit by eliciting their voices instead of them being overwhelmed by other voices such as the healthcare professionals, or, in other words, those who are used to making decisions (Donetto et al., 2014, p.25). The hypothesis was that distinguishing the patients' from the professionals' voices might contribute to bringing a balance power between the voices of the professional and the individual (Boyle and Harris, 2009) in this context of the mealtime. Other adaptations were related to place. This research needed to be flexible, or, in other words, move within a complex real-world of the clinical healthcare and the home setting. Think, for example, how design situations were pursued in a variety of physical locations such as the patients' homes and the healthcare professionals' workplaces rather than "design" spaces, such as laboratories (Binder, 2007). Fundamentally, this was a process where tools, techniques and people were "connected" to accommodate individual patients "voices" and allow them to collaborate and contribute to design for desirable change.

9.3 Adapting tools and techniques

In this idea of adapting tools and techniques, I considered a model for design connectedness. The notion of connectedness that emerges from this research resonates with the conception of interaction between the socio-material (Ehn, 2008) in relation to participatory design. This model describes the relationship between tools, techniques and people to offer the possibility for voices to emerge and valuable dialogues to happen; see, for example, Figures 5.14 and 5.21. As discussed in Chapter 2, when a stroke happens it becomes part of a person's everyday life, it can require a series of everyday adjustments or adaptations so that a person can conduct his/her life on a daily basis. As demonstrated in Chapters 7 and 8, patients recovering from stroke at home can still present a series of difficulties; these are difficult to explain, predict and, consequently, design for. One of the

concerns, therefore, was on how to involve patients in design situations, considering that these particular patients might present a number of difficulties, such as speaking and/or moving one side of their bodies. Thus, I suggested tools and techniques that support individual capability to enable the engagement of these patients. These tools and techniques needed to consider how to support the patients so that their verbal expression ("voices") would be "loud" and consequently generate valuable dialogues. The tools included diagrams, storyboards and games in order to support communication. The techniques involved stroke support nurses to support the verbalisation of the patients' voices and design students to allow visual representation of these voices. The objective was to provide ways that inspire and support patients to participate despite the difficulties posed by their health conditions. To support this argument, I have adapted methods not only from PD but also from other research methods, for example, interviews. In conducting this research in this way, I wanted to evaluate the proposed tools and techniques in order to reflect about designing for patients' engagement.

Interviews

Interviews in this research did not only involve prompting open-ended questions but also presenting illustrations and/or diagrams to expand and explore issues, as demonstrated in Chapters 6 and 7. The issue raised here was on how to adapt these research methods through design so as to provide different kinds of information about the mealtime. In doing so, it revealed a variety of information, capturing the mealtime stages and the issues emerging from the present situation (see Figure 7.6). Adapting methods to involve patients, as discussed in Chapter 5, sections 5.1.6 and 5.1.7.1, necessitated the use of techniques to help verbalise information. In this context of stroke, the support nurses have a strong background role in supporting these patients affected by stroke, a factor which I consider to be significant in design situations working with and for the patient experience. In dialogues with patients, the nurses were already aware of the need to intervene when something from the patient and/or the design researcher was said but not explicitly understood by the other. In doing so, it allowed the patients to make a number of explicit verbal expressions that made the involvement of the nurses relevant throughout the process of inquiry. My main concern relating to this idea was originally that the healthcare professionals (nurses) voices might dominate those of the patients in this kind of interview situation. However, by the way I was able to design the materials to support the interview, these helped rebalance the focus, so that the nurses were playing more of an assisting role both for the patient, and for the researcher. Patients were still undergoing stroke

rehabilitation care at home, where trust becomes expected. However, involving nurses assured support in communicating with these patients.

Workshops

Co-design workshops in this research did not request that participants must perform physical tasks and/or make things. In other words, tools, as games, were used to open up different ways to think about and discuss the mealtime. The assumption was that patients, in being supported to actively express issues verbally in response to visual components, would provide useful information, and that this was a more appropriate method for gathering information than requesting that they move around and or perform physical tasks (Sanders and Westerlund, 2011). Taking this approach also considers the issue about how this type of activity might influence feelings of embarrassment (Perry and McLauren, 2003). Both workshops with patients and healthcare professionals involved design students in illustrating their voices while playing games, as discussed in Chapter 5, section 5.1.7. In this way, the patients and the healthcare professionals were able to see what they were doing together, as demonstrated in Chapter 8. In return, these visual illustrations prompted discussion of the mealtime experience. For example, patients often expressed "aye" (yes) in a sense of agreeing with what had been said and/or added more information by expanding their views and ideas. Conducting a co-design workshop with patients and healthcare professionals and connecting tools and techniques (see Figure 5.21) revealed that different issues were raised by each group. Although using games generated empathy to discuss issues in different ways with patients, it also revealed some challenges in getting patients engaged in this idea of thinking about the future. Consider, for example, in playing the Magical game, how it revealed that there are some challenges in getting patients to create a sense of imagining. They were able to project to their past rather than forward to their future. Perhaps, it highlights here an issue of patients' confidence about their future. In contrast, using games with healthcare professionals revealed experiences of laughing while playing to envision the future. Another issue that emerged from the co-design workshop with patients was related to the fatigue experienced by patients. While we were playing, a patient felt the need to take some fresh air. Although this situation was quickly adapted to the immediate circumstances in order to support the patient's well-being, it revealed the importance of design in focusing on supporting and encouraging individual patients to participate; things that work with some patients might not work with others.

However, tools, techniques and how patients respond are elements that are connected in order to support patients' participation, perhaps empowering their voices. This notion of empowerment leads us to think of what Hofstede et al. (2010) define as "power distance"; to equalise the power relationship in order to establish more democratic societies. In other words, this concept is based on recognising the value of less powerful group members or the potential for a small power distance. These issues of promoting a small power distance are important to discuss in this context of stroke rehabilitation in hospital. Think, for example, how the current application of the ICF model demonstrates the significant power distance between the predominant medical voice and the largely unheard or silent patient voice. What this research approach recognises is the significance of gathering both patients' and healthcare professionals' voices to raise and voice issues that are different but equally valid.

9.4 A framework method of analysis to demonstrate multi-voicedness

One of the questions in this thesis is (how) can design elicit the patients' and healthcare professionals' voices more effectively than other methods? The priority of this research has been to demonstrate the voices from those patients and healthcare professionals who are involved in a Stroke Rehabilitation Unit in a hospital. This research supported multi-voicedness in order to bring new insights (Bødker and Buur, 2002). Supporting these patients' and healthcare professionals' voices was accomplished through the adoption of tools and techniques as a way of letting different voices become "loud" in design activities. In this way, this research was able to bring new insights about the mealtime forward.

One of the challenges of this research has been to explore how to move from an initial descriptive and narrative mode of knowledge to a playful mode of knowledge. In other words, the challenge has been about how to move from explicit knowledge to tacit and then latent knowledge (see Figure 5.1). Instead of focusing on this movement as interpreting schemes to open up new avenues for interpretation, I used the framework method of analysis to demonstrate these different voices in the context of two different scenarios – I wanted to look at the present to identify emerging issues, and then, using these to looking forward to the future to see what might be envisioned as a desirable change. Using a framework method was useful to begin organising and managing the information collected, as discussed in Chapter 5, section 5.4. Part of the reason behind

adopting a framework method of analysis was to preserve the integrity of these patients' and healthcare professionals' accounts, or "voices" (Green and Thorogood, 2004).

Using the framework method I was able to summarise these "voices" and by looking closely at them it allowed new themes and issues to emerge. I wanted to see how far this understanding could go by using this framework (see Figure 5.17). This method could lead us to think about, for example, in a future mealtime scenario, what might the patients' socialising be like while he/she is waiting for her/his food? This was achieved by asking *What if?* and then continuing to extend the thoughts and ideas brought forth by these imaginings. Although the framework I used was useful as a starting point, I found that both patients and healthcare professionals tended to talk in a similar way about this particular aspect of environment which reflected the kind of questions I asked, following the framework. However, during the analysis stage the data also began to reveal other themes, such as familiarity and personality, which suggested the need for an adjustment to my original framework which would have been interesting to explore further. What becomes clear was that the framework I used suggested other thematic areas. In essence, the framework became a tool for me to look at different information about the mealtime in a structured rather than a random way. By using this methodological approach, this research was able to understand two temporary contextual and experiential situations: the mealtime of today and the desirable mealtime of tomorrow (see Figure 9.1).

THE MEALTIME IN HOSPITAL

Present	Future
An **essential** part of functional swallowing restoration in stroke rehabilitation.	A moment for patients and healthcare professionals **celebrate life together**.
A **focus** to eat.	Creating spaces to **accommodate** invididual **patients' needs**.
A **lack of personalisation** to promote more choice and autonomy.	Creating appealing food to offer **little pleasures of life**.
A **lack of social dimension**, and its ability to facilitate the patient socialisation.	Facilitating autonomy to empower patients with a **sense of control**.
A **lack of environment** to accommodate individual patients' needs.	Promoting **conviviality and privacy**.
Poor food and ambience presentation, causing further demotivation to eat.	Triggering patients to be **relaxed**. Enabling patients to experience **normalities of life**.

Figure 9.1 The mealtime based upon what it is today and what it should be tomorrow.

Today, there is a pre-occupation with functional swallowing restoration and how to motivate patients at the mealtime in stroke rehabilitation. According to healthcare professionals, patients tend to be demotivated due to the impacts of stroke. However, this research showed how the current mealtime is problematic in relation to the patient experience and how this situation is not benefiting the patients' emotions. The healthcare professionals recognised the fact that each patient situation is unique, and therefore requires personalised care in stroke rehabilitation in hospital. However, the mealtime showed a lack of personalisation. For example, patients revealed experiencing limited food choice. What healthcare professionals revealed was that food in hospital follows standard rather than personal food service and patients do not have a choice. Although healthcare professionals revealed ways of facilitating personalisation, such as adapting tableware to the patients' needs, they also demonstrated concerns in encouraging patients to use the tableware due to its associated connotations. Using tableware showed that patients experience limited autonomy. However, experiencing limited autonomy revealed further impacts on the patients' motivations at the mealtime. Consider, for example, how patients recounted refusing to eat certain food, feeling frustrated and/or struggling to eat. There is also a lack of environment and ambience here. For example, patients expressed two types of experiences; those patients who can and those who cannot eat in a traditional sense. Those patients who shared a physical space revealed uncomfortable experiences. What these healthcare professionals' and patients' voices highlighted was that the mealtime lacks a social dimension. Consider, for example, how healthcare professionals revealed a tendency for patients to focus on eating while patients expressed that some patients are not eating in the conventional sense and of those who are eating they eat individually and "alone". Moreover, the healthcare professionals revealed concerns with the smells around the mealtime. Experiencing bad smells showed that patients lose their appetite and interest at the mealtime. These were key issues that emerged, which show that the mealtime requires consideration, not only to functional, but also to emotional and social restoration.

In exploring what should be a desirable mealtime tomorrow, there is an aspiration to facilitate personalisation, or, in other words, to better accommodate individual patients' needs at the mealtime. According to patients, it is not pleasant when everybody else around you is eating when you cannot. Within this view, the patients suggested how the mealtime should allow spaces to adapt to the patients' needs and how this situation might benefit the patients' emotions. For example, patients revealed a desire to experience change at the mealtime, engaging in a more familiar and social setting. Although healthcare

professionals see this as an important aspect, they considered that socialising requires "coordination" and "appropriate grouping" in order to accommodate better individual patients' needs. For example, it might be appropriate for some patients to chat during the mealtime but others might benefit from eating in silence. According to the patients, a desirable mealtime should facilitate not only personal needs but also likes and goals. For example, patients would like to experience an environment decorated with familiar tastes, they would like to be able to choose food that they like and when receiving it that it would look appealing. The healthcare professionals also recognised the importance of knowing patients' likes and dislikes, providing more food choice and facilitating patients to choose what they want but taking into consideration what is appropriate to them at the time. What this research found was this idea of creating empathy to facilitate autonomy, promote conviviality and privacy and enable patients to experience the normalities of life.

In fact, what seems to be highlighted in this multi-voicedness is that both patients and healthcare professionals desire to experience a good time together, an act that involves socialising with each other. Perhaps more interesting is the idea of the mealtime as a temporary "break" from the "mechanistic" clinical routine which can bring about a moment in which to celebrate life to influence the patients' emotional states in positive ways. This finding opens up exciting opportunities for intervention studies in the future. For example, imagine how addressing this one aspect of the patients' hospital experience might influence the overall effect/impact on patients' recovery. By eliciting the voices of "the real virtuosos of the experience" (Sanders, 2001), this research challenges ways of thinking about what could make a significant difference at the mealtime in using a non-medical type of intervention, revealing possibilities that we can drawn from here. Even more interesting, these patient-voiced issues are potentially important in improving their well-being, they can: a) be designed in as part of the treatment; and b) how the challenge of personalising the individual personal experienced can be practically introduced (or not). This research highlights what we do not yet know but what is equally important to explore in the future.

9.5 A multi-voiced process

Throughout this thesis I have been discussing the importance of bringing forth these patients' and healthcare professionals' voices, not only exposing them as active partners, but fundamentally engaging them in creative dialogues to reflect and think in a diversity of ways, particularly in this context of the mealtime in stroke rehabilitation. However, this

research showed that engaging patients, those affected by stroke, can be difficult and challenging, possibly explaining the dearth of published research in this area. The results of this research showed that Participatory Design (PD) has a role to play in supporting multi-voicedness in this context of stroke and healthcare which not only engages with those who are already more able, but also with those who are relevant to obtaining valuable forms of evidence. Fundamentally, I advocate that those who live with a health condition have the experience, opinions and the right to have a say in design for desirable change. For example, they can contribute to developing spaces that become flexible and adaptive to allow them to be better supported and to accommodate their physical and verbal difficulties. In other words, this research was about establishing socio-material connectedness in which to support, facilitate and motivate patients' ideation. These connections between the social and material promote communication and idea generation in design practices within healthcare. Looking back, it becomes apparent that involving "the real virtuosos" (Sanders, 2001) has brought forth new insights and issues. The achievement was that both patients and healthcare professionals were able to participate with their views, opinions and ideas in the discussion of the patient experience at the mealtime. In doing so, the design researcher's role was not only towards infrastructuring and facilitating, it also involved ethical commitments to legitimate their participation. This can also be seen as role in motivating healthcare authorities to consider who should be participating and why in order to provide valuable insights that can help to promote the quality of the patient experience in stroke rehabilitation in hospital, especially at the mealtime.

On the other hand, stroke rehabilitation might benefit from a Participatory Design (PD)-based approach. Consider, for example, how the application of the ICF model was shown to be unbalanced, highlighting a single view, the medical, rather than multiple views, involving both the social and medical. Using a PD approach, this research shows how to support the healthcare models in becoming more balanced. Promoting the healthcare models draws attention to bringing forth social accomplishments in order to provide a multiple view of the matter in discussion with the real virtuosos.

Another aspect that characterises the relevance of this research is that the findings from this study, using a PD approach, showed a focus on understanding the patient experience which is not only focused on what is but also how it should be. In other words, it demonstrated an understanding of the patient experience, involving initially understanding what is currently happening to proceed into what would be desirable in the future, which I

considered to be distinct from the EBCD approaches (Donetto et al., 2014). Although EBCD approaches have also taken place in challenging settings such as breast and lung cancer contexts (Tsianakas et al., 2012) and it is apparently concerned with "patient experience" and "co-design", it might be more concerned with improving healthcare services. Consider, for example, how the co-design situation has involved both patients and healthcare professionals to work together on the key problems identified from their experiences to implement solutions to healthcare service improvements (The King's Fund, 2011; Tsianakas et al., 2012; Bowen et al, 2013; Donetto at al, 2014). Despite all of these achievements, however, this process of inquiry has highlighted issues that may limit the relevance of the findings in this thesis. In the following section I will discuss the limitations of this research.

9.6 Limitations

The limitations of this research, as I see them, are related to the time and space in which the research took place and the strength of the findings from the patients' voices which are based on information generated by involving two forms of verbal expression: direct and indirect (see Figures 5.14 and 5.21). However, there are other issues, such as the number of participants involved and the process of selection of these participants, which must be discussed here. Although the participants of this research study possessed the key illustrative characteristics of the population being studied, as demonstrated in Chapter 5, section 5.2.3, the small number of participants might limit the findings and might not be indicative of general trends in the data. Regarding the process of selection of participants, patients and healthcare professionals were participants who volunteered to participate in different design situations, so the data obtained in this thesis were only gathered from those who attended these different activities. Another consideration is about how the patients were recruited. The healthcare professionals, or "local nurses", suggested suitable patients, so, as such, they were acting as "gatekeepers" and perhaps, in protecting some of the patients who were not invited to take part, their perceptions may have inadvertently excluded some individuals from taking part who may have been able to offer further, or at least varied, insights. Another limitation is that the research in this thesis was performed in both private and public spaces. Private spaces, such as the patients' homes, displayed comfort zones for them but revealed that the design researcher would have a limited time to meet with them and get to know them better before the interview. Although the design researcher was already familiar with the patients' needs due to prior discussions with the support nurses, I found that having more time could be a benefit to connect better with

patients, tools and techniques and, consequently, to enrich dialogues. Think, for example, how Patient 2, as demonstrated in Chapter 7, section 7.2, could not eat at the mealtime in hospital. Although I made some "improvisation" adaptations during the course of the interviews, I think that the findings could have been different if, when conducting interviews with patients, I had interviewed on more than one occasion. This would have allowed me to know the patient better, and would have provided ample time to interview the patient. Taking more time to conduct the interviews would provide tools that better support personal narratives, because they will be better connected as a result.

Public spaces in hospitals were revealed to be "turbulence" zones. Developing a workshop with patients in a day-hospital room aimed to support eventual needs during the activities. However, the time it would take to conduct the workshop involved a commitment between the researcher and the day-hospital. Having flexible time to conduct a workshop in a day-hospital space can be difficult; I had to conduct the workshop within a set amount of time to allow for these needs to be met. For example, while we were playing a game, a patient needed to take some air fresh, as mentioned earlier. Giving the patient time is crucial to get them motivated to participate. Although I accommodated the patient's immediate needs during the workshop, I think my findings could have been different if I had conducted this workshop over several different times. Think, for example, if the three games were played by meeting three times; this might have promoted more comfortable zones in which to play. Perhaps more interesting, could be expanding this idea of connectedness to this view of the "patient appointment card" to attend a series of design activities to play games in order to create new possibilities of the matters of concern around the patient's experience in healthcare. Conducting only one workshop also brought issues of patients dropping out; an issue which requires further attention.

Despite these limitations, eliciting the patient's voice did involve techniques such the assistance of the support nurse to allow communicating with these patients. Although the findings showed that the patients' expressions were revealed, intertwining their own voices with the professionals' voices, I still created the opportunity for these patients' voices to be "loud".

9.7 Summary

In summary, this chapter began by discussing participatory design as an adopted approach, where I suggested tools and techniques to support individual capabilities to enable the patients to participate in ways that better accommodate their individual needs. Afterwards,

I suggested a model for design connectedness and discussed the relationship among tools, techniques and people to demonstrate how the patients' voices emerged in design activities. Here I emphasised design practices in working with and for the patient experience becoming flexible and adapted to promote well-being and motivation in design activities. Next, I illustrated design as a mode of transferring and translating knowledge. Here I discussed a framework method of analysis to summarise voices and as a tool which looked at different information about the mealtime. Using this methodological approach, this research was able to understand two temporary contextual and experiential situations: the mealtime today and the desirable mealtime tomorrow. This method provided a deep and rich way to explore what I found by eliciting the patients' and healthcare professionals' voices. I concluded this chapter by discussing a multi-voiced process, demonstrating how this brings about the generation of valuable forms of evidence. Fundamentally, this chapter demonstrated, on one hand, that participatory design has a role to play in supporting multi-voicedness in this context of stroke and healthcare. On the other hand, it was about emphasising how stroke rehabilitation might benefit from PD approaches in order to rebalance healthcare models, in particular in stroke rehabilitation in hospital. This chapter also illustrated the achievements and limitations of the research, involving issues of time, space and giving patients a voice. The following chapter will present the conclusions drawn from this research study.

10

Conclusions

This thesis has conducted a process of inquiry with a focus on how to enhance the patient experience at the mealtime in stroke rehabilitation using a Participatory Design (PD) approach. The process of inquiry has provided a deep understanding of the patient experience, involving initially exploring the present mealtime scenario and experience, and based on these findings, to proceed into explorations for a desirable mealtime experience in the future. Moreover, it has demonstrated considerable significance and value in eliciting voices, particularly those patients and healthcare professionals who are considered "the real virtuosos" (Sanders, 2001) of the mealtime experience. This research has adapted PD methods, tools and techniques to support the multi-voicedness of those patients and healthcare professionals in order to bring new insights into our understanding of the mealtime.

This research study has explored a range of data using an approach that was tailored to the context of stroke rehabilitation in hospital and an analytical (thematic) framework to produce a set of findings. Some of the issues that have emerged are fairly straightforward, but it was this process of inquiry that enabled these to emerge and be made "visible". However, other findings from this research have suggested opportunities for intervention within this context in order to evaluate the effects and impacts of the mealtime in stroke rehabilitation in hospital on the patients' recovery. Here PD has provided a valuable approach to directly involve the patients' and healthcare professionals' voices in the gathering of this information and had the benefit, through the connectedness of the social and material, of supporting multi-voicedness in this context of stroke and healthcare.

The following contributions to knowledge result from this study. Firstly, from a healthcare perspective, the approach taken has provided evidence of factors other than the requirement for the patients' functional restoration which may have an important bearing on their recovery. Secondly, it has adapted and extended PD approaches into a challenging and complex healthcare environment involving patients who have suffered significant trauma and found these to be effective in gathering new data and insights. Thirdly, it has provided a means of enabling patients to articulate issues such that these could be communicated through communication channels such as the Patients Association. How

each of these claims provides a new contribution to knowledge will now be discussed in more detail.

10.1 A contribution to stroke rehabilitation

From a healthcare perspective, the approach taken has provided evidence of factors other than the requirement for the patients' functional restoration which may have an important bearing on their recovery. One of the main questions discussed in this thesis has been: what could design do to promote and support the applied International Classification of Functioning (ICF) model in stroke rehabilitation to allow the social to be "voiced" at the mealtime in stroke rehabilitation in hospital? I attempted to answer this question by discussing design as a social and collaborative model of design practices, able to involve many social agendas. It is the design model that offers that possibility and it is also the design practices that build on participatory inquiry to give corpus to this view (see Figure 10.1).
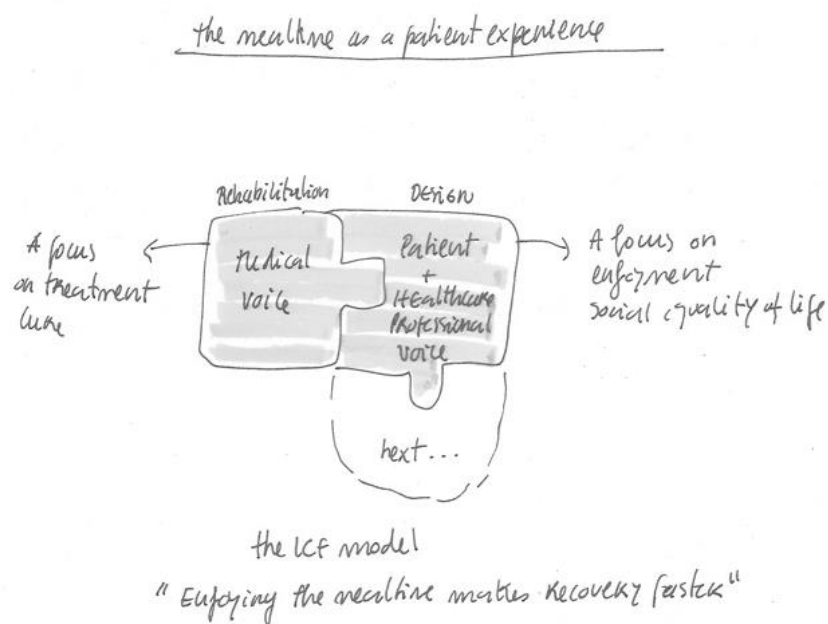
Figure 10.1 Design supporting the ICF model.

This idea becomes perhaps more clear if we think that this thesis is an attempt to contribute to the evolution of the rehabilitation model. On one hand, it discusses the direct involvement of patients and healthcare professionals in this "micro-level" of the mealtime as part of the total patient experience in hospital as a way of giving a democratic voice to patients and healthcare professionals. On the other hand, it perhaps provides a picture of the "macro-level" of the world in this context of stroke.

This evolution consists of the acknowledgment of the fact that in hospital mealtimes, patients will have to undergo the unpleasant and sometimes distressing process of having to functionally rehabilitate by (re)learning how to use their tongue, swallowing and facial muscles while eating Texture Modified Food (TMF). There will be, therefore, an unfortunate but unavoidable association between food, mealtimes and this unpleasant rehabilitation process. However, it also must be accepted and acknowledged that this process of rehabilitation is a priority for survival. The issue of poor presentation and appearance of food and mealtimes is also a more generic issue across the healthcare sector. Dieticians are obliged to tackle both nutritional issues and the rheology of functional swallowing restoration (see Figure 10.2). However, the issue of subjective well-being (SWB) is also important in improving patients' outcomes and there is much evidence in this thesis to support the significance of its importance.
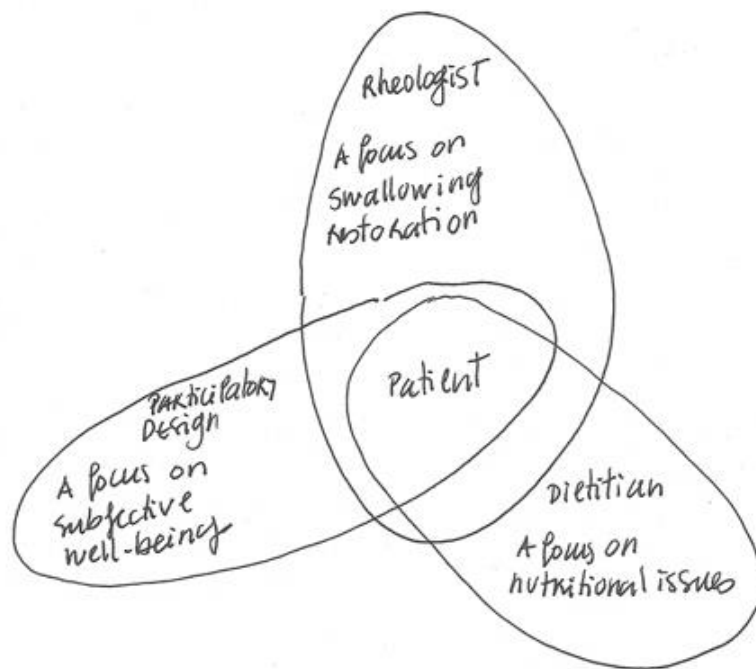
Figure 10.2 A conceptualisation of the three main issues at the mealtime in stroke rehabilitation in hospital.

Looking at these three facets of the mealtime, combining functional swallowing restoration, nutrition and SWB, perhaps highlights how the current "medical" regime deprioritises the attention it pays to the role SWB could play in rehabilitation and recovery of patients, and herein we find an opportunity for the role of PD. I suggest that creating new spaces in which to explore these SWB issues can help bring forth new insights. Fundamental issues about the patients' SWB can be addressed by paying close attention to the kinds of evidence that are elicited by uncovering and listening to these patients' and

healthcare professionals' voices. I argue that, in stroke rehabilitation, the applied ICF model slips into one with a pre-occupation with functional restoration, while the SWB issues remain unaddressed, even though the ICF model quite clearly recommends this. The application of the ICF model at the mealtime faces the necessity for contributing to both functional and emotional and social restoration and, I argue, using a participatory design model to uncover and acknowledge these SWB issues might help to highlight their relevance and suggest a rebalance of the ICF model in clinical practice.

This research has revealed new information (see figure 10.3) that could certainly be considered as having the potential to influence patients' recovery. Think, for example, of the mealtime involving a diversity of considerations. On the one hand is the medical view, more focused on the functional aspects of the patient's recovery. On the other hand is the view which has been elicited through PD, emphasising the sensorial, emotional and social issues to promote the quality of the patient experience while he/she is in recovery at this time in hospital.
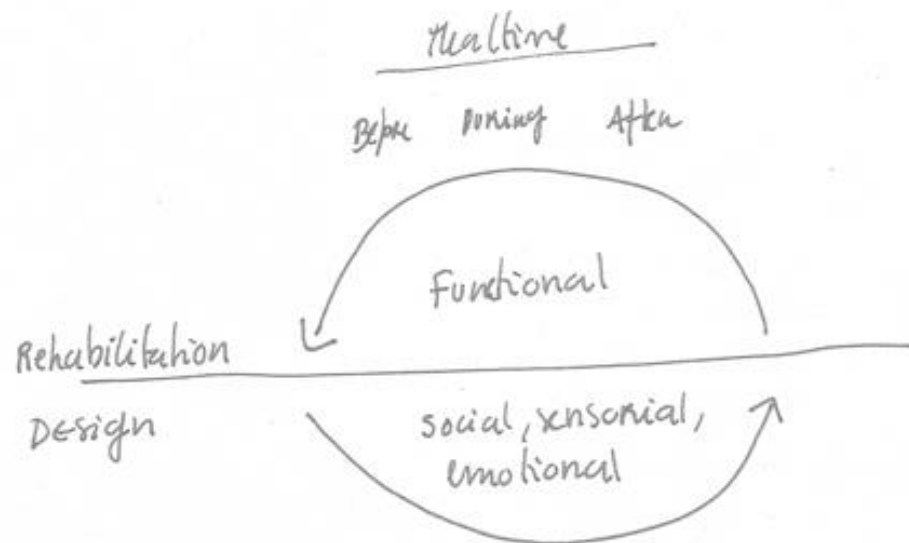
Figure 10.3 Rehabilitation and design interventions, revealing social accomplishments at the mealtime.

The results from such divergent views, the medical and design, could also reveal a more complementary ICF model, revealing "social accomplishment" (Kimbell, 2012) in these ongoing routines of functional, emotional and social restoration.

This importance of the interconnectedness between functional, emotional and social restoration which has been revealed has another dimension; that of the patient as an individual, and here the concept of "personhood" as distinct from "patienthood" comes

into play. Socialisation in the routines of daily life is this relationship of social networks or, in other words, interactions between the social and the material (Ehn, 2008). The mealtime is a well-known day-to-day experience that we know from our own experiences and we also recognise that it can influence and perhaps enrich our lives and it can promote convivial situations such as being a guest in others people's homes. Personalisation of this socialisation leads to recognising the person behind the patient, one who has individual feelings and preferences. Although personalisation of the mealtime might be difficult to consider in today's challenging healthcare environment it may be a factor which enhances the patient's experience and potential recovery. What I have suggested in this thesis is that using a participative and collaborative design model can be a vehicle to support this idea of the medical to become "supra-medical". Used in this way, it offers another model for stroke rehabilitation which may ameliorate some of the negatives of the experience and assist recovery.

10.2 A contribution to participatory design

This thesis has adapted and extended PD approaches into a challenging and complex healthcare environment involving patients who have suffered significant trauma and found these to be effective in gathering new data and insights. Another main question has been on how eliciting the patients' and healthcare professionals' voices through participatory design approaches could contribute to highlighting ways to promote the quality of the patient experience at the mealtime. Participatory design in this research has been a relevant model to develop a way of inquiry that places emphasis on the direct participation of patients and healthcare professionals through the actual rather than a representative voice (Macdonald et. al., 2010; Bowen et al., 2010a). The outputs have illustrated a multi-voiced process of gaining access to, personalising methods for, and engaging a diversity of voices, as the context is one of dynamic interaction between the healthcare professionals and the patients. This view has adopted a line of thinking of design as a collaboratorium (Bødker and Buur, 2002), atelier (Binder et al., 2011a) and laboratory (Binder, 2007) and it insists that establishing working relations based on participation or collaboration must be a practice of recognising it as an ongoing process, or in other words, infrastructuring "design after design" (Ehn, 2008). In this way, this research has presented an approach for infrastructuring based on prior infrastructure practices by making information-sharing between different voices possible and by allowing them to articulate their worlds in a shared language. This approach demonstrates a process that documents what is the present and what is imagined to be a desirable future. The result has demonstrated a new scenario

that shows, in a sense, these new possibilities in a tangible way. At the same time this new scenario is open for multiple interpretations or for promoting further ideas when it is shared with other "voices".

PD is a well-established approach and much of its strength is on design practices to bring change, or in other words, to explore desirable futures. In this research, PD methods have helped to interrogate and evaluate the way the ICF model is currently being applied in this context of stroke rehabilitation. In doing so, it highlights the issues that remain unaddressed in the ICF model and demonstrates what is seen as being important by uncovering and evidencing to the patients' and healthcare professionals' voices. In developing and testing PD approaches and methods in this kind of clinical setting, this research has provided insights into the modifications required of these approaches, and the appropriate methods and their implications for participants. We need to acknowledge that we are living in societies which are facing a growth in chronic conditions (Cottam and Leadbeater, 2004; Murray et al., 2006), where participatory design approaches, in particular in this context of stroke and healthcare, offer the opportunity to bring tools and methods to go beyond those that are "shaped and sharpened by the issues and concerns of the participants" (Binder, 2010); they must be designed to support and facilitate inclusiveness rather than influence exclusiveness. We can no longer continue to involve just those who are able to articulate or who are physically capable of making things because we all have a voice and we all live and are affected by design changes. Let me be clear here. This idea of exploring desirable futures in healthcare needs to recognise limitations to capability and disabilities and support them in PD practices. Fundamentally, this exploration requires the creating of spaces in which to provide participants not only the opportunity to experience playfulness and sociability, but also in which to support their well-being. This view of well-being requires us to focus on individuality. Think, for example, of the fatigue experienced by patients in the co-design workshop. This research study demonstrates the considerable significance and value of customising methods, tools and techniques because things that work with some people might not work with others, in particular people who live with some kind of disability. In this regard, the design of PD materials requires to be context specific, for instance, customised for the particular nature of the enquiry. Another main issue in this research has been the question of how do we obtain access to and engage with patients? What makes this research interesting is that it shows the importance of ethics in participatory design in this context of stroke and healthcare. By applying for National Health Service (NHS) ethical approval, I was able to

engage patients, those affected by stroke, or, in other words, to legitimise their participation in this research. Perhaps more interesting is that giving people a voice requires that PD practices take responsibility for and safeguard their participants. In this way, this research provided useful insights for the PD communities.

Patients' involvement in design practices is important because they can demonstrate, both to the healthcare profession and to themselves, new ways of thinking by providing knowledge from their prior experiences, as "virtuosos". Here this thesis is an attempt to contribute to the evolution of PD tools and techniques to work with and for the patient experience in design practices. This research has created tools and techniques that could certainly benefit other design practices to involve patients with similar needs. What I see as being relevant is to establish a connectedness between the social and material in order to inspire, support and facilitate patients' participation in design practices.

10.3 A contribution to the Patients Association

Giving patient a voice has been considered significant to bring forth new insights on how to enhance the patient experience at the mealtime. By placing a focus on creating methods and practices to engage patients, in particular those affected by stroke, this research has provided the uncovering and articulating of the patient voice in such a way that they could be clearly communicated through such advocacy/campaigning groups as the Patients Association (whose motto is "Listening to Patients, Speaking up for Change") as a means for lobbying for change. What makes this research significant is that design practices show the importance of accessing and helping the patient's voice to be "loud" in this context of stroke and healthcare. I was able to allow communication to happen in healthcare communities by sharing voices. Perhaps, the findings of this study emphasise not only the right for patients to be involved but also the significance of their involvement in discussions about healthcare improvements regarding their health experiences.

10.4 Critical reflection on the research approach

The study of stroke care is highly complex, and by involving the direct participation of patients and healthcare professionals it became even more complex. Design with patients, in particular those affected by stroke, demanded adhering to the governance requirements of community care research in the UK which highlight an ethical discourse around human rights, safety and confidentiality This thesis has demonstrated ethical and political agendas expressed by close collaboration with the Health Research Authority, NHS Lanarkshire

Research and Development and the Glasgow School of Art Research Ethics Committee. Having to respond to such a staid ethical commitment has illuminated the ethical issues around designing with patients and healthcare professionals. The defining role of ethics in this research was significant to enable the genuine participation of patients and healthcare professionals. I believe that the arguments made in this thesis, if conducted in any other way, might present a different process or result.

Conducting design research within NHS ethical approval is valuable but also challenging due to the implications of this doctoral research undertaken by design researchers on the heavy demands on time to prepare design proposals, completing NHS forms, having meetings with the collaborators and the sponsors, and obtaining permission to conduct the study, as demonstrated in Chapter 5, section 5.2.2. Issues of time required to conduct such a study is also affected by available funding, perhaps a reason why work of this kind in this setting is not that common. What would help in the future, as I see it, is if the necessity and processes for ethical access is better understood and becomes a more common form of practice in design communities, structured and integrated into the research design and research methodology. After all, design has always been interested in working towards improving healthcare. What I see as being important here is design playing a role in developing meaningful approaches for social engagement to benefit the impact of co-design approaches in healthcare (Donetto et al., 2014). Fundamentally, design can empower voices by using tools and techniques to support them in creative dialogues. However, this requires not only making things tangible and visual, but also using appropriate approaches to generate robust forms of evidence that will be recognised by and acceptable to the fields that have the power to adopt new practices in light of this evidence, in this study's case, the stroke rehabilitation community. Think, for example, what kind of data can PD approaches bring to complement medical data? I believe this marriage will flourish and produce meaningful outcomes. Another thought is about what would design and healthcare researchers do and bring differently in exploring the same situation? Would they ask the same questions? How might asking different questions bring forth different insights? Given this reflection on ethical considerations in this thesis, it highlights that the design researcher's role within this context of healthcare can be expanded. Think, for example, if the design researcher can operate as a member of the stroke rehabilitation team, collaborating with patients and healthcare professionals, promoting and supporting meaningful design initiatives for the patient experience. Each of these individuals can

promote participation using their creativity to motivate multi-voiced engagement in ways that can help communication happen in the healthcare community in a useful way.

10.5 Recommendations for future research

This thesis has demonstrated a process of inquiry with a focus on exploring new possibilities to promote the quality of the patient experience at the mealtime in stroke rehabilitation in hospital. This research has also revealed many different aspects of this phenomenon. However, there are other aspects that require further consideration.

Collaboration across healthcare organisations and communities

The findings in this research have been based on the views of stakeholders in only one Stroke Rehabilitation Unit setting in Scotland, and therefore it reflects a particular rather than a general perspective. Although Scotland presents the highest incidence of stroke in the UK, involving other healthcare organisations and communities with a high incidence of stroke such as Portugal could be valuable to enhance the knowledge of patient experience at the mealtime in context of stroke rehabilitation.

Design as an ongoing multi-voice process

This research has demonstrated the patients' and healthcare professionals' voices in separate ways at this early stage of exploration. Creating opportunities to bring both voices together in combined workshop sessions could enable further translations. At the same time, expanding the numbers of key stakeholders in the research can also be relevant, for example, the food producers, caterers ward staff and health environment consultants.

Expanding tools and techniques to support creative dialogues in healthcare

The tools and techniques presented in this research have been created to support patients with physical and verbal difficulties in this context of stroke. These tools and techniques have been shown to be of great significance to involve patients in idea generation. However, the tools used in the workshop with patients, as demonstrated in Chapter 8, show great significance for communication and idea generation. Further research could focus on supporting the balance of voices, but might also sustain inspiration in participation.

Opportunities for pilot feasibility trials

The findings from this research have produced some issues that suggest they could be introduced and evaluated as pilot feasibility trials in the context of the stroke rehabilitation in hospital to see what benefits these might bring to the patient experience and recovery. Think, for example, of the issues related to the idea of the mealtime as a temporary distraction from the clinical routine and/or issues about the promotion of personalisation at the mealtime. What this research demonstrates here is design as an ongoing exploratory process. By providing evidence of the benefit of providing a space in which to elicit multi-voicedness from these patients' and healthcare professionals' voices, this research reveals new possibilities on which other studies can draw upon and expand to the benefit of the patient experience as a whole.

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Appendices

Appendix A: The designing of the mealtime into daily practice with restaurateurs

This study was conducted with restaurateurs to obtain insights into the daily practice of designing the mealtime for a customer experience. By having restaurateurs participate in the research, I wanted to understand who has experience on what is designing for the customer experience at the mealtime, and what should be considered to deliver an enjoyable and pleasant mealtime experience?

I initially intended to collect a diversity of views from professionals working at different types of restaurants, for example, fast food and dining restaurants. However, contacting restaurants can be challenging due to the heavy demands on my time spent meeting them to discuss the study and receive their feedback and interest to take part in the research. For example, four restaurants were contacted in Glasgow but only two restaurateurs participated in the study. Both showed their interest in sharing their work experience related to the mealtime for customer experience. I conducted interviews focused on how restaurateurs create the mealtime for their customers' experiencing. In each interview, open-ended questions were prompted to create dialogues in order to explore the restaurateurs' views about designing.

A.1 Inviting restaurateurs

I started by making a list of restaurants and then I contacted them by email to present the study aims and inviting them to participate. Here I received their feedback on whether they were to participate or not and consequently a meeting was scheduled. Meeting restaurateurs was to explain and discuss issues about the study and, consequently, define a schedule to conduct the study. Later, we met to discuss the designing of the mealtime. The meeting before the interview was significant because it allowed me to personally express to the restaurateurs how I considered their participation to be significant to this study but also it allowed the restaurateur to get to know me. The preparation and planning took place over the period of three months.
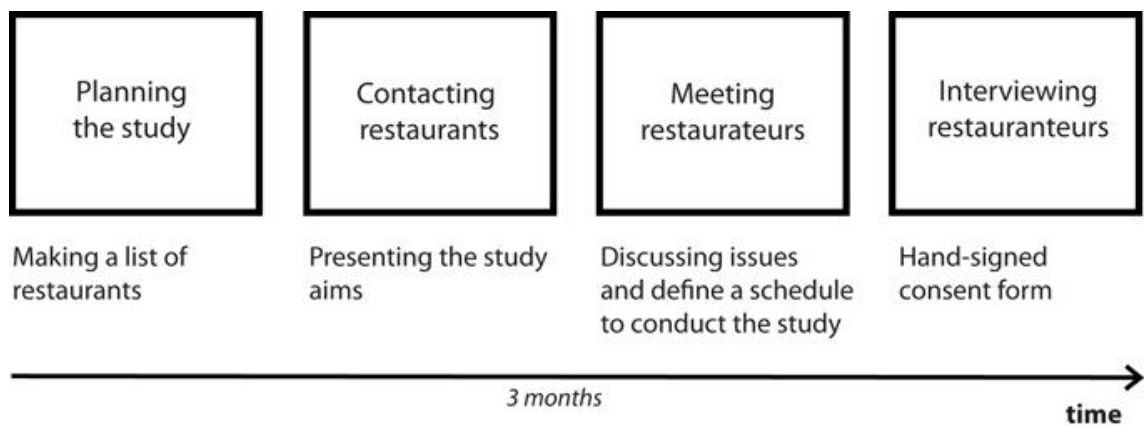
Figure 1: An overview of the invitation process.

A.2 Who participated?

There were two participants in this part of the study (see Table 1), both restaurateurs of dining restaurants. Those restaurateurs were a manager and a chef, as these individuals are considered experts in planning and creating the mealtime into daily practice for customer experience.

Restaurateur	Specialism	Work experience (in years)	Type of restaurant	Gender
R1	Manager	18	Dining	Man
R2	Chef	28	Dining	Man

Table 1: The restaurateurs who participated in the study.

The table illustrates who participated, demonstrating the characteristics of the restaurateur in relation to their unique identifier code, specialism, work experience and gender. By illustrating the restaurateurs' characteristics, I have introduced those who participated in this study. In what follows I will focus on describing how the interviews were conducted.

A.3 Interviews

Two interviews were conducted which took place in the restaurateurs' work places. In each interview, I began by thanking the restaurateur for his participation and recapitulating the aims of the study to them in order to clarify any issue. Our dialogue was audio-recorded. I conducted these interviews following ethical principles, including voluntary participation and informed consent form. Starting the dialogue (see Figure 2) with each restaurateur, I invited them to talk about their experiences and practices in designing the mealtime with

an aim to explore information related to the experiential considerations. In what follows I will illustrate the restaurateurs' voices from their participation in these interviews.

Figure 2: The environmental overview of the interviews conducted with restaurateurs.

A.4 Analysis

Analysing the information involved transcribing all the audio-recorded interviews verbatim, and reading and re-reading the transcripts. These interviews were predetermined by the question of how to design the mealtime for customer experience. To become familiar with the data, I organised and managed the information collected within this thematic issue. I especially studied the parts of the audio-recorded interviews where participants explained their views on creating the mealtime. The following section provides a sample of the issues identified in discussing the designing of the mealtime with restaurateurs.

A.5 Restaurateur 1

In prompting the question *what kind of experience do you want to create at the mealtime?* the restaurateur revealed his thoughts related with a combination of experiential aspects. He said:

> *R1: It's not just the food that matters (...) the environment and the way the room looks and how the person interacts with their server, the music that's playing, so every*

single facet of what going on around the table is very important and has a really strong bearing on the experience to the person who's eating and how they enjoy it.

This view from Restaurateur 1 shows that designing the mealtime is not only a focus on food. The restaurateur highlights attention to the importance of environment and social context. Think for example, of his views related with sensorial aspects and people's interactions. In continuing our conversation, I was interested in knowing more about how the restaurateur 'constructs' the mealtime to respond to the enjoyable experience. He expressed thoughts in this way:

> *R1: This place is quite old fashioned which is why we use antique roses, antique roses are quite difficult to find (...) but it's important (...) it's the same kind of flower every time because people (...) they're used to it and it's something unique to coming here.*

> *R1: We use (...) antique cups (...) when you get your cup of coffee or cup of tea at the end of your meal (...) every single, guys appreciate it (...) but usually it's women when they get their cup they look at it and thing oh my god and they look underneath to see where it came from and they look at the spoon and they're already enjoying it before they've even tasted it.*

> *R1: When the customer walks in through the door first thing they've got to feel is warm especially in Scotland, so when you walk in here you feel a little bit cosy (...) before you sit (...) you get your drink in the bar it's got to look spectacular it's got to taste perfect (...) when you sit down (...) your table it's got to look spectacular.*

> *R1: The waiter, the pleasant comment the smile.*

> *R1: When they get their food put down on the plate (...) something pretty (...) the cutlery (...) matches the food that you're going to have (...) it should be a feast for their eyes from start to finish.*

According to this restaurateur, the designing of the mealtime is in creating a stronger emotional connection with the customers in particular when the customers' expectations are leaning towards to experience something that he called "unique". Simultaneously, it highlights attention to this idea of designing to provide what customers appreciate. Here the restaurateur demonstrated a focus on designing the mealtime in ways of making people feel appreciated. This view also shows the importance of social context in experiencing. Consider, for example the people who are serving the customer promoting social pleasure

by revealing pleasant comments and facial expression. Another interesting point is this view of "to look spectacular" which perhaps shows a design intention to seduce or surprise the customer through visual appearance. Afterwards, our discussion was related on how the restaurateur does coordinate all elements, for example, food, people, tableware and others. According to him, it is important to establish a collaborative process, involving people with specific roles to work together and in sequential coordination to deliver the best experience. He expressed:

> *R1: They're from the kitchen to the dining room (...) everyone who is working is very (...) clear in what they are doing (...) there's usually two managers (...) one will be doing (...) the orders from the customers, the other one will be watching the door and making sure everything's ok (...) the waiters are specifically given certain jobs (...) some of them (...) they'll be doing the wine. Some of them (...) they'll be (...) carrying trays of food (...) when it comes to the chef's they're very (...) more specific (...) there will be pastry chefs that only do desserts, there'll be larder chefs who only do starters, there'll be grill chefs who only cook meat and fish (...) then there's usually a chef on the pass, there's usually the head chef (...) everything has to pass his eyes (...) before the plate goes in the lift to get sent down the head chef does the final garnish so his eyes see everything single thing that goes before it gets to the customer.*

This view of Restaurateur 1 demonstrated a "mechanistic" process, revealing interconnected services such as ordering, preparing and delivering where a multidisciplinary team with different roles are involved in the designing of the mealtime. What seems to be highlighted here is the significance of multidisciplinary roles at the mealtime in order to create a diversity of elements required to promote an enjoyable experience at the mealtime.

In concluding this conversation, I asked the restaurateur if he had to design a mealtime experience for a stroke patient, what did he think would be important to consider for the person in that situation? According to him, the sensorial aspects become important but also the ritual of the mealtime such as "things that actually go around the actual food (...) the ritual of having a napkin". The restaurateur seems to show thoughts associated with considerations to enhance the environmental experience when eating food can be restricted.

A.6 Restaurateur 2

In prompting the question *what kind of experience do you want to create at the mealtime?* the restaurateur began by expressing what he considered important as an experience at the start of the mealtime. For example:

> *R2: The customer comes in and (...) as they sit down they are given some bread (...) I want the customer to feel relaxed and I want the food to be tactile (...) really touchy feely so they pick the bread from the basket straight into the dip (...) they have a drink immediately (...) then you relax and read the menu.*

What is emphasised from this restaurateur is that designing the mealtime in this context of customer experience is stimulating people's sensing and feeling. Think, for example, the restaurateur expressed thoughts on how designing the mealtime is intentionally created to promote certain emotional responses such as relaxed and or what he called a sort of "touchy feely". It seems to show similar views with Restaurateur 1 within this idea of designing the mealtime in ways of making people feel appreciated. As our discussion proceeded, he added:

> *R2: The food is now more what people know and like (...) designing a menu (...) you have to know what people want but you have to know who your customer is.*

> *R2: It's got to look like someone really cared about making (...) somebody who's in the kitchen (...) loves cooking, and loves the food you've got (...) you've got to make that relationship between you and the customer (...) about how the customer is going to eat it, how's the customer going to approach it (...) is it familiar to the customer (...) it's trust.*

What seems to be highlighted in this view is the designing of the mealtime involving a customer-centred approach. Consider, for example, how designing the menu involves obtaining an understanding of what people like and want to eat. There is also this view of experiencing "loveliness". According to the restaurateur, showing passion and care about designing the mealtime can influence in creating a positive relationship which he called "trust" between those who prepare and those who experience. This view of trust seems to be significant to influence the customer to experience again. In contrast with Restaurateur 1, food here is an element continuously highlighted. For example:

R2: It should be easy to eat.

R2: There always has to be some colour in food, I think green is a really important colour (...) green looks healthy and it tastes healthy (...) visually (...) the food comes and it's like wow (...) smell (...) it make you hungry (...) it's like 70% of your enjoyment of food is in the visuals and the smells and the other 30% is in eating of it.

The view from the restaurateur shows designing the mealtime is taking considerations on how people are going to eat. Consider, for example, the restaurateur expressed thoughts that food should be easy to eat. Simultaneously, the food visual appearance should be coloured in order to promote enjoyment. Following this line of thinking, the restaurateur expressed thoughts revealing the importance of personalising the mealtime. Creating personalisation, as he expressed, is emotionally appreciated.

R2: I've got a vegetarian (...) what does this person want to eat (...) what's going to make them feel good and then how do I make it looks good and how do I give them the right amount (...) there was one guy who used to come once a week and he would (...) have haddock fish cake poached egg and béarnaise sauce and he said to me one day you know this is the happiest hour in my week (...) that's how it can affect you (...) presenting it carefully and making it visually nice (...) people appreciated it more (...) it does emotionally.

What is emphasised from Restaurateur 2 here is the designing of the mealtime as a personalising service to promote personal experience. By saying "what's going to make them feel good", shows an intention in creating what people appreciate. In return it might evoke a positive emotional response.

By prompting the question *if you had to design a mealtime experience for a stroke patient what do you think would be important for the person in that situation?* the restaurateur expressed his views by demonstrating considerations to personalise. He said:

R2: It depends on where you're coming from, there's so much you can do (...) something like that easy to eat, but it looks spectacular, it also someone's really made an effort for you and that's going to make you feel good (...) a bit of fun at mealtime as well.

By prompting this question, I intended to gain an understanding of what the restaurateur would consider valuable to promote the quality of the patient experience at the mealtime. Fundamentally, it was to give him the opportunity to express his opinions about it. The views from the restaurateur show an emphasis on the significance of designing personalisation by combining elements of aesthetic and joy.

Appendix B: Exploring the present mealtime situation with healthcare professionals in Portugal

In this appendix, I will outline a similar study, as described in Chapter 6, but in the context of stroke in rehabilitation centre (day hospital) in Portugal. The aim of this study was to obtain an understanding of the present situation at the mealtime in stroke rehabilitation from the healthcare professionals' experiences "voices". Fundamentally, I intended to highlight issues about the patient experience at the mealtime.

B.1 Inviting Healthcare professionals

I started by planning the study, involving developing a proposal and conceiving the study tools. The first contact with the day hospital was with the Nurse Manager by email where I presented the study aims and revealed the criteria for healthcare professionals' participation. Afterwards, I was informed that I would need to send a proposal of the study, describing the aims and issues of confidentiality, by email to the clinical committee to obtain approval to conduct the study in the rehabilitation centre (day hospital). In doing so, I obtained approval and then I contacted the Nurse Manager by email to discuss issues and define a schedule for I conduct the study. Through our e-mails we discussed the potential participants. The Nurse Manager, on my behalf, discussed the study first-hand with healthcare professionals and collected their informed decision on whether they were to participate or not. Then I met the healthcare professionals to develop the study. This process took place over the period of three months.
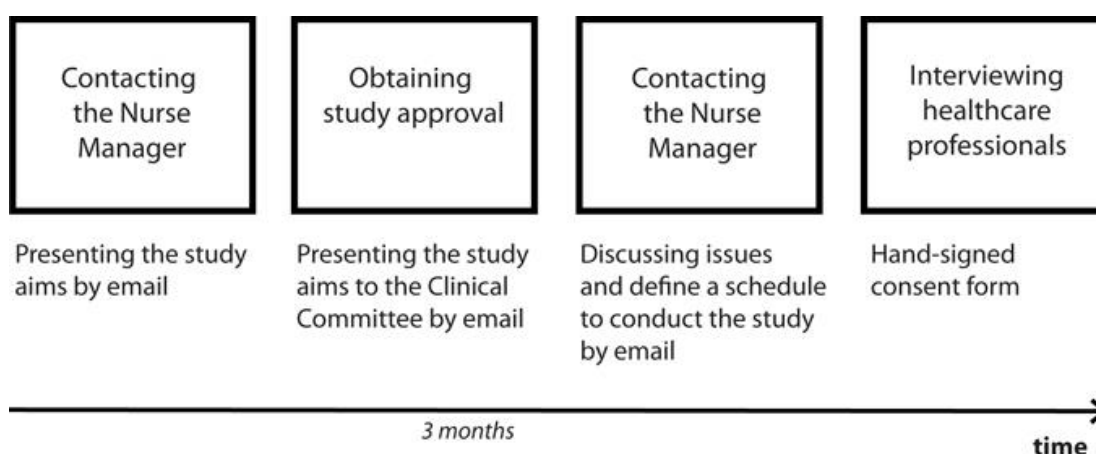
Figure 1: An overview of the invitation process.

B.2 Who participated?

Participants in this study were four healthcare professionals: all clinical practitioners in the rehabilitation centre. These healthcare professionals were a nurse, a speech therapist, an occupational therapist and a dietician, as these individuals are considered to constitute the multidisciplinary team who work with patients at the mealtime within stroke rehabilitation.

Table 1: The healthcare professionals who participated in the interviews.

Healthcare professionals	Specialism	Work experience (in years)	Gender
HP1_PT	Nurse	6	Women
HP2_PT	Speech therapist	6	Women
PH3_PT	Occupational therapist	28	Women
PH4_PT	Dietician	-	Women

The table above illustrates who participated, demonstrating the characteristics of the healthcare professionals in relation to their unique identifier code, specialism, work experience and gender. The following sections will focus on describing how the interviews were conducted.

B.3 Interviews, conversations and observations

Table 2 gives an overview of each interview, conversation and observation to demonstrate each design situation: who was interviewed and who was observed, in which space, and the length of time.

Table 2: Conducting interviews, conversations and observations.

Interviewing	*Observing*	Interviewing	Talking		*Observing*
Nurse	*Patients and Healthcare professionals*	Speech T.	Dietician	Occupational T.	*Cooking /plating up process*
1 hour	*1 hour*	47 minutes	15 minutes	15 minutes	*1 hour*
Room	*Dining room*	Room	Room	Room	*Kitchen*
Rehabilitation centre (Day hospital)					

Before I start to describe how these interviews, conversations and observations were conducted, it is important to explain first how these socialised and materialised situations were created in order to promote valuable dialogues and collect useful information (see Figure 2).

Figure 2: The environmental overview of the interviews/talks with healthcare professionals.

This process started with me individually interviewing the nurse. After I interviewed the nurse, she showed me where patients had their mealtimes, revealing a dining room. This provided the opportunity to explore issues by talking while watching. In each interview/conversation, I began by thanking the healthcare professional for his participation and recapitulating the aims of the study to them in order to clarify any issues. The nurse and the speech therapist dialogues were audio-recorded the others were not. I had conversations rather than interviews with the occupational therapist and dietician, following them in their work practices. I conducted these interviews/conversations following ethical principles, including voluntary participation and providing information about the study and asking them to sign a consent form.

Starting the dialogue with the nurse and the speech therapist, I invited them to talk about their experiences and practices in stroke rehabilitation, following the topic guide (see Appendix E).

B.4 Analysis

Analysing the information involved transcribing all the audio-recorded interviews verbatim, and reading and re-reading the transcripts. These interviews were predetermined by the three main themes: i) the main impacts of stroke, ii) the stroke pathway, and iii) the mealtime for patients in rehabilitation centre. To become familiar with the data, I developed a visual map (see Figure 3), grouping the information in each theme by each individual and also the information collected using a notebook and digital camera.

Figure 3: Mapping the information reported by the healthcare professionals and collected in the notebook and by the digital camera. Here the healthcare professionals' voices were underlined as HP1_PT (orange), HP2_PT (yellow), HP3_PT (rose) and HP4_PT (green) to help identify who the insights come from.

The following section provides, from the analysis of data, a sample of some of the issues identified in discussing the theme about the mealtime, using samples of quotes/statements made by the healthcare professionals.

B.5 The mealtime in rehabilitation centre

The healthcare professionals' views related with the patient's conditions at the mealtime.

> HP2_PT_Speech therapist: *Patients with swallowing difficulties requires texture modified, everything is gradual in rehabilitation, if the patient starts with a purée then goes to soft food and then onto habitual food.*
>
> (Há uma suspeita da alteração da deglutição é pastoso tudo na reabilitação é gradual se iniciou com uma pastosa depois vai-se avançado para a mole e da mole para a geral).
>
> HP1_PT_Nurse: *At mealtimes monitoring is done every day because we stand with them at all their mealtimes. At mealtimes a check is done to see if the patient choked, or make more of an effort to swallow a particular food, if they take a long time to chew, if they put food on their mouth and don't realize they still have food in their*

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mouth. We need to be at their side to alert them. Our aim is to record their meals for our colleagues to access the information and pass it to the dietician.

(O acompanhamento em refeitório é feito diariamente por nós, porque somos nós que estamos com os utentes no refeitório todas as refeições. Na refeição é feita uma vigilância para ver se o doente se engasga, ou se fez mais força para engolir um determinado alimento, se demora mais tempo a mastigar, se mete a comida à boca e não se apercebe que tem lá a comida acumulada. Nós temos que estar ao pé deles [para] chamar à atenção. A nossa preocupação é deixar isso registado na colheita de dados para todos os colegas terem acesso e passar essa informação à dietista para ela ter em atenção).

HP2_PT_Speech therapist: *Initially, it is made an assessment. If the stroke patient has communication difficulties speech therapy is carried out in terms of coordination of breathing to enable speech, joint movements for reading and practice to check if they have the abilities to develop speech. Regarding swallowing, an evaluation is done to check if they have problems and with what type of food whether it is solids or liquids.*

(Sessão inicial é feita a avaliação. Se o utente com AVC tem uma alteração da comunicação é feita uma intervenção ao nível da fala em termos da coordenação da respiração para falar, de movimentos articulatórios, de leitura e prática para ver se tem capacidades para desenvolver a fala. No caso das alterações da deglutição fazemos uma avaliação em que tipo de alimentos è que há alteração, se nos líquidos se nos sólidos).

HP3_PT_Occupational therapist: *In the first week, an assessment is done with the patient to evaluate their abilities. In the second week, an action plan is developed for the patient relearning movements, functions which enable the patient have maximum autonomy.*

(Na primeira semana é feita uma avaliação do doente, quais são as suas capacidades. Na segunda semana vamos planear uma estratégia com o doente para reaprender movimentos, funções para que ele possa obter o máximo de autonomia possivel).

HP4_PT_Dietician: *Trying to understand the cause of food refusal, it is the smell, look; it is trying to respond to the patients' expectations. The doctor and the dietician plan their meals.*

(Perceber a causa da recusa alimentar, é o cheiro, o aspecto, tentar responder às expectativas do doente. O médico e a dietista planeiam as refeições).

The healthcare professionals expressed their views through a diagram that illustrated different types of food involving six scales of textures: a) smooth and pourable: b) smooth

and thin: c) smooth and thick purée: d) moist and some texture: e) soft and moist; and f) solid (see Figure 4).
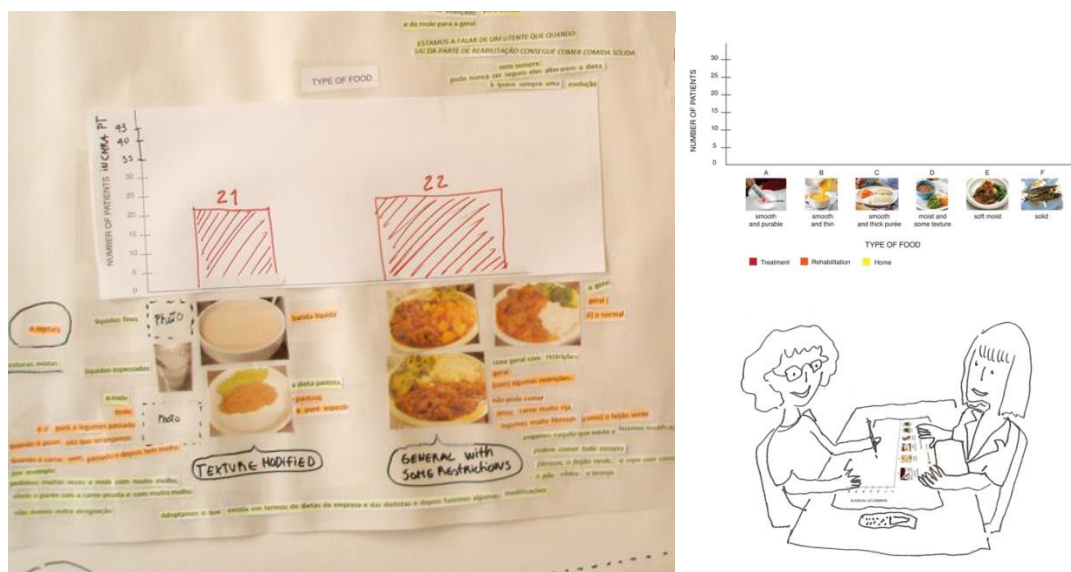
Figure 4: The healthcare professionals' views in the interview focusing on the texture of food for patients affected by stroke.

> HP2_PT_Speech therapist: *The diet changing from habitual to modified (...) the patient isn't used to it, the unpleasant look, the food which is the same as only the colour and smell change. The patient loses their interest to eat.*
>
> (Alteração da dieta geral para uma dieta pastosa ou dieta mole (…) a pessoa (…) não está habituada, o aspecto desagradável é tudo igual só a cor é que muda e o odor (...) a pessoa perde o interesse pela alimentação).

Figure 5: The researcher's observations in the kitchen focusing on the texture-modified food.

Figure 5 illustrates a type of texture-modified food as a meal for patients. Although the researcher was looking at meat and peas, they all have the same grade of texture suited to a particular patient's needs. Observations were performed in the kitchen environment, which identified a cooking and plating up food process, demonstrating that food is cooked on-site following the dietician's recommendations for each individual patient.

The healthcare professionals expressed their views through a diagram that illustrated three different types of tableware: a) standard tableware; b) standard tableware with adaptations; and c) specialised (or specially adapted) tableware (see Figure 6).
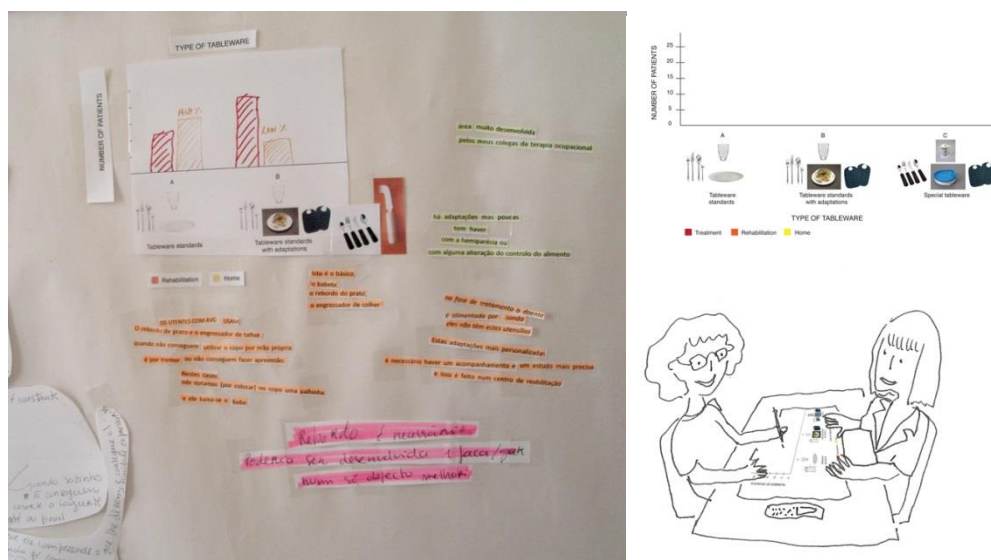
Figure 6: **The healthcare professionals' views in the interview focusing on the tableware**.

> *HP1_PT_Nurse: The bib, the plastic food guard on the plate and thickening of the spoon handle and a straw for the patient who has a tremor.*
>
> (O babete, o rebordo de prato, o engrossador de colher, e a palhinha para o utente que tem tremor).

The healthcare professionals showed their views related with patients eating.

> HP1_PT_Nurse: *They are going to depend on others to alert them that there is food on the other side and turning around the plate.*
>
> (Vão estar dependente de outra pessoa para chamar a atenção que à alimentos daquele lado, ir chamando a atenção para ir rodando o prato).
>
> HP1_PT_Nurse: *Encouraging the patient never to talk while they eat, and not to put more food in while they already have food in their mouth, to be able to chew food well. It is necessary to be near them to explain everything because they need practical stimulus.*
>
> (Incentivar a pessoa a nunca falar enquanto está a comer, a não meter mais comida na boca enquanto tiver alimentos na boca, a conseguir mastigar bem os alimentos. É preciso estar sempre ao pé deles, a explicar-lhes tudo, porque eles precisam de estimulo na prática).
>
> HP2_PT_Speech therapist: *Many of them need assistance, not only to cut food but also to control speed and the quantity of food put [in the mouth]. If they have dysphagia (...) they need to eat using some techniques of head flexion otherwise they will choke, spit or vomit.*

(Muitos deles necessitarem de terceira pessoa, não só, para fraccionarem os alimentos como em controlar a velocidade e a quantidade de alimento que é introduzida [na boca]. No caso de existir a "*dysphagia*" *(...)* tem de ingerir utilizando algumas técnicas, flexão da cabeça, caso contrario vão-se engasgar, cuspir ou vomitar).
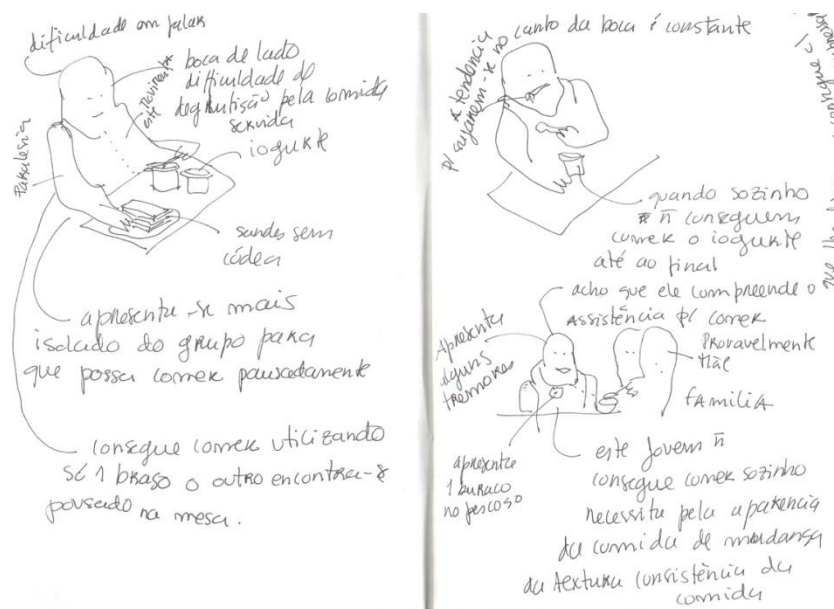
Figure 7: **The researcher's observations while patients were eating.**

Figure 7 illustrates notebook notes and illustrations made in the dining room environment, demonstrating some patients' difficulties to eat and healthcare professionals or family around helping. Moreover, the healthcare professionals also expressed their views about patients at their mealtimes in this way:

> HP2_PT_Speech therapist: *Patients are usually seated at long tables to interact with others which is good as they can see other patients with more or less acute eating problems and it gives a perspective of how they can improve which is important to adapt to living with their difficulties.*
>
> (Utentes geralmente estão distribuídos por mesas muito longas e acabam por socializar entre eles, o que é bom porque vêem outras pessoas com problemas de alimentação que dá uma perspectiva de que podem evoluir ou que há outros como eles e acaba por ser importante habituam-se a viver com essas dificuldades).
>
> HP2_PT_Speech therapist: *For some patients it was important to eat alone in a very peaceful environment to enable them to take control of all strategies such as not speaking and being attentive.*

(Há utentes que era importante comerem sozinhos, num ambiente muito calmo para terem um controlo de todas as estratégias, inclusivamente o de não falar, de não estarem desatentos. Portanto para alguns utentes é necessário um afastamento da confusão).

Appendix C: Ethical approval by the Health Research Authority in the UK

09 August 2012

Ms Sandra Neves

Dear Ms Neves

Study title:	**Using people-centred design methods to co-design a new stroke mealtime experience in rehabilitation**
REC reference:	**12/WM/0265**
IRAS Project reference:	**109686**

The Proportionate Review Sub-committee of the NRES Committee West Midlands - Solihull reviewed the above application on 08 August 2012.

Ethical opinion

Discussion

- The Committee agreed that this is a difficult area to research in that mealtimes can be a very sensitive area for patients who have had a stroke. However, they agreed that it is a very important area.

- The Committee agreed that as Rehabilitation Professionals will be participating in workshops, there is potential to identify malpractice or neglect.

- The Consent Forms state that interviews will be audio recorded, and workshops audio and video recorded. There is a brief mention of this in the Participant Information Sheets. However, this should also be made more explicit and prominent.

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Additional conditions:-

1. There should be a statement in the Participant Information Sheet for Rehabilitation Professionals stating that 'If any malpractice or neglect is identified whilst participating in the research it is professional practice to report this'.

2. The Consent Forms states that interviews will be audio recorded and workshops audio and video recorded. There is a brief mention of this in the Participant Information Sheets that interviews will be audio recorded and workshops audio and video recorded. However, the Committee request that this be made more explicit and prominent.

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Evidence of insurance or indemnity		06 July 2012
Interview Schedules/Topic Guides	Stroke Survivors V1	30 July 2012
Investigator CV	Sandra M P Neves	30 July 2012
Investigator CV	Professor Alastair S Macdonald	

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Letter from Sponsor	31/07/2012	
Other: Workshop Design Overview (Stroke Survivors)	1	30 July 2012
Other: Workshop Design Overview Sheet (Rehabilitation Professionals)	1	30 July 2012
Participant Consent Form: Rehabilitation Professionals (Workshop)	3	01 August 2012
Participant Consent Form: Stroke Survivors (Interview)	3	01 August 2012
Participant Consent Form: Stroke Survivors (Workshop)	3	01 August 2012
Participant Information Sheet: Rehabilitation Professionals	1	30 July 2012
Participant Information Sheet: Stroke Survivors	1	30 July 2012
Protocol	2	30 July 2012
REC application	109686/347342/1/975	30 July 2012

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/WM/0265	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Rex J Polson
Chair

Email: trish.wheat@nottspct.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

                                "After ethical review – guidance for researchers"

Copy to: *Alison Hay, The Glasgow School of Art*

                                Mr Raymond Hamill, R&D Department Corporate Services Building

                                Professor Alastair Macdonald – Academic Supervisor

Attendance at PRS Sub-Committee of the REC meeting on 08 August 2012

Committee Members:

Name	Profession	Present	Notes
Mrs Irene Linder	Assistant Manager, Local Authority - Retired	Yes	
Dr Rex J Polson	Consultant Physician - Chair	Yes	
Dr Timothy Priest	Consultant in Anaesthesia & Pain Management - Vice Chair	Yes	
Ms Gill Tomlinson	Head of Radiology, Solihull Hospital	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mrs Lisa Gregory	Committee Coordinator
Ms Trish Wheat	Committee Coordinator

RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

After ethical review – guidance for sponsors and investigators

This document sets out important guidance for sponsors and investigators on the conduct and management of research with a favourable opinion from a NHS Research Ethics Committee. Please read the guidance carefully. A failure to follow the guidance could lead to the committee reviewing its opinion on the research.

1.   Further communications with the Research Ethics Committee

1.1   Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.

2.   Commencement of the research

2.1   It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

2.2   The research must not commence at any site until the local Principal Investigator (PI) or research collaborator has obtained management permission or approval from the organisation with responsibility for the research participants at the site.

2.3   Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay

2.4   Should the research not commence within 24 months, the Committee may review its opinion.

3.   Duration of ethical approval

3.1   The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.

3.2   Where the research involves the use of "relevant material" for the purposes of the Human Tissue Act 2004, authority to hold the material under the terms of the ethical approval applies until the end of the period declared in the application and approved by the Committee.

4.   Progress reports

4.1   Research Ethics Committees are expected to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2   Progress reports should be in the format prescribed by NRES and published on the website (see www.nres.npsa.nhs.uk/applicants/after-ethical-review/).

4.3   The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

5.   Amendments

5.1   If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

5.2   A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

        (a)   the safety or physical or mental integrity of the trial participants
        (b)   the scientific value of the trial
        (c)   the conduct or management of the trial.

5.3   Notices of amendment should be in the format prescribed by NRES and published on the website, and should be personally signed by the Chief Investigator. The agreement of the sponsor should be sought before submitting the notice of amendment.

5.4   A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

5.5   Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

6.   Changes to sites

        Management permission (all studies)

6.1   For all studies, management permission should be obtained from the host organisation where it is proposed to:

- include a new site in the research, not included in the list of proposed research sites in the original REC application
- appoint a new PI or Local Collaborator at a research site
- make any other significant change to the conduct or management of a research site.

In the case of any new NHS site, the Site-Specific Information (SSI) Form should be submitted to the R&D office for review as part of the R&D application.

Site-specific assessment (where required)

6.2   The following guidance applies only to studies requiring site-specific assessment (SSA) as part of ethical review.

6.3   In the case of *NHS/HSC sites*, SSA responsibilities are undertaken on behalf of the REC by the relevant R&D office as part of the research governance review. The Committee's favourable opinion for the study will apply to any new sites and other changes at sites provided that management permission is obtained. There is no need to notify the Committee (or any other REC) about new sites or other changes, or to provide a copy of the SSI Form.

6.4   Changes at *non-NHS sites* require review by the local REC responsible for site-specific assessment (SSA REC). Please submit the SSI Form (or revised SSI Form as appropriate) to the SSA REC together with relevant supporting documentation. The SSA REC will advise the main REC whether it has any objection to the new site/PI or other change. The main REC will notify the Chief Investigator and sponsor of its opinion within a maximum of 35 days from the date on which a valid SSA application has been received by the SSA REC.

Studies not requiring SSA

6.5   For studies designated by the Committee as not requiring SSA, there is no requirement to notify the Committee of the inclusion of new sites or other changes at sites, either for NHS or non-NHS sites. However, management permission should still be obtained from the responsible host organisation (see 6.1 above).

7.   Urgent safety measures

7.1   The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

7.2   The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

8.   Serious Adverse Events

8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:

    (a)   results in death
    (b)   is life-threatening
    (c)   requires hospitalisation or prolongation of existing hospitalisation
    (d)   results in persistent or significant disability or incapacity
    (e)   consists of a congenital anomaly or birth defect
    (f)   is otherwise considered medically significant by the investigator.

8.2 A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief Investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.

8.3 Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by NRES and published on the website.

8.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.

8.5 Reports should not be sent to other RECs in the case of multi-site studies.

9. <u>Conclusion or early termination of the research</u>

9.1 The Chief Investigator should notify the Committee in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.

9.2 If the research is terminated early, the Chief Investigator should notify the Committee within 15 days of the date of termination. An explanation of the reasons for early termination should be given.

9.3 Reports of conclusion or early termination should be submitted in the form prescribed by NRES and published on the website.

10. <u>Final report</u>

10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.

11. <u>Review of ethical opinion</u>

11.1 The Committee may review its opinion at any time in the light of any relevant information it receives.

SL-AR2 After ethical review - research other than CTIMP
Version 4.0 April 2009

11.2 The Chief Investigator may at any time request that the Committee reviews its opinion, or seek advice from the Committee on any ethical issue relating to the research.

NHS
Lanarkshire

Sandra Neves

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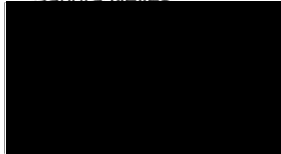
R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date	27 August 2012
Enquiries to	Margaret Stewart
	R&D Facilitator
Direct Line	01236 712445
Email	Margaret.stewart@lanarkshire.scot.nhs.uk

Dear Sandra

PROJECT TITLE: Using people-centred design methods to co-design a new stroke mealtime experience in rehabilitation

R&D ID NUMBER: L12050

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Katrina Brennan	Stroke Managed Clinical Network Manager	Local Collaborator / Principal Investigator	Monklands Hospital

For the study to be carried out you are subject to the conditions outlined overleaf:

Cont/...

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Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.

- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website:

  http://www.show.scot.nhs.uk/cso/ or the Research & Development Intranet site: http://firstport/sites/randd/default.aspx.

- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.

- You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.

- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire.

- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.

- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.

- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

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I trust these conditions are acceptable to you.

Yours sincerely,
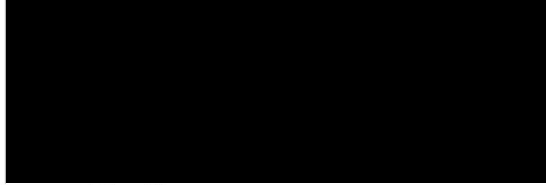
Raymond Hamill
Research & Development Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Katrina Brennan	Stroke Managed Clinical Network Manager	Coathill Hospital	Principal Investigator / Local Collaborator
Dr Alison Hay		The Glasgow School of Art	Sponsor Contact

Appendix D: Ethics application via IRAS

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Using people-centred design methods to co-design a new stroke mealtime

1. Is your project research?

◉ Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

○ Basic science study involving procedures with human participants

○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

◉ Study involving qualitative methods only

○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

○ Study limited to working with data (specific project only)

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?   ○ Yes   ◉ No

b) Will you be taking new human tissue samples (or other human biological samples)?   ○ Yes   ◉ No

c) Will you be using existing human tissue samples (or other human biological samples)? ○ Yes   ◉ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

☐ England
☑ Scotland
☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England
◉ Scotland
○ Wales
○ Northern Ireland
○ This study does not involve the NHS

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4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☑ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

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5. Will any research sites in this study be NHS organisations?

◉ Yes   ○ No

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6. Do you plan to include any participants who are children?

○ Yes   ◉ No

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7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes   ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

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8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes   ◉ No

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9. Is the study or any part of it being undertaken as an educational project?

◉ Yes   ○ No

Please describe briefly the involvement of the student(s):
The student is the chief investigator which will be involved in designing and conducting the research project such as carrying out interviews and workshops.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes   ○ No

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10. Will this research be financially supported by the United States Department of Health and Human Services or any of

its divisions, agencies or programs?

○ Yes   ◉ No

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Integrated Research Application System
Application Form for Research involving qualitative methods only

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NHS
National Patient Safety Agency
National Research Ethics Service

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Using people-centred design methods to co-design a new stroke mealtime

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Please complete these details after you have booked the REC application for review.

REC Name:
West of Scotland REC 5

REC Reference Number: **Submission date:**
12/WS/0193   31/07/2012

PART A: Core study information

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1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Using people-centred design methods to co-design a new stroke mealtime experience in rehabilitation

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A2-1. Educational projects

Name and contact details of student(s):

Student 1

            Title   Forename/Initials   Surname
            Ms   Sandra   Neves
Address   ████████████████████████

Post Code   ████████████████
E-mail   s.neves1@student.gsa.ac.uk
Telephone   01413534442
Fax

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:
Doctor of Philosophy in Design

Name of educational establishment:
The Glasgow School of Art

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Professor	Alastair	Macdonald
Address	The Glasgow School of Art		
	167 Renfrew Street Glasgow		
Post Code	G3 6RQ		
E-mail	a.macdonald@gsa.ac.uk		
Telephone	01413534715		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Ms Sandra Neves	☑ Professor Alastair Macdonald

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

◉ Student
○ Academic supervisor
○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Ms	Sandra	Neves
Post	Student		
Qualifications	Postgraduate degree in Inclusive Design		
	Graduate in Product and Interior Design		
Employer			
Work Address	The Glasgow School of Art		
	167 Renfrew Street Glasgow		
Post Code	G3 6RQ		

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Work E-mail	s.neves1@student.gsa.ac.uk
* Personal E-mail	snevesp@gmail.com
Work Telephone	01413534442
* Personal Telephone/Mobile	07554975212
Fax	

> *This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
> *A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Dr	Alison	Hay
Address	The Glasgow School of Art		
	167 Renfrew Street Glasgow		
Post Code	G3 6RQ		
E-mail	a.hay@gsa.ac.uk		
Telephone	01415661408		
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	SNEVES/MEALTIMES/001
Sponsor's/protocol number:	
Protocol Version:	N/A
Protocol Date:	
Funder's reference number:	Scholarship
Project website:	

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

◯ Yes   ⦿ No

Please give brief details and reference numbers.

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2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Design involvement with healthcare has been influenced by co-design approaches, which considers patients' and professionals' collaborations in the research design process. Stroke impacts on peoples' abilities to eat creating a number of physical, cognitive and psychological difficulties, which require rehabilitation with mealtimes currently structured more on clinical/functionalist models. The aim of this research is to co-design a new mealtime experience with stroke survivors and rehabilitation professionals.

Stage 1
The chief investigator (CI) views stroke survivors' voices as significant to express their lived experiences about their mealtimes in the post-stroke phase. This research aims to interview stroke survivors to collect their retrospective accounts of their mealtime experiences during their stroke rehabilitation in hospital. The semi-structured interviews will be conducted with six stroke survivors face-to-face using a topic guide which will allow their thoughts and feelings to be put into words. This will provide new data and insights into the experiences of stroke survivors through their individual responses. Participants will also be invited to participate in the next stage of this study.

Stage 2
The chief investigator also considers stroke survivors as experts who can bring new ideas based on their past experiences. As this research aims to use co-design approaches through workshop methods both stroke survivors and rehabilitation professionals will be asked to participate in separate workshops. These workshops will bring new knowledge through the sharing of ideas about how the stroke mealtime experience could be improved in the future with less focus on the functional model and more focus on the sensorial and emotional models.

This research believes through the design techniques and tools used in both workshops the chief investigator will collect new insights, which will help in designing a new stroke mealtime experience for future stroke survivors.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

As the purpose of this study is to explore the mealtime experience with stroke survivors and rehabilitation professionals, the main ethical issues to be addressed are around recruitment, informed consent, confidentiality and data protection.

Stroke survivors

Interviews: The stroke manager for NHS Lanarkshire will identify potential participants through the local community stroke survivors support group and introduce the chief investigator to the group/s. The CI will be invited to present the study to the support group members and provide information sheets and criteria for participation (see appendices attached). She will be on hand to answer any questions or queries regarding the study and arrange with the members of the support group a date and time to return to recruit potential participants. Prior to gaining written informed consent the CI will ensure participants meet the study criteria and fully understand the purpose of the study.
Study participants will be interviewed individually at a time and place, which is convenient and suitable for them. Any information which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio-recorded information gathered from participants during the interviews will be destroyed once the project is completed.

Workshop: At the end of the interview participants will be invited to attend a workshop to share their ideas on the co-design of a new mealtime experience. Again they will be informed that their participation is voluntary and they can withdraw at any time. The CI will liaise with potential participants on a date venue and time that will be suitable for the majority. Potential participants will be provided with an overview of the workshop programme and written informed consent gained prior to their participation in the workshop.

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Any information, which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio/video-recorded information gathered from participants during the workshop will be destroyed once the project is completed.

Rehabilitation professionals

Workshop: The stroke manager for NHS Lanarkshire will identify potential rehabilitation therapists who represent the multidisciplinary team involved in stroke care. The stroke manager will organise a meeting with them to meet the Chief Investigator (CI) who will be invited to present her study. The CI will discuss their participation in the study and provide them with information sheets (see appendix attached). The CI will be on hand to answer any questions or queries regarding the study and arrange to contact the therapists several days later to discuss their full participation in the workshop. A date and time will be organised for the workshop where informed consent will be gained. The workshop for rehabilitation professionals will be conducted in a meeting space at The Glasgow School of Art campus in Glasgow. Lunch and transport costs will be provided.

Any information, which is collected about the therapists, or is provided during the study, will be kept strictly confidential. The therapists' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow school of Art. However, any audio/video-recorded information gathered from the therapists during the workshop will be destroyed once the project is completed.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

◉ Yes - proportionate review   ○ No - review by full REC meeting

Further comments (optional):

Following the table as a guide of the PRS SOPs V1 1 - No Material Ethical Issues Tool, the Chief Investigator consideres, IV- Questionnaire research that does NOT include highly sensitive areas or where accidental disclosure would NOT have serious consequences, the category appropriate for proportionate review for this study.

Note: This question only applies to the REC application.

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3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A 10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

(How) could design bring mealtime experience improvements for stroke rehabilitation patients?

A 11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Could people-centred design methods help in identifying opportunities for improving the mealtime experience?

At which point in the stroke mealtime model would design interventions benefit patient non-functional needs?

What kind of design interventions could best address sensorial and emotional aspects missing from the stroke mealtime model?

A 12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

This research aims to explore the current thinking in design literature about patients and professionals collaboration in the research design process help to bring healthcare improvements(Cottam and Leadbeater 2004; Bate and Robert 2007).

A 13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This study is an explorative qualitative study using both semi-structured interviews and workshop methods with the aim of co-designing a new mealtime experience for stroke survivors. A qualitative methodology is appropriate as the focus of the study is to gather the experiences both past and present of stroke survivors and rehabilitation professionals involved in their care. This study has three linked phases:

i)Phase 1 (which has been completed) was a review of stroke and stroke rehabilitation literature and a pilot observation of the rehabilitation practices in stroke mealtimes. The main findings from the literature review and the observations identified that there is an overall lack of studies exploring the mealtime experience with the focus primarily on the functional aspects of eating. These findings influenced the design and development of phase two of the study.
ii)Phase 2 (which has been completed) was a review of mealtime experience (non-stroke) literature and a pilot observation of restaurants' practices in customer mealtimes. The main findings from this phase identified the mealtime experience as an emotional and sensorial experience. These findings influenced the design and development of phase three of the study.
iii)Phase 3 (which is in progress) involves a review of design methods literature and the co-designing of a new mealtime experience with stroke survivors and rehabilitation professionals. This phase will include two stages. Stage 1 will adopt one semi-structured interview with a minimum of six stroke survivors and stage 2 will adopt two workshops one with a group of six stroke survivors and one with a group of four rehabilitation professionals involved in stroke care.

Stage 1 - Interviews
Aim is to explore the mealtime experience with stroke survivors.

Sample – a convenience sample of at least six stroke survivors recruited from a local support group who meet the following criteria (see appendix attach).

Method – a face-to-face semi-structured interview will be conducted using a topic guide, which will allow their thoughts and feelings to be put into words. The topic guide will be designed and developed from the findings of my literature reviews. All interviews will be digital recorded and transcribed per verbatim.

Analysis – a framework analysis of the data will allow for the transparent and rigorous data management using a thematic framework (Green and Thorogood, 2004). This will provide mapping and interpreting new insights into the mealtime experience of stroke survivors through their individual accounts.

Stage 2 - Workshops
Aim is to map ideas to redesign a new mealtime experience with stroke survivors and rehabilitation professionals.

Sample – a group of six stroke survivors recruited from a local support group and a group of four rehabilitation professionals involved in stroke care.

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Method – two separate semi-structured activities will be conducted using design techniques and tools, which will allow stroke survivors and rehabilitation professionals' ideas to be translated into visual maps. The design techniques and tools will be designed and developed from the findings of the literature review.   Both workshops will be audio/video-recorded and transcribed per verbatim.

Analysis – a framework analysis of the data will allow for the transparent and rigorous data management using a thematic framework (Green and Thorogood, 2004). This will provide mapping and interpreting of new insights into the improvement of the mealtime experience of stroke survivors and rehabilitation professional through their ideas.

A 14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☐ Design of the research
- ☐ Management of the research
- ☑ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
This study is to involve the Chief investigator and the study participants, which the CI around recruitment, informed consent, confidentiality and data protection and the study participants in learning and sharing knowledge and experiences of the mealtimes.

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4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A 17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

This study considers two lists of inclusion criteria one for stroke survivors and one for rehabilitation professionals.

Stroke survivors

. Clinical diagnosis of stroke
. Post-acute stroke rehabilitation in hospital
. Of either gender
. Age ≥ 25 years
. Have English first language
. Had swallowing difficulty and care assistance during mealtimes in acute rehabilitation.
. Able to understand and follow simple instructions
. Able to give informed consent when assisted to do so with suitable communication aids if required.

Rehabilitation professionals

. Clinical rehabilitation professionals
. Have English first language
. Have involved with stroke rehabilitation care at mealtimes
. Able to give informed consent
. Have represented a specific role at mealtimes
. A nurse
. A speech therapist
. An occupational therapist
. A dietitian

A 17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Exclusion criteria

Stroke survivors

. Severe visual or cognitive problems precluding participation study
. Involved in another research study

Rehabilitation professionals

. Involved in another research study

RESEARCH PROCEDURES, RISKS AND BENEFITS

A 18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.

2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

3. Average time taken per intervention/procedure (minutes, hours or days)

4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Stroke survivors Interviews	4	-	9h	i) The stroke manager for NHS Lanarkshire will identify potential participants through the local community stroke survivors support group and introduce the chief investigator to the group/s. (1h) ii) The CI will be invited to present the study to the support group members and provide information sheets and criteria for participation (see appendices attached). She will be on hand to answer any questions or queries regarding the study and arrange with the members of the support group a date and time to return to recruit potential participants. (1h) iii) Prior to gaining written informed consent the CI will ensure participants meet the study criteria and fully understand the purpose of the study. (1h) iv) Study participants will be interviewed individually at a time and place, which is convenient and suitable for them. Each interview will allow participants individually share with the CI their retrospective accounts of their mealtime experience during their stroke rehabilitation in hospital. (1h each (x6))
Stroke survivors Workshop	3	-	9h	i) At the end of the interview participants will be invited to attend a workshop to share their ideas on the co-design of a new mealtime experience. Again they will be informed that their participation is voluntary and they can withdraw at any time. (30 minutes each (x6)) ii)The CI will liaise with potential participants on a date venue and time that will be suitable for the majority. Potential participants will be provided with an overview of the workshop programme and written informed consent gained prior to their participation in the workshop. (2h) iii) A group of study participants will be participating in a workshop at a time and place, which is convenient and suitable for them. The workshop will allow which participants share with the CI and other similar participants their ideas about how the stroke mealtime experience could be improved in the future. (3h)
Rehabilitation professionals Workshop	4	-	6h	i) The stroke manager for NHS Lanarkshire will identify potential rehabilitation therapists who represent the multidisciplinary team involved in stroke care. (1h) ii) The stroke manager will organise a meeting with them to meet the Chief Investigator who will be invited to present her study. The CI will discuss their participation in the study and provide them with information sheets (see appendix attached). The CI will be on hand to answer any questions or queries regarding the study. (1h) iii) The CI will contact the therapists several days later to arrange a date venue and time that will be suitable for them. Therapists will be provided with an overview of the workshop programme and written informed consent gained prior to their participation

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in the workshop. (1h)
iv) A multidisciplinary group of therapists will be participating in a workshop at a time, which is suitable for them and a designated space at The Glasgow School of Art campus in Glasgow. The workshop will allow which the therapists share with the CI and other therapists their ideas about how the stroke mealtime could be improved in the future. (3h)

A21. How long do you expect each participant to be in the study in total?

Stroke survivors: participants and the chief investigator will meet twice, once for an interview and once for a workshop. The interview will last between thirty minutes and one hour depending on how much participants have to say. The interview will take place towards the end of their meeting group to discuss their experiences at the mealtimes during their rehabilitation in hospital. The workshop will take place over 3 hours to discuss and share participants' ideas with the CI and other similar participants of how we could bring improvements to the mealtime experience in rehabilitation. The interviews and workshop will be arranged at a time and date that suits participants within the support group site. The CI will secure a space where participants feel comfortable to participate in both interview and workshop.

Rehabilitation professionals: participants and the chief investigator will meet once for a workshop. The workshop will be during 3 hours to discuss and share ideas with the CI and other rehabilitation professionals to improve the mealtime in rehabilitation. The workshop will take place at The Glasgow School of Art campus in Glasgow. The workshop will be arranged at a time and date that suits the participants.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

It is unlikely that study participants will come to any harm as a result of taking part in the study, and no special arrangements have been put place for compensation. If study participants have any concerns about the way they are approached or treated during the course of the study, they can contact the academic supervisor or alternatively they can contact the normal National Health Service complaints mechanisms which will be available to them.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

○ Yes ● No

A24. What is the potential for benefit to research participants?

The chief investigator cannot promise that taking part in this study will be of direct benefit to the participants but by telling the CI their experiences and ideas they will help to give to this study in design a great understanding of what are the experiences and ideas of stroke survivors and rehabilitation professionals which might help to contribute in improving the mealtimes for other people in rehabilitation in the future. However, the CI aims to enable social interaction between study participants through the participatory research process, and an opportunity to share experiences as an informed, workshop based environment.

A26. What are the potential risks for the researchers themselves? *(if any)*

It is unlikely that the chief investigator will come to any harm as a result of conducting this study. However, the CI will follow some security procedures such as prior informing the stroke manager and academic supervisor about the location, date and time of the study. On the day, the CI will phone call and/or text her academic supervisor to inform him that she is able to safely conduct the study which will start and involve x hours. When the study will finish she will also phone call and/or text her academic supervisor to inform him that she is well and safe.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for

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different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Stroke survivors

The stroke manager for NHS Lanarkshire will identify potential participants through the local community stroke survivors support group and introduce the chief investigator to the group/s. The CI will be invited to present the study to the support group members and provide information sheets and criteria for participation (see appendices attached).

Rehabilitation professionals

The stroke manager for NHS Lanarkshire will also identify potential rehabilitation therapists who represent the multidisciplinary team involved in stroke care. The stroke manager will organise a meeting with them to meet the chief investigator who will be invited to present her study, provide information sheets and criteria for participation (see appendices attached).

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes   ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes   ◉ No

A29. How and by whom will potential participants first be approached?

All participants will be firstly approached by the stroke manager for NHS Lanarkshire.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes   ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

This study aims to require consent for participation both interviews and workshop(s). The chief investigator will speak with potential participants about the study, check if they are willing to take part of the study and if they agree the CI will then ask them to sign a standard consent form and study participants will be given a copy of this to keep (see appendix attached).

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes   ○ No

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A31. How long will you allow potential participants to decide whether or not to take part?

The nurse specialist NHS Lanarkshire will give stroke survivors the study information sheet on the chief investigator behalf and stroke survivors will inform her/him if they permit them to pass on their contact details to me. If stroke survivors have given permission the CI will contact them over the next three to four days to give stroke survivors time to consider whether they wish to take part in the study. When the CI contacts stroke survivors, she will discuss the study with them and answer any questions they may have. If they are considering taking part in the study the CI will arrange to meet them at their next support group meeting. At that meeting the CI will speak with stroke survivors about the study again and check that they are still willing to take part, if they agree the CI will then ask them to sign a standard consent form and study participants will be given a copy of this to keep.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

This study will provide different ways of presenting information using verbal, written and visual such as diagrams and illustrations to facilitate communication.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

◉ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team

☐ Electronic transfer by magnetic or optical media, email or computer networks

☐ Sharing of personal data with other organisations

☐ Export of personal data outside the EEA

☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers

☑ Publication of direct quotations from respondents

☐ Publication of data that might allow identification of individuals

☑ Use of audio/visual recording devices

☑ Storage of personal data on any of the following:

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☐ Manual files including X−rays
☐ NHS computers
☐ Home or other personal computers
☐ University computers
☐ Private company computers
☑ Laptop computers

Further details:

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Any information on this study will be kept confidential and anonymous.

Stroke survivor interviews: Any information, which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio-recorded information gathered from participants during the interviews will be destroyed once the project is completed.

Stroke survivor workshop: Any information, which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio/video-recorded information gathered from participants during the workshop will be destroyed once the project is completed.

Rehabilitation professional workshop: Any information, which is collected about the therapists, or is provided during the study, will be kept strictly confidential. The therapists' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio/video-recorded information gathered from the therapists during the workshop will be destroyed once the project is completed.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Any participants' personal data information will be managed by the chief investigator. However, this study will require a transcriber to transcribe audio-data. The transcriber will have access to the interview recording once the interview has taken place but as that recording will not contain anything personal or any identifiable marks that could trace this to a particular stroke survivor, there is no issue on confidentiality.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

○ Less than 3 months
○ 3 – 6 months
○ 6 – 12 months
○ 12 months – 3 years
◉ Over 3 years

If longer than 12 months, please justify:
When the results of the study have been analysed, a PhD thesis will be prepared to present at The Glasgow School of Art and also reports will be prepared for publication in journals and presentation at conferences. Any study participants' personal information will be anonymised.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes   ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
The workshop for rehabilitation professionals will be conducted in a meeting space at The Glasgow School of Art campus. Lunch and transport cost will be provided.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes   ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes   ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes   ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes   ◉ No

Please give details, or justify if not registering the research.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals
☐ Internal report
☑ Conference presentation
☑ Publication on website
☐ Other publication
☐ Submission to regulatory authorities

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☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☐ Other (please specify)

Thesis

A53. Will you inform participants of the results?

◉ Yes   ○ No

Please give details of how you will inform participants or justify if not doing so.
When the results of the study have been analysed, a summary of the results of the study will also be available for the participants if they wish. The chief investigartor will discuss this individually with each participant at the final of the study.

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5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review

☐ Review within a company

☐ Review within a multi-centre research group

☑ Review within the Chief Investigator's institution or host organisation

☐ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
This study has followed two stages of ethics review procedures.

Stage 1
A Preliminary Ethical Assessment Form at The Glasgow School of Art was completed with an overview of the study attached and reviewed by internal Ethics co-ordinator. Through the review some issues emerged such as the collaborator and rehabilitation professionals referred on the study are in the employ of NHS organizations. Advice by the Scottish Research Ethics Service was requested to clarify if the study involve to follow NHS Ethics review process.

Stage 2
This study will be an approval via IRAS, local NHS Research & Development Office, The Glasgow School of Art Ethics co-ordinator's and academic supervisor's reviews.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 10
Total international sample size (including UK): 10
Total in European Economic Area: 10

Further details:
The sample selected to this study reflects particular features, or specific groups within, the population under study. The sample selected is not intended, non-required to be statistically representative. The basis of selection is on the key characteristic of the specific population being studied (Ritchie and Lewis 2006). To achieve the aim, the chief

investigator needs to collect information-rich accounts from both stroke survivors and rehabilitation professionals. This study selects the sample, which will best answer the research questions.

Stroke survivors
The chief investigator decided on a sample size, a minimum of six adults was deemed large enough to capture the types of sources of information, which the study need, which are their experiences and ideas. The sample will be from a range of experiences across a number of eating difficulties associated with impacts of stroke.
Interviews will gather six participant's 'stories' accounts.
A workshop will collect a map of participant's ideas.

Rehabilitation professionals
The chief investigator decided on a sample size of four professionals who represent a multidisciplinary team involved with stroke care - a nurse, a speech therapist, an occupational therapist and a dietitian - was deemed large enough to capture the types of sources of information which the study need which are their ideas. The sample will be from a range of expertise involved to plan the mealtime in rehabilitation.
A workshop will collect a map of participants' ideas.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

As the purpose of this study is to give voice to participants and represent their experiences and ideas, the chief investigator indicates the sample selected to this study reflects the population under study.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

This study is not intended, nor requires to be statistically representative. The methods of analysis will be appropriate for qualitative research by which the data will be analysis through a framework analysis which provides a step-by-step guide to assist the chief investigator to manager, conceptualise and describe the data (Green and Thorogood, 2004). The study aims to bring a descriptive proposal for a co-designed new mealtime experience.

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6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname
	Mrs Katrina Brennan
Post	Stroke Managed Clinical Network Manager
Qualifications	RGN
Employer	NHS Lanarkshire
Work Address	GrenLyon Building, Coathill Hospital, Coatbridge
Post Code	ML5 4DN
Telephone	01236707724
Fax	
Mobile	07909111642
Work Email	katrina.Brennan@lanarkshire.scot.nhs.uk

A64. Details of research sponsor(s)

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A64-1. Sponsor

Lead Sponsor

Status: ○ NHS or HSC care organisation   Commercial status:
         ● Academic
         ○ Pharmaceutical industry
         ○ Medical device industry
         ○ Local Authority
         ○ Other social care provider (including voluntary sector or private organisation)
         ○ Other

         If Other, please specify:

Contact person

Name of organisation The Glasgow School of Art
Given name   Alison
Family name   Hay
Address   167 Renfrew Street
Town/city   Glasgow
Post code   G3 6RQ
Country   UNITED KINGDOM
Telephone   0141 566 1408
Fax
E-mail   a.hay@gsa.ac.uk

Is the sponsor based outside the UK?
○ Yes   ● No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

○ Standalone project
○ Project that is part of a programme grant
○ Project that is part of a Centre grant
● Project that is part of a fellowship/ personal award/ research training award
○ Other
Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another

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country?

○ Yes   ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Mr Raymond Hamill
Organisation	R&D Department Corporate Services Building
Address	Monkscourt Avenue Airdrie

Post Code	ML6 0JS
Work Email	raymond.hamill@lanarkshire.scot.nhs.uk
Telephone	01236712460
Fax	
Mobile	07779161388

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

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A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2012
Planned end date: 01/12/2012
Total duration:
Years: 0 Months: 3 Days: 0

A71-2. Where will the research take place? *(Tick as appropriate)*

☐ England
☑ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?
○ Yes   ○ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☐ NHS organisations in England
☐ NHS organisations in Wales
☑ NHS organisations in Scotland   1
☐ HSC organisations in Northern Ireland

☐ GP practices in England
☐ GP practices in Wales
☐ GP practices in Scotland
☐ GP practices in Northern Ireland
☐ Social care organisations
☐ Phase 1 trial units
☐ Prison establishments
☐ Probation areas
☐ Independent hospitals
☑ Educational establishments   1
☐ Independent research units
☐ Other (give details)

Total UK sites in study: 2

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

The Glasgow School of Art possess indemnity cover with company to be determined to the value of £2,000,000 for the management of the research.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☑ Other insurance or indemnity arrangements will apply (give details below)

The Glasgow School of Art possess indemnity cover with company to be determined to the value of £2,000,000 for the design of the research.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

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Note: *Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

The Glasgow School of Art possess indemnity cover with company to be determined to the value of £2,000,000 for the conduct of the research.

Please enclose a copy of relevant documents.

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PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	NHS Lanarkshire	Title	Mrs
Department name	Stroke MCN	First name/ Initials	Katrina
Street address	Coathill Hospital, Hospital Street		
Town/city	Coatbridge	Surname	Brennan
Post Code	ML5 4DN		
Institution name	The Glasgow School of Art	Title	Ms
Department name	Design	First name/ Initials	Sandra
Street address	167 Renfrew Street		
Town/city	Glasgow	Surname	Neves
Post Code	G3 6RQ		

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PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication(Not applicable for R&D Forms)

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

◉ Chief Investigator
◯ Sponsor

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◯ Study co-ordinator
◯ Student
◯ Other – please give details
◯ None

Access to application for training purposes (Not applicable for R&D Forms)
Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: ███████████████

Print Name: Sandra Neves

Date: 30/07/2012   (dd/mm/yyyy)

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D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature:

Print Name: Dr Ken Neil

Post: Acting Head of Research & Graduate School

Organisation: The Glasgow School of Art

Date: 30/07/2012   *(dd/mm/yyyy)*

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D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1	
Signature:	
Print Name:	Professor Alastair Macdonald
Post:	Senior Researcher School of Design
Organisation:	The Glasgow School of Art
Date:	30/07/2012 (dd/mm/yyyy)

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Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
              -centred design methods to co-design a new stroke mealtime

1. Is your project research?

◉ Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

○ Basic science study involving procedures with human participants

○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

◉ Study involving qualitative methods only

○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

○ Study limited to working with data (specific project only)

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?   ○ Yes ◉ No
b) Will you be taking new human tissue samples (or other human biological samples)?   ○ Yes ◉ No
c) Will you be using existing human tissue samples (or other human biological samples)? ○ Yes ◉ No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☐ England
☑ Scotland
☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

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○ England

◉ Scotland

○ Wales

○ Northern Ireland

○ This study does not involve the NHS

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4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☑ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

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5. Will any research sites in this study be NHS organisations?

◉ Yes   ○ No

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6. Do you plan to include any participants who are children?

○ Yes   ◉ No

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7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes   ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

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8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes   ◉ No

---

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes   ○ No

Please describe briefly the involvement of the student(s):
The student is the chief investigator which will be involved in designing and conducting the research project such as carrying out interviews and workshops.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes   ○ No

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10. Will this research be financially supported by the United States Department of Health and Human Services or any of

its divisions, agencies or programs?

○ Yes   ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

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| **NHS/HSC R&D Form (project information)** |

Please refer to the Submission and Checklist tabs for instructions on submitting R&D applications.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Using people-centred design methods to co-design a new stroke mealtime

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| **PART A: Core study information** |

| **1. ADMINISTRATIVE DETAILS** |

A1. Full title of the research:

Using people-centred design methods to co-design a new stroke mealtime experience in rehabilitation

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A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Ms	Sandra	Neves
Address			

Post Code	G41 3PZ
E-mail	s.neves1@student.gsa.ac.uk
Telephone	01413534442
Fax	

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctor of Philosophy in Design

Name of educational establishment:
The Glasgow School of Art

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Professor	Alastair	Macdonald
Address	The Glasgow School of Art		
	167 Renfrew Street Glasgow		
Post Code	G3 6RQ		
E-mail	a.macdonald@gsa.ac.uk		
Telephone	01413534715		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Ms Sandra Neves	☑ Professor Alastair Macdonald

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

◉ Student

◯ Academic supervisor

◯ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Ms	Sandra	Neves
Post	Student		
Qualifications	Postgraduate degree in Inclusive Design		
	Graduate in Product and Interior Design		
Employer			
Work Address	The Glasgow School of Art		
	167 Renfrew Street Glasgow		
Post Code	G3 6RQ		
Work E-mail	s.neves1@student.gsa.ac.uk		
* Personal E-mail	snevesp@gmail.com		
Work Telephone	01413534442		
* Personal Telephone/Mobile	07554975212		
Fax			

* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

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<table>
<tr><td rowspan="4">Address</td><td>Title Forename/Initials Surname</td></tr>
<tr><td>Dr   Alison   Hay</td></tr>
<tr><td>The Glasgow School of Art</td></tr>
<tr><td>167 Renfrew Street Glasgow</td></tr>
</table>

Post Code	G3 6RQ
E-mail	a.hay@gsa.ac.uk
Telephone	01415661408
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	SNEVES/MEALTIMES/001
Sponsor's/protocol number:	
Protocol Version:	N/A
Protocol Date:	
Funder's reference number:	Scholarship
Project website:	

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

◯ Yes   ⦿ No

Please give brief details and reference numbers.

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2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Design involvement with healthcare has been influenced by co-design approaches, which considers patients' and professionals' collaborations in the research design process. Stroke impacts on peoples' abilities to eat creating a number of physical, cognitive and psychological difficulties, which require rehabilitation with mealtimes currently structured more on clinical/functionalist models. The aim of this research is to co-design a new mealtime experience with stroke survivors and rehabilitation professionals.

Stage 1
The chief investigator (CI) views stroke survivors' voices as significant to express their lived experiences about their mealtimes in the post-stroke phase. This research aims to interview stroke survivors to collect their retrospective

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accounts of their mealtime experiences during their stroke rehabilitation in hospital. The semi-structured interviews will be conducted with six stroke survivors face-to-face using a topic guide which will allow their thoughts and feelings to be put into words. This will provide new data and insights into the experiences of stroke survivors through their individual responses. Participants will also be invited to participate in the next stage of this study.

Stage 2
The chief investigator also considers stroke survivors as experts who can bring new ideas based on their past experiences. As this research aims to use co-design approaches through workshop methods both stroke survivors and rehabilitation professionals will be asked to participate in separate workshops. These workshops will bring new knowledge through the sharing of ideas about how the stroke mealtime experience could be improved in the future with less focus on the functional model and more focus on the sensorial and emotional models.

This research believes through the design techniques and tools used in both workshops the chief investigator will collect new insights, which will help in designing a new stroke mealtime experience for future stroke survivors.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

As the purpose of this study is to explore the mealtime experience with stroke survivors and rehabilitation professionals, the main ethical issues to be addressed are around recruitment, informed consent, confidentiality and data protection.

Stroke survivors

Interviews: The stroke manager for NHS Lanarkshire will identify potential participants through the local community stroke survivors support group and introduce the chief investigator to the group/s. The CI will be invited to present the study to the support group members and provide information sheets and criteria for participation (see appendices attached). She will be on hand to answer any questions or queries regarding the study and arrange with the members of the support group a date and time to return to recruit potential participants. Prior to gaining written informed consent the CI will ensure participants meet the study criteria and fully understand the purpose of the study.
Study participants will be interviewed individually at a time and place, which is convenient and suitable for them.
Any information which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio-recorded information gathered from participants during the interviews will be destroyed once the project is completed.

Workshop: At the end of the interview participants will be invited to attend a workshop to share their ideas on the co-design of a new mealtime experience. Again they will be informed that their participation is voluntary and they can withdraw at any time. The CI will liaise with potential participants on a date venue and time that will be suitable for the majority. Potential participants will be provided with an overview of the workshop programme and written informed consent gained prior to their participation in the workshop.
Any information, which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio/video-recorded information gathered from participants during the workshop will be destroyed once the project is completed.

Rehabilitation professionals

Workshop: The stroke manager for NHS Lanarkshire will identify potential rehabilitation therapists who represent the multidisciplinary team involved in stroke care. The stroke manager will organise a meeting with them to meet the Chief Investigator (CI) who will be invited to present her study. The CI will discuss their participation in the study and provide them with information sheets (see appendix attached). The CI will be on hand to answer any questions or queries regarding the study and arrange to contact the therapists several days later to discuss their full participation in the workshop. A date and time will be organised for the workshop where informed consent will be gained. The workshop for rehabilitation professionals will be conducted in a meeting space at The Glasgow School of Art campus in

Glasgow. Lunch and transport costs will be provided.
Any information, which is collected about the therapists, or is provided during the study, will be kept strictly confidential. The therapists' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow school of Art. However, any audio/video-recorded information gathered from the therapists during the workshop will be destroyed once the project is completed.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

☐ Case series/ case note review
☐ Case control
☐ Cohort observation
☐ Controlled trial without randomisation
☐ Cross-sectional study
☐ Database analysis
☐ Epidemiology
☐ Feasibility/ pilot study
☐ Laboratory study
☐ Metanalysis
☑ Qualitative research
☐ Questionnaire, interview or observation study
☐ Randomised controlled trial
☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

(How) could design bring mealtime experience improvements for stroke rehabilitation patients?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Could people-centred design methods help in identifying opportunities for improving the mealtime experience?

At which point in the stroke mealtime model would design interventions benefit patient non-functional needs?

What kind of design interventions could best address sensorial and emotional aspects missing from the stroke mealtime model?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

This research aims to explore the current thinking in design literature about patients and professionals collaboration in the research design process help to bring healthcare improvements(Cottam and Leadbeater 2004; Bate and Robert 2007).

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This study is an explorative qualitative study using both semi-structured interviews and workshop methods with the aim of co-designing a new mealtime experience for stroke survivors. A qualitative methodology is appropriate as the focus of the study is to gather the experiences both past and present of stroke survivors and rehabilitation professionals involved in their care. This study has three linked phases:

i)Phase 1 (which has been completed) was a review of stroke and stroke rehabilitation literature and a pilot observation of the rehabilitation practices in stroke mealtimes. The main findings from the literature review and the observations identified that there is an overall lack of studies exploring the mealtime experience with the focus primarily on the functional aspects of eating. These findings influenced the design and development of phase two of the study.
ii)Phase 2 (which has been completed) was a review of mealtime experience (non-stroke) literature and a pilot observation of restaurants' practices in customer mealtimes. The main findings from this phase identified the mealtime experience as an emotional and sensorial experience. These findings influenced the design and development of phase three of the study.
iii)Phase 3 (which is in progress) involves a review of design methods literature and the co-designing of a new mealtime experience with stroke survivors and rehabilitation professionals. This phase will include two stages. Stage 1 will adopt one semi-structured interview with a minimum of six stroke survivors and stage 2 will adopt two workshops one with a group of six stroke survivors and one with a group of four rehabilitation professionals involved in stroke care.

Stage 1 - Interviews
Aim is to explore the mealtime experience with stroke survivors.

Sample – a convenience sample of at least six stroke survivors recruited from a local support group who meet the following criteria (see appendix attach).

Method – a face-to-face semi-structured interview will be conducted using a topic guide, which will allow their thoughts and feelings to be put into words. The topic guide will be designed and developed from the findings of my literature reviews. All interviews will be digital recorded and transcribed per verbatim.

Analysis – a framework analysis of the data will allow for the transparent and rigorous data management using a thematic framework (Green and Thorogood, 2004). This will provide mapping and interpreting new insights into the mealtime experience of stroke survivors through their individual accounts.

Stage 2 - Workshops
Aim is to map ideas to redesign a new mealtime experience with stroke survivors and rehabilitation professionals.

Sample – a group of six stroke survivors recruited from a local support group and a group of four rehabilitation professionals involved in stroke care.

Method – two separate semi-structured activities will be conducted using design techniques and tools, which will allow stroke survivors and rehabilitation professionals' ideas to be translated into visual maps. The design techniques and tools will be designed and developed from the findings of the literature review.   Both workshops will be audio/video-recorded and transcribed per verbatim.

Analysis – a framework analysis of the data will allow for the transparent and rigorous data management using a thematic framework (Green and Thorogood, 2004). This will provide mapping and interpreting of new insights into the improvement of the mealtime experience of stroke survivors and rehabilitation professional through their ideas.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☐ Design of the research

☐ Management of the research

☑ Undertaking the research

☐ Analysis of results

☐ Dissemination of findings

☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
This study is to involve the Chief investigator and the study participants, which the CI around recruitment, informed consent, confidentiality and data protection and the study participants in learning and sharing knowledge and experiences of the mealtimes.

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4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

☐ Blood
☐ Cancer
☐ Cardiovascular
☐ Congenital Disorders
☐ Dementias and Neurodegenerative Diseases
☐ Diabetes
☐ Ear
☐ Eye
☐ Generic Health Relevance
☐ Infection
☐ Inflammatory and Immune System
☐ Injuries and Accidents
☐ Mental Health
☐ Metabolic and Endocrine
☐ Musculoskeletal
☐ Neurological
☐ Oral and Gastrointestinal
☐ Paediatrics
☐ Renal and Urogenital
☐ Reproductive Health and Childbirth
☐ Respiratory
☐ Skin
☑ Stroke

Gender: Male and female participants

Lower age limit: 25   Years

Upper age limit: 70   Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

This study considers two lists of inclusion criteria one for stroke survivors and one for rehabilitation professionals.

Stroke survivors

. Clinical diagnosis of stroke
. Post-acute stroke rehabilitation in hospital
. Of either gender
. Age ≥25 years
. Have English first language
. Had swallowing difficulty and care assistance during mealtimes in acute rehabilitation.
. Able to understand and follow simple instructions
. Able to give informed consent when assisted to do so with suitable communication aids if required.

Rehabilitation professionals

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. Clinical rehabilitation professionals
. Have English first language
. Have involved with stroke rehabilitation care at mealtimes
. Able to give informed consent
. Have represented a specific role at mealtimes
. A nurse
. A speech therapist
. An occupational therapist
. A dietitian

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Exclusion criteria

Stroke survivors

. Severe visual or cognitive problems precluding participation study
. Involved in another research study

Rehabilitation professionals

. Involved in another research study

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

    1. Total number of interventions/procedures to be received by each participant as part of the research protocol.

    2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

    3. Average time taken per intervention/procedure (minutes, hours or days)

    4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Stroke survivors Interviews	4	-	9h	i) The stroke manager for NHS Lanarkshire will identify potential participants through the local community stroke survivors support group and introduce the chief investigator to the group/s. (1h) ii) The CI will be invited to present the study to the support group members and provide information sheets and criteria for participation (see appendices attached). She will be on hand to answer any questions or queries regarding the study and arrange with the members of the support group a date and time to return to recruit potential participants. (1h) iii) Prior to gaining written informed consent the CI will ensure participants meet the study criteria and fully understand the purpose of the study. (1h) iv) Study participants will be interviewed individually at a time and place, which is convenient and suitable for them. Each interview will allow participants individually share with the CI their retrospective accounts of their mealtime experience during their stroke rehabilitation in hospital. (1h each (x6))
Stroke survivors Workshop	3	-	9h	i) At the end of the interview participants will be invited to attend a workshop to share their ideas on the co-design of a new mealtime experience. Again they will be informed that their participation is voluntary and they can withdraw at any time. (30 minutes each (x6)) ii)The CI will liaise with potential participants on a date venue and time that will be suitable for the majority. Potential participants will be provided with an overview of the workshop programme and written informed consent gained prior to their participation in the workshop. (2h)

iii) A group of study participants will be participating in a workshop at a time and place, which is convenient and suitable for them. The workshop will allow which participants share with the CI and other similar participants their ideas about how the stroke mealtime experience could be improved in the future. (3h)

Rehabilitation professionals Workshop	4 - 6h	i) The stroke manager for NHS Lanarkshire will identify potential rehabilitation therapists who represent the multidisciplinary team involved in stroke care. (1h) ii) The stroke manager will organise a meeting with them to meet the Chief Investigator who will be invited to present her study. The CI will discuss their participation in the study and provide them with information sheets (see appendix attached). The CI will be on hand to answer any questions or queries regarding the study. (1h) iii) The CI will contact the therapists several days later to arrange a date venue and time that will be suitable for them. Therapists will be provided with an overview of the workshop programme and written informed consent gained prior to their participation in the workshop. (1h) iv) A multidisciplinary group of therapists will be participating in a workshop at a time, which is suitable for them and a designated space at The Glasgow School of Art campus in Glasgow. The workshop will allow which the therapists share with the CI and other therapists their ideas about how the stroke mealtime could be improved in the future. (3h)

A21. How long do you expect each participant to be in the study in total?

Stroke survivors: participants and the chief investigator will meet twice, once for an interview and once for a workshop. The interview will last between thirty minutes and one hour depending on how much participants have to say. The interview will take place towards the end of their meeting group to discuss their experiences at the mealtimes during their rehabilitation in hospital. The workshop will take place over 3 hours to discuss and share participants' ideas with the CI and other similar participants of how we could bring improvements to the mealtime experience in rehabilitation. The interviews and workshop will be arranged at a time and date that suits participants within the support group site. The CI will secure a space where participants feel comfortable to participate in both interview and workshop.

Rehabilitation professionals: participants and the chief investigator will meet once for a workshop. The workshop will be during 3 hours to discuss and share ideas with the CI and other rehabilitation professionals to improve the mealtime in rehabilitation. The workshop will take place at The Glasgow School of Art campus in Glasgow. The workshop will be arranged at a time and date that suits the participants.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

It is unlikely that study participants will come to any harm as a result of taking part in the study, and no special arrangements have been put place for compensation. If study participants have any concerns about the way they are approached or treated during the course of the study, they can contact the academic supervisor or alternatively they can contact the normal National Health Service complaints mechanisms which will be available to them.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

○ Yes   ◉ No

A24. What is the potential for benefit to research participants?

The chief investigator cannot promise that taking part in this study will be of direct benefit to the participants but by telling the CI their experiences and ideas they will help to give to this study in design a great understanding of what are the experiences and ideas of stroke survivors and rehabilitation professionals which might help to contribute in improving the mealtimes for other people in rehabilitation in the future. However, the CI aims to enable social interaction between study participants through the participatory research process, and an opportunity to share experiences as an informed, workshop based environment.

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A26. What are the potential risks for the researchers themselves? *(if any)*

It is unlikely that the chief investigator will come to any harm as a result of conducting this study. However, the CI will follow some security procedures such as prior informing the stroke manager and academic supervisor about the location, date and time of the study.   On the day, the CI will phone call and/or text her academic supervisor to inform him that she is able to safely conduct the study which will start and involve x hours. When the study will finish she will also phone call and/or text her academic supervisor to inform him that she is well and safe.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Stroke survivors

The stroke manager for NHS Lanarkshire will identify potential participants through the local community stroke survivors support group and introduce the chief investigator to the group/s. The CI will be invited to present the study to the support group members and provide information sheets and criteria for participation (see appendices attached).

Rehabilitation professionals

The stroke manager for NHS Lanarkshire will also identify potential rehabilitation therapists who represent the multidisciplinary team involved in stroke care. The stroke manager will organise a meeting with them to meet the chief investigator who will be invited to present her study, provide information sheets and criteria for participation (see appendices attached).

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes   ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes   ◉ No

A29. How and by whom will potential participants first be approached?

All participants will be firstly approached by the stroke manager for NHS Lanarkshire.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes   ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

This study aims to require consent for participation both interviews and workshop(s). The chief investigator will speak with potential participants about the study, check if they are willing to take part of the study and if they agree the CI will

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then ask them to sign a standard consent form and study participants will be given a copy of this to keep (see appendix attached).

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes   ◯ No

A31. How long will you allow potential participants to decide whether or not to take part?

The nurse specialist NHS Lanarkshire will give stroke survivors the study information sheet on the chief investigator behalf and stroke survivors will inform her/him if they permit them to pass on their contact details to me. If stroke survivors have given permission the CI will contact them over the next three to four days to give stroke survivors time to consider whether they wish to take part in the study. When the CI contacts stroke survivors, she will discuss the study with them and answer any questions they may have. If they are considering taking part in the study the CI will arrange to meet them at their next support group meeting. At that meeting the CI will speak with stroke survivors about the study again and check that they are still willing to take part, if they agree the CI will then ask them to sign a standard consent form and study participants will be given a copy of this to keep.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

This study will provide different ways of presenting information using verbal, written and visual such as diagrams and illustrations to facilitate communication.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

◯ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

◉ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

◯ The participant would continue to be included in the study.

◯ Not applicable – informed consent will not be sought from any participants in this research.

◯ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team

☐ Electronic transfer by magnetic or optical media, email or computer networks

☐ Sharing of personal data with other organisations

☐ Export of personal data outside the EEA

☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers

☑ Publication of direct quotations from respondents

☐ Publication of data that might allow identification of individuals

☑ Use of audio/visual recording devices

☑ Storage of personal data on any of the following:

    ☐ Manual files including X–rays

    ☐ NHS computers

    ☐ Home or other personal computers

    ☐ University computers

    ☐ Private company computers

    ☑ Laptop computers

Further details:

A37. Please describe the physical security arrangements for storage of personal data during the study?

Any information in this study will be locked filing cabinet.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Any information on this study will be kept confidential and anonymous.

Stroke survivor interviews: Any information, which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio-recorded information gathered from participants during the interviews will be destroyed once the project is completed.

Stroke survivor workshop: Any information, which is collected about the study participants, or is provided during the study, will be kept strictly confidential. Participants' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio/video-recorded information gathered from participants during the workshop will be destroyed once the project is completed.

Rehabilitation professional workshop: Any information, which is collected about the therapists, or is provided during the study, will be kept strictly confidential. The therapists' personal details will be removed so that they will only be identifiable by a project number and only the CI and her supervisory team will have access to their details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio/video-recorded information gathered from the therapists during the workshop will be destroyed once the project is completed.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Any participants' personal data information will be managed by the chief investigator. However, this study will require a transcriber to transcribe audio-data. The transcriber will have access to the interview recording once the interview has taken place but as that recording will not contain anything personal or any identifiable marks that could trace this to a particular stroke survivor, there is no issue on confidentiality.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data collected will be analysed by Sandra, the Chief investigatora at The Glasgow School of Art.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Ms	Sandra	Neves
Post	Student		
Qualifications	Postgraduate Degree in Inclusive Design Graduate in Product and Interior Design		
Work Address	The Glasgow School of Art		
	167 Renfrew Street		
	Glasgow		
Post Code	G3 6RQ		
Work Email	s.neves1@student.gsa.ac.uk		
Work Telephone	01413534442		
Fax			

A43. How long will personal data be stored or accessed after the study has ended?

◯ Less than 3 months

◯ 3 – 6 months

◯ 6 – 12 months

◯ 12 months – 3 years

◉ Over 3 years

If longer than 12 months, please justify:
When the results of the study have been analysed, a PhD thesis will be prepared to present at The Glasgow School of Art and also reports will be prepared for publication in journals and presentation at conferences. Any study participants' personal information will be anonymised.

A44. For how long will you store research data generated by the study?

Years: 2

Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended.*Say where data will be stored, who will have access and the arrangements to ensure security.*

Any information related to audio/video will be password protected files and locked filing cabinet. The chief investigator will lodge hard and electronic copies with her academic supervisor. The academic supervisor has to comply with the GSA Data Protection Policy.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes   ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
The workshop for rehabilitation professionals will be conducted in a meeting space at The Glasgow School of Art
campus. Lunch and transport cost will be provided.

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or
incentives, for taking part in this research?**

○ Yes   ◉ No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g.
financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may
give rise to a possible conflict of interest?**

○ Yes   ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

**A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible
for their care) that they are taking part in the study?**

○ Yes   ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes   ◉ No

Please give details, or justify if not registering the research.

Registration of research studies is encouraged wherever possible.
*You may be able to register your study through your NHS organisation or a register run by a medical research charity,
or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of
publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have
entered registry reference number(s) in question A5-1.*

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals
☐ Internal report
☑ Conference presentation
☑ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee
on behalf of all investigators
☐ No plans to report or disseminate the results
☐ Other (please specify)
Thesis

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

N/A

A53. Will you inform participants of the results?

◉ Yes   ○ No

Please give details of how you will inform participants or justify if not doing so.
When the results of the study have been analysed, a summary of the results of the study will also be available for the participants if they wish. The chief investigartor will discuss this individually with each participant at the final of the study.

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5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review

☐ Review within a company

☐ Review within a multi–centre research group

☑ Review within the Chief Investigator's institution or host organisation

☐ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
This study has followed two stages of ethics review procedures.

Stage 1
A Preliminary Ethical Assessment Form at The Glasgow School of Art was completed with an overview of the study attached and reviewed by internal Ethics co-ordinator. Through the review some issues emerged such as the collaborator and rehabilitation professionals referred on the study are in the employ of NHS organizations. Advice by the Scottish Research Ethics Service was requested to clarify if the study involve to follow NHS Ethics review process.

Stage 2
This study will be an approval via IRAS, local NHS Research & Development Office, The Glasgow School of Art Ethics co-ordinator's and academic supervisor's reviews.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 10
Total international sample size (including UK): 10
Total in European Economic Area: 10

Further details:
The sample selected to this study reflects particular features, or specific groups within, the population under study. The sample selected is not intended, non-required to be statistically representative. The basis of selection is on the key characteristic of the specific population being studied (Ritchie and Lewis 2006). To achieve the aim, the chief investigator needs to collect information-rich accounts from both stroke survivors and rehabilitation professionals. This

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study selects the sample, which will best answer the research questions.

Stroke survivors
The chief investigator decided on a sample size, a minimum of six adults was deemed large enough to capture the types of sources of information, which the study need, which are their experiences and ideas. The sample will be from a range of experiences across a number of eating difficulties associated with impacts of stroke.
Interviews will gather six participant's 'stories' accounts.
A workshop will collect a map of participant's ideas.

Rehabilitation professionals
The chief investigator decided on a sample size of four professionals who represent a multidisciplinary team involved with stroke care - a nurse, a speech therapist, an occupational therapist and a dietitian - was deemed large enough to capture the types of sources of information which the study need which are their ideas. The sample will be from a range of expertise involved to plan the mealtime in rehabilitation.
A workshop will collect a map of participants' ideas.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

As the purpose of this study is to give voice to participants and represent their experiences and ideas, the chief investigator indicates the sample selected to this study reflects the population under study.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

This study is not intended, nor requires to be statistically representative. The methods of analysis will be appropriate for qualitative research by which the data will be analysis through a framework analysis which provides a step-by-step guide to assist the chief investigator to manager, conceptualise and describe the data (Green and Thorogood, 2004). The study aims to bring a descriptive proposal for a co-designed new mealtime experience.

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6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Mrs	Katrina	Brennan
Post	Stroke Managed Clinical Network Manager		
Qualifications	RGN		
Employer	NHS Lanarkshire		
Work Address	GrenLyon Building, Coathill Hospital, Coatbridge		
Post Code	ML5 4DN		
Telephone	01236707724		
Fax			
Mobile	07909111642		
Work Email	katrina.Brennan@lanarkshire.scot.nhs.uk		

A64. Details of research sponsor(s)

A64-1. Sponsor

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Lead Sponsor

Status: ○ NHS or HSC care organisation   Commercial status:
          ● Academic
          ○ Pharmaceutical industry
          ○ Medical device industry
          ○ Local Authority
          ○ Other social care provider (including voluntary sector or private organisation)
          ○ Other

          If Other, please specify:

Contact person

Name of organisation The Glasgow School of Art
Given name   Alison
Family name   Hay
Address   167 Renfrew Street
Town/city   Glasgow
Post code   G3 6RQ
Country   UNITED KINGDOM
Telephone   01415661408
Fax
E-mail   a.hay@gsa.ac.uk

Is the sponsor based outside the UK?
○ Yes   ● No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

○ Standalone project
○ Project that is part of a programme grant
○ Project that is part of a Centre grant
● Project that is part of a fellowship/ personal award/ research training award
○ Other
Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes   ◉ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes   ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Mr	Raymond	Hamill

Organisation   R&D Department Corporate Services Building
Address   Monkscourt Avenue   Airdrie

Post Code   ML6 0JS
Work Email   raymond.hamill@lanarkshire.scot.nhs.uk
Telephone   01236712460
Fax
Mobile   07779161388

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

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A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2012
Planned end date: 01/12/2012
Total duration:

Years: 0 Months: 3 Days: 0

A71-1. Is this study?

◉ Single centre
○ Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☐ England
☑ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?

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○ Yes   ○ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☐ NHS organisations in England
☐ NHS organisations in Wales
☑ NHS organisations in Scotland   1
☐ HSC organisations in Northern Ireland
☐ GP practices in England
☐ GP practices in Wales
☐ GP practices in Scotland
☐ GP practices in Northern Ireland
☐ Social care organisations
☐ Phase 1 trial units
☐ Prison establishments
☐ Probation areas
☐ Independent hospitals
☑ Educational establishments   1
☐ Independent research units
☐ Other (give details)

Total UK sites in study: 2

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

○ Yes   ◉ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

This study will be reviewed regularly by the Director of Studies as a standing agenda item. The Research Developer from the Research Ethics Committee at The Glasgow School of Art will advice and monitor ethical issues.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

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A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the <u>management</u> of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

The Glasgow School of Art possess indemnity cover with company to be determined to the value of £2,000,000 for the management of the research.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the <u>design</u> of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

The Glasgow School of Art possess indemnity cover with company to be determined to the value of £2,000,000 for the design of the research.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the <u>conduct</u> of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

The Glasgow School of Art possess indemnity cover with company to be determined to the value of £2,000,000 for the conduct of the research.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes   ○ No   ◉ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	NHS Lanarkshire	Title	Mrs
Department name	Stroke MCN	First name/ Initials	Katrina
Street address	Coathill Hospital, Hospital Street		
Town/city	Coatbridge	Surname	Brennan
Post Code	ML5 4DN		
Institution name	The Glasgow School of Art	Title	Ms
Department name	Design	First name/ Initials	Sandra
Street address	167 Renfrew Street		
Town/city	Glasgow	Surname	Neves
Post Code	G3 6RQ		

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PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

   - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
   - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
   - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
   - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*
NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

◉ Chief Investigator
◯ Sponsor

○ Study co-ordinator
○ Student
○ Other – please give details
○ None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: ███████████████████

Print Name: Sandra Neves

Date: 30/07/2012   *(dd/mm/yyyy)*

109686/347355/14/863

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D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature:

Print Name: Dr Ken Neil

Post: Acting Head of Research & Graduate School

Organisation: The Glasgow School of Art

Date: 30/07/2012   *(dd/mm/yyyy)*

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D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1	
Signature:	..... █████████████████████
Print Name:	Professor Alastair Macdonald
Post:	Senior Researcher School of Design
Organisation:	The Glasgow School of Art
Date:	30/07/2012 *(dd/mm/yyyy)*

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Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Using people-centred design methods to co-design a new stroke mealtime

1. Is your project research?

◉ Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

○ Basic science study involving procedures with human participants

○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

◉ Study involving qualitative methods only

○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

○ Study limited to working with data (specific project only)

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?   ○ Yes ◉ No
b) Will you be taking new human tissue samples (or other human biological samples)?   ○ Yes ◉ No
c) Will you be using existing human tissue samples (or other human biological samples)?   ○ Yes ◉ No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☐ England
☑ Scotland
☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

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○ England
◉ Scotland
○ Wales
○ Northern Ireland
○ This study does not involve the NHS

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4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☑ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

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5. Will any research sites in this study be NHS organisations?

◉ Yes   ○ No

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6. Do you plan to include any participants who are children?

○ Yes   ◉ No

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7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes   ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

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8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes   ◉ No

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9. Is the study or any part of it being undertaken as an educational project?

◉ Yes   ○ No

Please describe briefly the involvement of the student(s):
The student is the chief investigator which will be involved in designing and conducting the research project such as carrying out interviews and workshops.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes   ○ No

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10. Will this research be financially supported by the United States Department of Health and Human Services or any of

its divisions, agencies or programs?

◯ Yes   ◉ No

Site-Specific Information Form (NHS sites)

Is the site hosting this research a NHS site or a non-NHS site? *NHS sites include Health and Social Care organisations in Northern Ireland. The sites hosting the research are the sites in which or through which research procedures are conducted. For NHS sites, this includes sites where NHS staff are participants.*

◉ NHS site
◯ Non-NHS site

This question must be completed before proceeding. The filter will customise the form, disabling questions which are not relevant to this application.

One Site-Specific Information Form should be completed for each research site and submitted to the relevant R&D office with the documents in the checklist. See guidance notes.

The data in this box is populated from Part A:

Title of research:
Using people-centred design methods to co-design a new stroke mealtime experience in rehabilitation

Short title: Using people-centred design methods to co-design a new stroke mealtime

Chief Investigator:	Title	Forename/Initials	Surname
	Ms	Sandra	Neves

Name of NHS Research Ethics Committee to which application for ethical review is being made:
West of Scotland REC 5

Project reference number from above REC: 12/WS/0193

1-1. Give the name of the NHS organisation responsible for this research site

NHS Lanarkshire

1-2. In which country is the research site located?

◯ England
◯ Wales
◉ Scotland
◯ Northern Ireland

1-3. Is the research site a GP practice or other Primary Care Organisation?

◯ Yes   ◉ No

2. Who is the Principal Investigator or Local Collaborator for this research at this site?

Select the appropriate title: ○ Principal Investigator
                                ◉ Local Collaborator

	Title	Forename/Initials	Surname
	Mrs	Katrina	Brennan

Post   Stroke Managed Clinical Network Manager
Qualifications   RGN
Organisation   NHS Lanarkshire
Work Address   GlenLyon Building, Coathill Hospital, Coatbridge

PostCode   ML5 4DN
Work E-mail   katrina.Brennan@lanarkshire.scot.nhs.uk
Work Telephone   01236707724
Mobile   07909111642
Fax

a) Approximately how much time will this person allocate to conducting this research? *Please provide your response in terms of Whole Time Equivalents (WTE).*
0.1 WTE

b) Does this person hold a current substantive employment contract, Honorary Clinical Contract or Honorary Research Contract with the NHS organisation or accepted by the NHS organisation?   ◉ Yes   ○ No

A copy of a current CV for the Principal Investigator (maximum 2 pages of A4) must be submitted with this form.

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3. Please give details of all locations, departments, groups or units at which or through which research procedures will be conducted at this site and describe the activity that will take place.

Please list all locations/departments etc where research procedures will be conducted within the NHS organisation, describing the involvement in a few words. Where access to specific facilities will be required these should also be listed for each location.

Name the main location/department first. Give details of any research procedures to be carried out off site, for example in participants' homes.

	Location	Activity/facilities
1	Ward 21, Monklands Hospital NHS Lanarkshire	Staff will have a meeting out with this location at Glasgow School of Art

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5. Please give details of all other members of the research team at this site.

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6. Does the Principal Investigator or any other member of the site research team have any direct personal involvement (e.g. financial, share-holding, personal relationship etc) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes   ◉ No

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7. What is the proposed local start and end date for the research at this site?

Start date: 01/09/2012

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End date: 01/12/2012
Duration (Months):   3

8-1. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *(These include seeking consent, interviews, non-clinical observations and use of questionnaires.)*

Columns 1-4 have been completed with information from A18 as below:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.

2. If this intervention would have been routinely given to participants as part of their care, how many of the total would have been routine?

3. Average time taken per intervention (minutes, hours or days)

4. Details of who will conduct the procedure, and where it will take place

Please complete Column 5 with details of the names of individuals or names of staff groups who will conduct the procedure at this site.

Intervention or procedure	1	2	3	4	5
Stroke survivors Interviews	4	-	9h	i) The stroke manager for NHS Lanarkshire will identify potential participants through the local community stroke survivors support group and introduce the chief investigator to the group/s. (1h) ii) The CI will be invited to present the study to the support group members and provide information sheets and criteria for participation (see appendices attached). She will be on hand to answer any questions or queries regarding the study and arrange with the members of the support group a date and time to return to recruit potential participants. (1h) iii) Prior to gaining written informed consent the CI will ensure participants meet the study criteria and fully understand the purpose of the study. (1h) iv) Study participants will be interviewed individually at a time and place, which is convenient and suitable for them. Each interview will allow participants individually share with the CI their retrospective accounts of their mealtime experience during their stroke rehabilitation in hospital. (1h each (x6))	i)Mrs Katrina Brennan ii) Mrs Katrina Brennan and Ms Sandra Neves iii) Ms Sandra Neves iv) Ms Sandra Neves
Stroke survivors Workshop	3	-	9h	i) At the end of the interview participants will be invited to attend a workshop to share their ideas on the co-design of a new mealtime experience. Again they will be informed that their participation is voluntary and they can withdraw at any time. (30 minutes each (x6)) ii)The CI will liaise with potential participants on a date venue and time that will be suitable for the majority. Potential participants will be provided with an overview of the workshop programme and written informed consent gained prior to their participation in the workshop. (2h) iii) A group of study participants will be participating in a workshop at a time and place, which is convenient and suitable for them. The workshop will allow which participants share with the CI and other similar participants their ideas about how the stroke mealtime experience could be improved in the future. (3h)	i) Ms Sandra Neves ii(Ms sandra Neves iii) Ms Sandra Neves
Rehabilitation professionals Workshop	4	-	6h	i) The stroke manager for NHS Lanarkshire will identify potential rehabilitation therapists who represent the multidisciplinary team involved in stroke care. (1h) ii) The stroke manager will organise a meeting with them to meet the Chief Investigator who will be invited to present her study. The CI will discuss their participation in the study and provide them with information sheets (see appendix attached). The CI will be on hand to answer any questions or queries regarding the study. (1h) iii) The CI will contact the therapists several days later to arrange a date venue and time that will be suitable for them. Therapists will be provided with an overview of the workshop programme and written	i) Mrs Katrina Brennan ii) Mrs Katrina Brennan and Ms Sandra Neves iii) Ms sandra Neves iv) Ms Sandra Neves

informed consent gained prior to their participation in the workshop.
(1h)
iv) A multidisciplinary group of therapists will be participating in a
workshop at a time, which is suitable for them and a designated
space at The Glasgow School of Art campus in Glasgow. The
workshop will allow which the therapists share with the CI and other
therapists their ideas about how the stroke mealtime could be
improved in the future. (3h)

8-2. Will any aspects of the research at this site be conducted in a different way to that described in Part A or the protocol?

○ Yes   ⦿ No

If Yes, please note any relevant changes to the information in the above table.

Are there any changes other than those noted in the table?

10. How many research participants/samples is it expected will be recruited/obtained from this site?

Stroke survivor people, Adults (N=6) to interview and participate in a workshop.

NHS rehabilitation professionals (N=4) to participate in a workshop.

11. Give details of how potential participants will be identified locally and who will be making the first approach to them to take part in the study.

The person that has agreed to collaborate with this research proposal is Mrs Katrina Brennan, Stroke Managed
Clinical Network Manager.

Mrs Brennan has identified one of stroke community group in Scotland as being suitable to recruit stroke survivor
people and has adviced the nurse specialist NHS Lanarkshire about the research. She has also identified one of
stroke rehabilitation Unit in hospital in scotland as being appropriated to recruit professionals and has adviced the
rehabilitation professional team about the research.

12. Who will be responsible for obtaining informed consent at this site? What expertise and training do these persons have in obtaining consent for research purposes?

Name	Expertise/training
Ms Sandra Neves	As part of her doctoral training, the chief investigator has been made aware of the importance of research ethics and embedded this in the design of her research. The process of gaining informed consent and the legislation governing this was outlined by the Glasgow School of Art ethics co-ordinator as part of training and, as part of obtaining institutional approval for this study, has been discussed in detail. We can meet to go through informed consent at some point prior to the study taking place.

15-1. Is there an independent contact point where potential participants can seek general advice about taking part in research?

N/A

15-2. Is there a contact point where potential participants can seek further details about this specific research project?

They can contact Professor Macdonald (Director of Studies) by email and/or phone.

16. Are there any changes that should be made to the generic content of the information sheet to reflect site-specific

issues in the conduct of the study? *A substantial amendment may need to be discussed with the Chief Investigator and submitted to the main REC.*

No

Please provide a copy on headed paper of the participant information sheet and consent form that will be used locally. Unless indicated above, this must be the same generic version submitted to/approved by the main REC for the study while including relevant local information about the site, investigator and contact points for participants (see guidance notes).

---

17. What local arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters etc.)*

This study will provide different ways of presenting information using, verbal, written and visual such as diagrams and illustrations to facilitate communication.

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18. What local arrangements will be made to inform the GP or other health care professionals responsible for the care of the participants?

N/A

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19. What arrangements (e.g. facilities, staffing, psychosocial support, emergency procedures) will be in place at the site, where appropriate, to minimise the risks to participants and staff and deal with the consequences of any harm?

Activity will be within Stroke Unit at NHS Lanarkshire Hospital and all of the local risk assessments will be in place.

The research presents little risk of harm or distress to participants.   The participant information sheet clearly signposts to mechanisms that participants can complain to if they feel the research has not been carried out with due care or has caused greater distress than anticipated.   The researcher will make herself aware of all policies and guidelines (Health and Safety, fire drills etc) at the site to help ensure the physical safety of herself and participants throughout the duration of the study.

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20. What are the arrangements for the supervision of the conduct of the research at this site? *Please give the name and contact details of any supervisor not already listed in the application.*

Professor Macdonald will ensure the researcher executes the research with all due care and diligence.
Mrs Katrina Brennan will oversee all activity in relation to this research in line with NHS Lanarkshire R & D Policies.

---

21. What external funding will be provided for the research at this site?

○ Funded by commercial sponsor
○ Other funding
◉ No external funding

How will the costs of the research be covered?

---

23. Authorisations required prior to R&D approval

This section deals with authorisations by managers within the NHS organisation. It should be signed in accordance with the guidance provided by the NHS organisation. This may include authorisation by clinical supervisors, line managers, service managers, support department managers, pharmacy, data protection officers or finance managers, depending on the nature of the research. Managers completing this section should confirm in the text what the authorisation means, in accordance with the guidance provided by the NHS organisation.

This section may also be used by university employers or research support staff to provide authorisation to NHS organisations, in accordance with guidance from the university.

1. Type of authorisation:

Title Forename/Initials Surname

Post
Qualifications
Organisation
Work Address

PostCode
Work E-mail
Work Telephone
Mobile
Fax

Signature: ....

Date: ....

Declaration by Principal Investigator or Local Collaborator

1. The information in this form is accurate to the best of my knowledge and I take full responsibility for it.

2. I undertake to abide by the ethical principles underpinning the World Medical Association's Declaration of Helsinki and relevant good practice guidelines in the conduct of research.

3. If the research is approved by the main REC and NHS organisation, I undertake to adhere to the study protocol, the terms of the application of which the main REC has given a favourable opinion and the conditions requested by the NHS organisation, and to inform the NHS organisation within local timelines of any subsequent amendments to the protocol.

4. If the research is approved, I undertake to abide by the principles of the Research Governance Framework for Health and Social Care.

5. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to the conduct of research.

6. I undertake to disclose any conflicts of interest that may arise during the course of this research, and take responsibility for ensuring that all staff involved in the research are aware of their responsibilities to disclose conflicts of interest.

7. I understand and agree that study files, documents, research records and data may be subject to inspection by the NHS organisation, the sponsor or an independent body for monitoring, audit and inspection purposes.

8. I take responsibility for ensuring that staff involved in the research at this site hold appropriate contracts for the duration of the research, are familiar with the Research Governance Framework, the NHS organisation's Data Protection Policy and all other relevant policies and guidelines, and are appropriately trained and experienced.

9. I undertake to complete any progress and/or final reports as requested by the NHS organisation and understand that continuation of permission to conduct research within the NHS organisation is dependent on satisfactory completion of such reports.

10. I undertake to maintain a project file for this research in accordance with the NHS organisation's policy.

11. I take responsibility for ensuring that all serious adverse events are handled within the NHS organisation's policy for reporting and handling of adverse events.

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12. I understand that information relating to this research, including the contact details on this application, will be held by the R&D office and may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

13. I understand that the information contained in this application, any supporting documentation and all correspondence with the R&D office and/or the REC system relating to the application will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

Signature of Principal Investigator
or Local Collaborator:
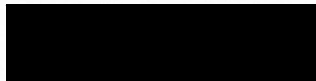
Print Name: Ms Sandra Neves
Date: 30/07/2012

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APPLICATION TO NHS R&D OFFICE

All studies except clinical trials of investigational medicinal products

Short Title of Study: Using people-centred design methods to co-design a new stroke mealtime
Name of Principal Investigator or Local Collaborator: Mrs Katrina Brennan
Sponsor: The Glasgow School of Art

Please complete this checklist and send it with your application to each relevant R&D office

- Please send a disk containing one file for each document. Application form files should be saved in both pdf and XML format.
- Where signed documents are required, please send either a hard copy, a faxed copy or a scanned electronic file. Check that the submission code appears on each page of the application form before sending. It is acceptable to send hard copies of signature pages separately, as long as the submission code at the top of the page is the same as on the electronic version.
- All letters must be dated. All other accompanying documents must bear version numbers and dates.
- All documents listed below that are applicable to the application must be submitted for the application to be valid.
- When sending hard copies, please do NOT staple documents as they may need to be photocopied.
- This button ⬚ allows you to add extra documents of the same type. Include subtitles if appropriate, e.g. "Information sheet for relative".

Document	Subtitle	Enclosed	Office Use
R&D Form (signed/authorised)	NHS R&D Form	Yes	
NHS/HSC Site-Specific Information (SSI) Form (signed/authorised)		No	
Summary CV for Chief Investigator (CI)	Sandra M P Neves	Yes	
Summary CV for Principal Investigator (PI)		No	
Summary CV for local researchers and research nurses		No	
Summary CV for student		No	
Research protocol or project proposal	Using people-centred design methods to co-design a new mealtime experience in rehabilitation	Yes	
Participant information sheet (PIS) - local version	Stroke Survivors	Yes	
Participant information sheet (PIS) - local version	Rehabilitation Professionals	Yes	
Participant consent form - local version	Stroke Survivors (Interview)	Yes	
Participant consent form - local version	Stroke Survivors (Workshop)	Yes	
Participant consent form - local version	Rehabilitation Professionals (Workshop)	Yes	

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Letters of invitation to participant - local version		No	
GP/consultant information sheets or letters - local version		No	
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)	Glasgow School of Art: Professional Indemnity Cover 2012-13	Yes	
Letter from statistician		No	
Letter from funder		No	
Referee's report or other scientific critique report		No	
Summary, synopsis or diagram (flowchart) of protocol in non-technical language		No	
Interview schedules or topic guides for participants	Topic Guide Interview Sheet (Stroke Survivors)	Yes	
Interview schedules or topic guides for participants	Workshop Design Overview Sheet (Stroke Survivors)	Yes	
Interview schedules or topic guides for participants	Workshop Design Overview Sheet (Rehabilitation Professionals)	Yes	
Validated questionnaire		No	
Non-validated questionnaire		No	
Copies of advertisement materials for research participants		No	
Instructions for use of medical device		No	
Documents required prior to final NHS permission (may be submitted after the initial application)			
Letter from sponsor		No	
REC favourable opinion letter and all correspondence		No	
Confirmation of REC favourable opinion for any substantial amendments and all correspondence		No	
Confirmation of any other regulatory approvals (e.g. NIGB) and all correspondence		No	

West of Scotland REC
Ethics Department
Ground Floor, The Tennent Institute
Western Infirmary
38 Church Street
GLASGOW G11 6NT

30.07.12
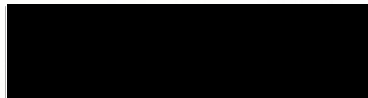
AH/KN

Sponsor Declaration Letter

To Whom It May Concern;

I confirm that Glasgow School of Art will act as Sponsor for the study entitled *using people-centred design methods to co-design a new stroke mealtime experience in rehabilitation* and will use all best endeavours to comply will the requirements of the role. This study is being run by Ms Sandra Neves as part of her doctoral degree training under the supervision of Professor Alastair Macdonald, School of Design.

Yours sincerely,

Dr Ken Neil
Acting Head of Research & Graduate School

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THE GLASGOW
SCHOOL OF ART

To Whom It May Concern

6th July 2012

Dear Sir/Madam

Glasgow School of Art: Professional Indemnity Cover 2012-13

This is to confirm that the School will have Professional Indemnity insurance in place from 2012/13 onwards.

The School is presently tendering its insurance arrangements from 2012/13 onwards through the Advanced Procurement for Universities and Colleges (APUC) procedure, and will consider tender applications shortly. Included in the tender specification is Professional Indemnity cover with a Limit of Liability of £2,000,000.

When the tender outcome is known and contracts awarded, I shall be happy to provide details of the School's broker and individual policies.

Yours sincerely

John Martin
Assistant Company Secretary
j.martin@gsa.ac.uk

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Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Exploring lived experiences during mealtimes in rehabilitation

Topic Guide Interview Sheet (Stroke Survivors)

Style: Interviews will be conducted face to face in a semi-structured style. The interviewer will probe the responses given by the interviewee.

Data capture: All interviews will be recorded using a digital voice recorder and subsequently fully transcribed per verbatim.

Introduction

I would like to thank you for agreeing to participate in this interview. This interview is to gather your views and opinions of your experience of mealtimes during your stroke rehabilitation. There are no right or wrong answers and I would like you to be open and honest about your experience of mealtimes during your stay in hospital after your stroke. Please feel free to expand on any question that I ask you and if there are any questions that I do not ask that you think are particularly relevant to your involvement in the study then please let me know.

Participant ID number...

Date/Time..

Overview of the Interview

Question	What insights about mealtime experiences during hospital rehabilitation can stroke survivors reveal?
Rationale	This topic guide is designed to enable stroke survivors to express their lived experiences about their mealtimes during rehabilitation in hospital.

1

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Description   A group of 6 participants will be individually interviewed by the researcher (facilitator) of the study. The interview will be structured using the conceptual framework (fig 1) which considers four inter-related aspects of the mealtime experience:

1) Sensorial
2) Emotional
3) Physical
4) Social
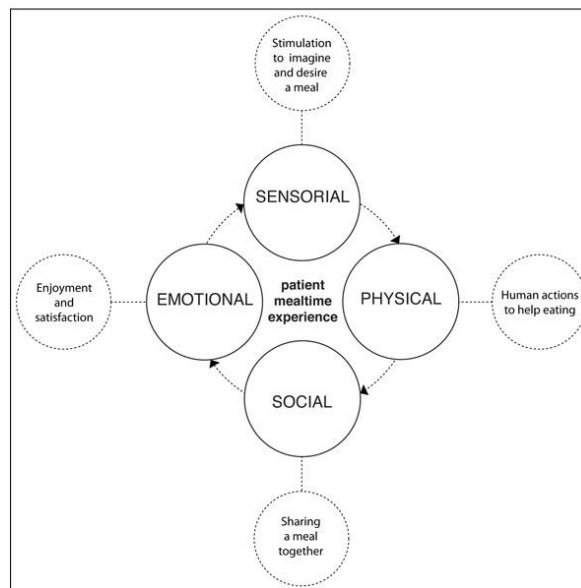
Fig 1: Conceptual framework

Interview Script

ABOUT YOUR STROKE

1. Can you remember how long you were in hospital?

2. Did you experience any difficulties during hospital mealtimes?

- **Can you give me an example?**

2

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3. Did you receive care assistance to help you eat?

- **Can you explain why you needed care assistance?**

4. Did this change over time during your stay?

MEALTIMES

My understanding of the mealtimes for stroke patients in rehabilitation in hospital is shown in the diagram (fig 2). *(Show diagram to participant)*

5. Could you describe briefly to me how you experienced the sequence of events during a typical mealtime?

Before you received your meal
My understanding of the type of environment you ate your food in is shown in the picture. *(Show picture to participant)*

6. Is this how you experienced the ward environment at mealtimes? If not, how would you describe this?

7. Was it an attractive or unattractive place to eat?

- What kinds of smells were there?
- What were the sounds did you heard?
- What were you seeing and/or looking at while you ate your meal?

8. How did these sensory aspects affect you at mealtimes?

9. Can you provide an example of an environment attractive or conductive to eating in – perhaps that you did not have there but wish you had been in?

When you received your food
My understanding of the type of food you receive in the hospital is shown in this picture. *(Show picture to participant)*

10. Is this how you remember seeing the food? If not could you describe it?

11. How did you find the visual appearance of the food at your mealtimes? Can you explain your reply thinking?

- What was the shape like?
- What was the colour like?
- How was it arranged on the plate?

3

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- What kind of thoughts did you have when you looked at the food for the first time?
- Did you express your food likes and dislikes at mealtimes to anyone?
- Did the care assistance and/or ward staff take into account your likes and dislikes about food?

12. How did these visual aspects of food stimulate your appetite and interest in eating?

During the mealtime

13. In what ways did the care assistant help you eat at the mealtimes?

- Can you give me an example?

14. Was there any form of social interaction with patients during mealtimes?

- Can you give me an example?

After you ate the meal

15. What kind of thoughts did you have at this stage?

Overall

16. What in your opinion, are the positive aspects you experienced at mealtime during your hospital stay?

17. What in your opinion, are the aspects that you experienced at mealtime during your hospital stay?

OTHERS

18. Is there anything else you would like to mention that you thought about whilst we have been talking?

Thank you

4

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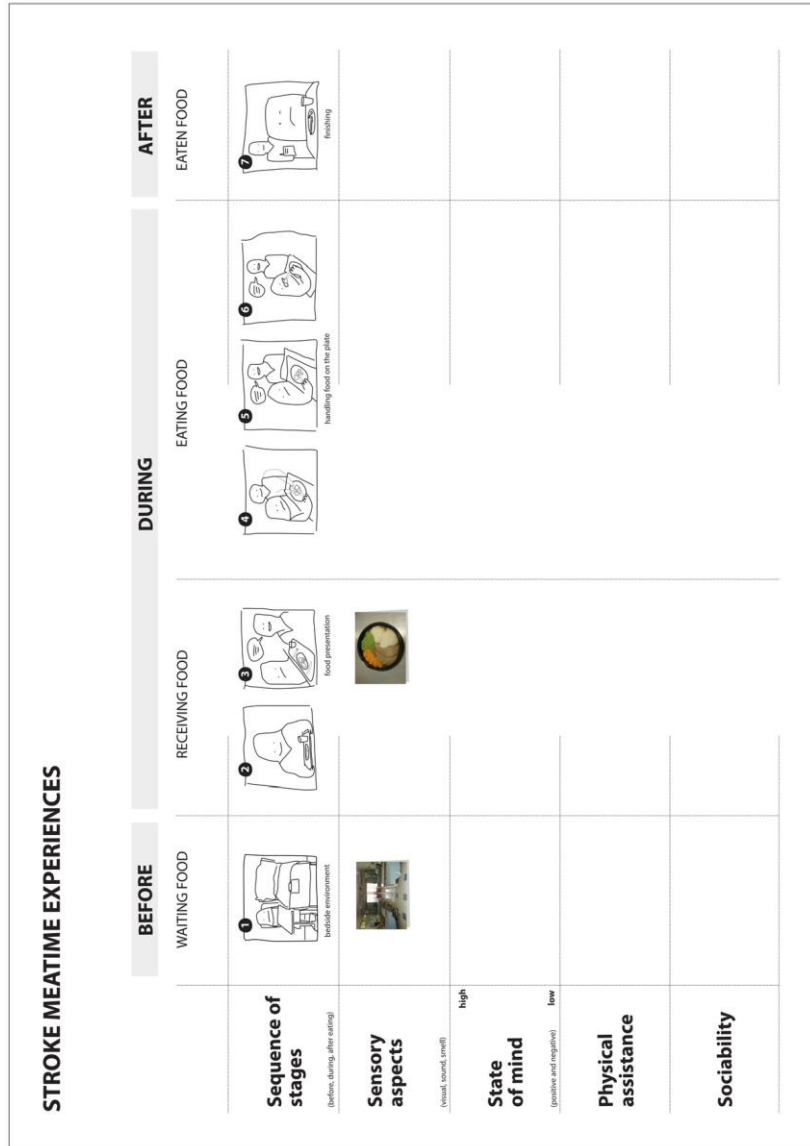
Fig. 2 Example of the diagram on view throughout the interview

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SCHOOL OF DESIGN THE GLASGOW SCHOOL OF ART

Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Mapping ideas to redesign the mealtime experience in rehabilitation

Workshop Design Overview Sheet (Stroke Survivors)

Style: Workshop design will be conducted with a group of six participants in a meeting room. The participants will co-design a new mealtime experience through design methods.

Data capture: The workshop activities will be recorded using a digital audio/video recorder and subsequently some parts transcribed per verbatim.

Introduction

I would like to thank all of you for agreeing to participate in this workshop. This workshop is to gather your knowledge through the sharing of ideas about how the mealtime experience could be improved during stroke rehabilitation for future patients. There are no right or wrong ideas and I would like all of you to be open and honest to share your ideas and thoughts about what can be done. Please feel free to ask any question that you think are particularly relevant to involve in the study.

Workshop 1
Date/Time………..

Overview of Activity

Question	What ways of improving the mealtime experience for stroke patients during rehabilitation in hospital would stroke survivors propose?
Rationale	This activity is designed to help stroke survivors in sharing their knowledge among those who experienced mealtimes in rehabilitation. It will be important for participants to form a shared focus to think about what can be done to improve the stroke mealtime experience.

1

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Description	A group of 6 participants will work with the researcher (facilitator) of the study in each session. Following a brainstorming session the group will develop their ideas using a version of the conceptual framework introduced in Activity 1 as a mealtime experience map.

Activity script

Introduction
15 minutes

The researcher briefly introduces the activity and the stroke mealtime event in rehabilitation.

Presentation of the stroke mealtime event
The researcher will prepare a short overview (15 min PowerPoint) of how the stroke mealtime event could be improved in the future with less focus on the functional model and more focus on the sensorial and emotional models. This presentation will be prepared in advance and printouts of the slides will be provided to give the participants an opportunity to take notes.

Activity 1   **Sharing ideas**

5 minutes

The researcher will brief the group for the next part of the activity.

40 minutes

The group of participants will be asked to imagine the ideal mealtime experience which they would suggest for future patients during rehabilitation in hospital.
The activity will be structured using the conceptual framework (fig 1) which considers four inter-related aspects of the mealtime experience:

1) Sensorial
2) Emotional
3) Physical
4) Social.

2

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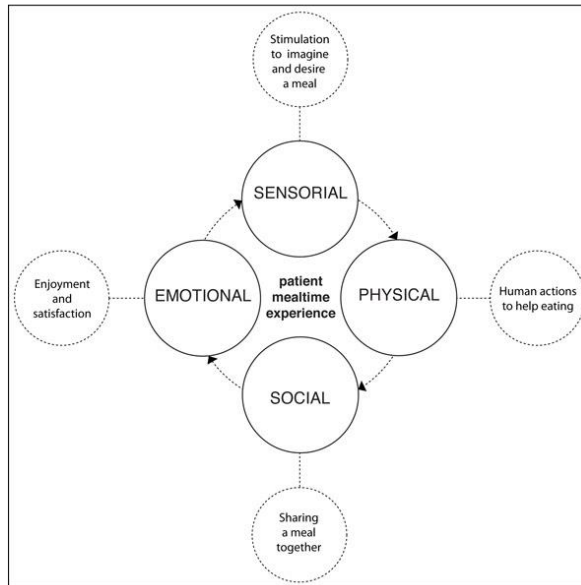
Fig 1: Conceptual framework

The participants will be given a large board for each aspect of the framework (sensorial, emotional, physical and social) on which they can place post-its annotated with their ideas (see fig 2)

Fig 2: Example of brainstorm board with post-its

To encourage participants' thoughts during the brainstorming activity the researcher will ask a series of questions to help stimulate responses, for example:

3

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What should the ideal mealtime experience be like?
How would one best stimulate the patient's desire for the meal?
What should food look like and how should it be presented to the patient?
What kind of physical assistance should be provided?
What kind of social rituals should be encouraged?
What additional aspects should the mealtime provide?

It proposes 10 minutes of activity for each of the 4 categories: sensorial, emotional, physical and social

The output of this session will be ideas to help stimulate thinking for part 2 of the activity.

10 minutes	The group will discuss the ideas they have generated. The researcher will summarise the key points for the group.

15 minutes	*Coffee break*

Activity 2	**Mapping ideas**
5 minutes	The researcher will brief the group for the second activity.
40 minutes	The group will be asked to further develop their ideas using a version of the conceptual framework introduced in Activity 1 this time structured as a mealtime experience map (fig 3), which illustrates the sequence of events – before, during and after the mealtime and outlines each of the 4 aspects of the mealtime experience. Again, 10 minutes will be allowed per aspect.

The output of part 2 will be a 'co-designed' new stroke mealtime experience for discussion. |
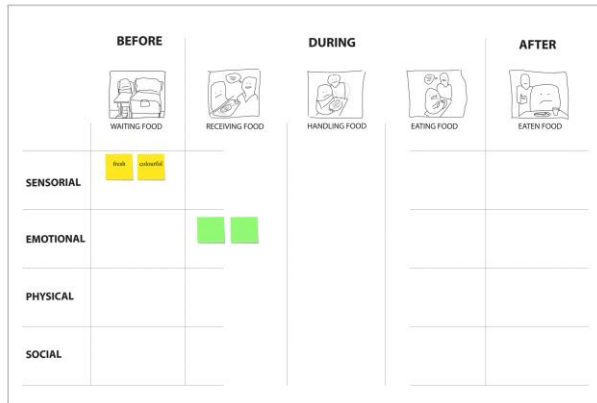
Fig 3: Example of the mealtime experience map

| 10 minutes | The group will discuss the mealtime experience map (10 minutes). |
| 20 minutes | The researcher summarises the day pointing out some of the most popular and innovative ideas. She then ends the workshop by thanking all participants, and gives them the study information to receive a summary of the findings and get in touch if they have any additional thoughts following the workshop. |

Total: 2h and 45 minutes

5

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**SCHOOL:
OF DESIGN
THE GLASGOW
SCHOOL :OF: ART**

Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Mapping ideas to redesign the mealtime experience in rehabilitation

Workshop Design Overview Sheet (Rehabilitation Professionals)

Style: Workshop design will be conducted with a group of four participants in a meeting room. The participants will co-design a new mealtime experience through design methods.

Data capture: The workshop activities will be recorded using a digital audio/video recorder and subsequently some parts transcribed per verbatim.

Introduction

I would like to thank all of you for agreeing to participate in this workshop. This workshop is to gather your knowledge through the sharing of ideas about how the mealtime experience could be improved during stroke rehabilitation for future patients. There are no right or wrong ideas and I would like all of you to be open and honest to share your ideas and thoughts about what can be done. Please feel free to ask any question that you think are particularly relevant to involve in the study.

Workshop 2
Date/Time………..

Overview of Activity

Question	What ways of improving the mealtime experience would rehabilitation professionals propose for stroke patients during rehabilitation in hospital?
Rationale	This activity is designed to enable rehabilitation professionals to 'think differently' about their current practices and to consider how they might improve their patients' mealtime experiences and to imagine a quality mealtime experience for

1

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the patient by reflecting on aspects of the mealtime they would not normally consider.

Description   A group of 4 participants will work with the researcher (facilitator) of the study in each session. Following a brainstorming session the group will develop their ideas using a version of the conceptual framework in Activity 2 as a mealtime experience map.

Activity Script

Introduction
15 minutes   The researcher briefly introduces the activity and the stroke mealtime event in rehabilitation.

Presentation of the stroke mealtime event
The researcher will prepare a short overview (15 min PowerPoint) of how the stroke mealtime event could be improved in the future with less focus on the functional model and more focus on the sensorial and emotional models. This presentation will be prepared in advance and printouts of the slides will be provided to give the participants an opportunity to take notes.

Activity 1   *Feeling differently*

5 minutes   The researcher will brief the group for the next part of the activity.

30 minutes   The group of participants will be asked to develop the patients' current mealtime experience. This activity will be structured by distributing a storyboard template (fig 1) which considers three stages of the mealtime experience: before, during and after.

2
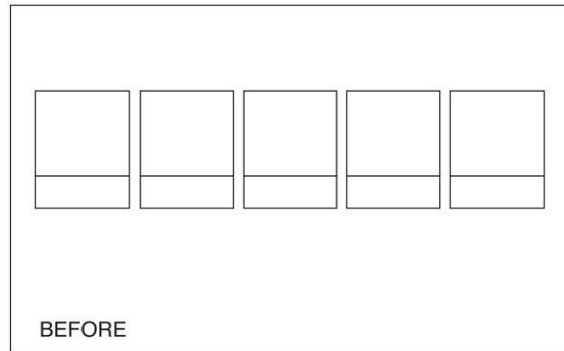
Fig 1: Example of storyboard template

To encourage participants' thoughts the researcher will ask them to role play a fictional character whose profile represents the characteristics of stroke patients. In this way participants consider the characteristics of stroke patients they represent, which enables them to think about the mealtime more from a patient perspective.

It proposes 10 minutes of activity for each of the 3 stages: before, during and after.

The output of this session will be to stimulate thinking for part 2 of the activity.

Activity 2   *Sharing ideas*

5 minutes   The researcher will brief the group for the second activity.

40 minutes   The group of participants will be asked to imagine the ideal mealtime experience which they would suggest for future patients during rehabilitation in hospital.
The activity will be structured using the conceptual framework (fig 2) which considers four inter-related aspects of the mealtime experience:

1) Sensorial
2) Emotional
3) Physical
4) Social

3

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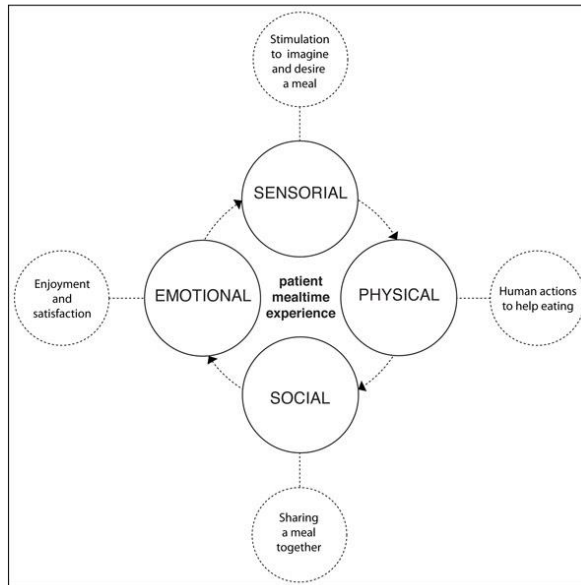
Fig 2: Conceptual framework

The participants will be given a large board for each aspect of the framework (sensorial, emotional, physical and social) on which they can place post-its annotated with their ideas (fig 3)

Fig 3: Example of brainstorm board with post-its

To encourage participants' thoughts during the brainstorming activity the researcher will ask a series of questions to help stimulate responses, for example:

4

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What should the ideal mealtime experience be like?
How would one best stimulate the patient's desire for the meal?
What should food look like and how should it be presented to the patient?
What kind of physical assistance should be provided?
What kind of social rituals should be encouraged?
What additional aspects should the mealtime provide?

It proposes 10 minutes of activity for each of the 4 categories: sensorial, emotional, physical and social

The output of this session will be ideas to help stimulate thinking for part 3 of the activity.

10 minutes	The group will discuss the ideas they have generated. The researcher will summarise the key points for the group.

---

15 minutes	*Coffee break*

Activity 3	**Mapping ideas**
5 minutes	The researcher will brief the group for the third activity.
40 minutes	The group will be asked to further develop their ideas using a version of the conceptual framework introduced in Activity 2 this time structured as a mealtime experience map (fig 4), which illustrates the sequence of events – before, during and after the mealtime and outlines each of the 4 aspects of the mealtime experience. Again, 10 minutes will be allowed per aspect.

The output of part 3 will be a 'co-designed' new stroke mealtime experience for discussion.

5
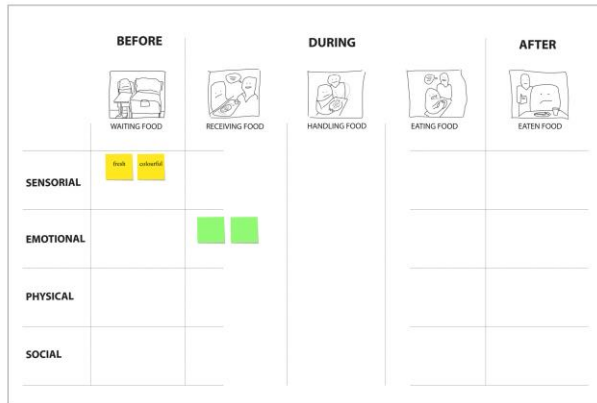
Fig 4: Example of the mealtime experience map

| 10 minutes | The group will discuss the mealtime experience map (10 minutes). |
| 20 minutes | The researcher summarises the day pointing out some of the most popular and innovative ideas. She then ends the workshop by thanking all participants, and gives them the study information to receive a summary of the findings and get in touch if they have any additional thoughts following the workshop. |

Total: 3h and 15 minutes

6

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Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

PROJECT TITLE

Using people-centred design methods to co-design a new stroke mealtime experience in rehabilitation

Context

Recent design involvement with healthcare has been influenced by participative and 'co-design' approaches, which considers patients and professionals as collaborators in the research process. This collaboration allows for a significant contribution by professionals and patients to explore a wide range of issues and capture their different lived experiences respectively. Design emotion and user-experience literature indicates that design can play a significant role in identifying peoples' emotions to create more positive experiences, for example, constructing 'user' profiles based on an individual's lifestyle and using narrative-based scenarios to describe imagined events and experiences. However, there has been no design involvement with the stroke survivors with the intention of improving hospital food services and mealtimes for these patients. In fact, the 'patient voice' is absent even in clinical studies. This study aims to explore the hypothesis that by involving stroke survivors and rehabilitation professionals in this research they can bring new insights that may contribute to the improvement of the mealtime experience for stroke rehabilitation patients.

The World Heath Organisation (WHO) estimates that stroke affects 15 million people worldwide each year with Scotland and Portugal having the highest incidence. Stroke impacts on people's abilities to eat creating a number of physical, cognitive and psychological difficulties, which require rehabilitation. Currently, mealtimes are structured more on clinical models aimed primarily at restoring function, which follow a number of Stroke recommendations from the National Health Service (NHS) on how to plan stroke mealtimes in rehabilitation. However, research into the stroke mealtime reveals that this experience might result in, for example, low morale and nutritional problems (Ekberg et al., 2002; Kumlien and Axelsson 2002; Westergren et a., 2002 and Wright et al., 2005).

The research proposal

This research aims to co-design an improved mealtime experience with stroke survivors and rehabilitations professionals.

Stage 1

The researcher views survivors' voices as significant to express their lived experiences about mealtimes in the post-stroke phase. This research aims to

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interview stroke survivors to collect their retrospective accounts of their mealtime experiences during their stroke rehabilitation in hospital. The semi-structured interviews will be conducted with six stroke survivors face-to-face using a topic guide which will allow their thoughts and feelings to be put into words. This will provide new data and insights into the experiences of stroke survivors through their responses. Participants will also be invited to participate in the next stage of this study.

Stage 2
The researcher also considers the stroke survivors as experts who can bring new ideas to improve mealtimes during rehabilitation following stroke based on their past experiences. As this research aims to use co-design approaches through workshop methods both stroke survivors and rehabilitation professionals will be asked to participate in separate workshops, as each of these two groups will have a different perspective on issues. These workshops will bring new knowledge through the sharing of ideas about how the stroke mealtime experience could be improved in the future with less focus on the functional model and more focus on the sensorial and emotional models.

This ethics application is concerned with collecting stroke survivors' past experiences through interviews (dataset 1), stroke survivors' ideas through Workshop 1 (dataset 4), and professionals' ideas through Workshop 2 (dataset 5) (see table 1).

This researcher believes that through design techniques and tools used in both workshops she will collect new insights, which will help in designing a new stroke mealtime experience for future stroke survivors.

Participant numbers
As the purpose of this study is to give voice to participants and represent their experiences and ideas, the researcher indicates the sample selected to this study reflects particular features, or specific groups within, the population under study. The sample selected is not intended, non-required to be statistically representative. The basis of selection is on the key characteristic of the specific population being studied (Ritchie and Lewis 2006). To achieve the aim, the researcher needs to collect information-rich accounts from both stroke survivors and rehabilitation professionals. This study selects the sample, which will best answer the research questions.

Stroke survivors
The researcher decided on a sample size, a minimum of six adults was deemed large enough to capture the types of sources of information, which the study need, which are their experiences and ideas. The sample will be from a range of experiences across a number of eating difficulties associated with impacts of stroke. Interviews will gather six participant's 'stories' accounts. A workshop will collect a map of participant's ideas.

2

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Rehabilitation professionals
The researcher decided on a sample size of four professionals who represent a multidisciplinary team involved with stroke care - a nurse, a speech therapist, an occupational therapist and a dietitian - was deemed large enough to capture the types of sources of information which the study need which are their ideas. The sample will be from a range of expertise involved to plan the mealtime in rehabilitation. A workshop will collect a map of participants' ideas.

Analysis of data
This study is not intended, nor requires to be statistically representative. The methods of analysis will be appropriate for qualitative research by which the data will be analysis through a framework analysis which provides a step-by-step guide to assist the researcher to manager, conceptualise and describe the data (Green and Thorogood, 2004). The study aims to bring a descriptive proposal for a co-designed new mealtime experience.

Research ethics
All participants will provide consent to take part in the research study.
They will also be informed that this study is to generate ideas in how to improve the stroke mealtime experience.

Ethical approval will be approved by IRAS, local NHS Research & Development Office, The Glasgow School of Art ethics co-ordinator's and academic supervisor's reviews.
This ethical approval relates to an exploration of the stroke mealtime experience conducted with stroke survivors and healthcare professionals to bring a response/answer to the research study hypothesis. This study will have the support and approval of the Stroke Manager of rehabilitation services in Scotland where the study will be conducted.

Table 1 Datasets

	'Voice'	Ideas
Stroke Survivors	Interviews (data 1)	Workshop 1 (data 4)
Rehabilitation Professionals	Literature review (data 2) Interviews (data 3)	Workshop 2 (data 5)

3

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SCHOOL:
OF DESIGN
THE GLASGOW
SCHOOL: of ARt

Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Exploring lived experiences during mealtimes in rehabilitation
and
Mapping ideas to redesign the mealtime experience in
rehabilitation

Participant Information Sheet (Stroke Survivors)

Invitation

Sandra (the researcher) is inviting you to take part in this research study. Before you
decide whether to take part, it is important for you to understand why the study is
being done and what it involves. Please take some time to read the following
information and discuss it with family or friends if you wish.

What is the purpose of this study?

The purpose of this study is to find out what are the mealtime experiences during
patients' rehabilitation in hospital. This forms part of a PhD study. To allow Sandra to
carry out this study she has been awarded a research grant for four years which will
support her PhD Thesis.

Why have you been chosen?

You have been chosen to take part in this study as you have recently been in
rehabilitation care in hospital with stroke and your experience and views are
important. I hope to recruit into the study 6 stroke survivors in total who are in post-
acute stroke rehabilitation in hospital.

Do I have to take part?

It is up to you to decide whether or not take part in the study. This information sheet
is yours to keep what ever you decide. If you decide to take part in the study and
then change your mind, you can withdraw at any time without giving a reason and

the support you receive will not be affected. **You do not have to make any decisions about the study today.**

Who is organizing the study?

The study has been funded by The Portuguese Foundation for Science and Technology. The sponsor of the study is the School of Design at the Glasgow School of Art.

The study has been approved by IRAS, local NHS Research & Development Office, GSA ethics co-ordinator's and academic supervisor's reviews.

What happens next?

The NHS Lanarkshire nurse specialist has given you this information sheet on the researcher's (Sandra's) behalf and you will inform the nurse specialist if you permit him/her to pass on your contact details to Sandra. If you have given permission she will contact you over the next three or four days to give you time to consider whether you wish to take part in the study. When Sandra contacts you, she will discuss the study with you and answer any questions you may have. If you are considering taking part in the study Sandra will arrange to meet you at your support group meeting. At that meeting she will speak with you about the study again and check that you are still willing to take part. If you agree she will then ask you to sign a standard consent form and you will be given a copy of this to keep.

What will taking part in the study mean for me?

Taking part in the study will mean that you and Sandra will meet twice, once for an interview and once for a workshop. The interview will last between thirty minutes and one hour depending on how much you have to say. The interview will take place towards the end of your support group meeting to discuss your experiences at mealtimes during your rehabilitation in hospital and will be audio recorded. The workshop will take place over 3 hours to discuss and share your ideas with Sandra and 5 other similar participants of how we could bring improvements to the mealtime experience in rehabilitation. The workshop will be audio and video recorded and will take place in your support group meeting. **The interviews and workshop will be arranged at a time that suits you within the support group site. The researcher will secure a space where you feel comfortable to participate in both interview and workshop.**

Will I benefit from taking part?

Sandra cannot promise that taking part in this study will be of direct benefit to you. But, by telling Sandra of your experience, your information and your ideas will be of immense value in understanding what the experiences and ideas of stroke survivors are. In turn, this might help to contribute to improving the mealtimes for people in stroke rehabilitation in the future.

Are there any risks involved in taking part?

It is unlikely that you will come to any harm as a result of taking part in the study, and no special arrangements have been put place for compensation. If you have concerns about the way you are approached or treated during the course of the study, please contact either Sandra or her supervisor Professor Alastair Macdonald at The Glasgow school of Art (0141 353 4715) or alternatively you can contact the National Health Service through the normal complaints mechanisms which will be available to you.

Will taking part influence my care / medical treatment?

Absolutely not. The study is independent of any care or medical treatment you are currently in receipt of. Whether or not you do decide to participate has no bearing on your treatment. If you do decide to participate, your information will be made available solely to the researcher (Sandra) for the purposes of her studies and will not be communicated to any medical professionals co-ordinating your care.

Will my taking part be kept confidential?

Any information which is collected about you, or that you provide during this study, will be kept strictly confidential. In any audio and video recorded material, your personal details will be removed so that you will only be identifiable by a project number and the researcher and her supervision team only will have access to your details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio and video-recorded information from you will be destroyed once the project is completed.

What will happen to the results of the study?

When the results of the study have been analysed, a PhD thesis will be prepared to present at The Glasgow School of Art and also reports will be prepared for publication in journals and presentation at conferences. A summary of the results of the study will also be available to you if you wish; Sandra can discuss this at the final of your interview and workshop.

Thank you for taking the time to read this information.

If you like to find more about the study please feel free to contact me

Sandra Neves
PhD student at The Glasgow School of Art

Tel. 0141 353 4442
Email. s.neves1@student.gsa.ac.uk

4

SCHOOL OF DESIGN THE GLASGOW SCHOOL OF ART

Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Mapping ideas to redesign the mealtime experience in rehabilitation

Participant Information Sheet (Rehabilitation Professionals)

Invitation

Sandra (the researcher) is inviting you to take part in this research study. Before you decide whether to take part, it is important for you to understand why the study is being done and what it involves. Please take some time to read the following information and discuss it with Sandra.

What is the purpose of this study?

The purpose of this study is to find out what are the ideas to contribute into the improvements of the mealtime experiences during patients' rehabilitation in hospital. This forms part of a PhD study. To allow Sandra to carry out this study she has been awarded a research grant for four years, which will support her PhD Thesis.

Why have you been chosen?

You have been chosen to take part in this study as you represent one of the multidisciplinary team members involved with stroke care at mealtimes in rehabilitation in hospital and your experience and views are important. I hope to recruit 4 rehabilitation professionals.

Do I have to take part?

It is up to you to decide whether or not take part in the study. This information sheet is yours to keep what ever you decide. If you decide to take part in the study and then change your mind, you can withdraw at any time without giving a reason. **You do not have to make any decisions about the study today.**

Who is organizing the study?

The study has been funded by The Portuguese Foundation for Science and Technology. The sponsor of the study is the School of Design at the Glasgow School of Art.

The study has been approved by IRAS, local NHS Research & Development Office, GSA ethics co-ordinator and academic supervisors reviews.

What happens next?

The researcher has discussed the study with you and answered any questions. If you are considering taking part in the study, if you agree she will then ask you to sign a standard consent form and you will be given a copy of this to keep.

What will taking part in the study mean for me?

Taking part in the study will mean that you and Sandra will meet once for a workshop. The workshop will last 3 hours to discuss and share your ideas with Sandra and 3 more rehabilitation professionals about how to improve the mealtime in rehabilitation. The workshop will be audio and video recorded and will take place at The Glasgow School of Art campus. **The workshop will be arranged at a time that suits you.**

Will I benefit from taking part?

Sandra cannot promise that taking part in this study will be of direct benefit to you. But, by telling Sandra of your experience, your information and your ideas will help give design research a greater understanding of what the experiences and ideas of rehabilitation professionals are. In turn, this might help to contribute to improving the mealtimes for people in stroke rehabilitation in the future.

Are there any risks involved in taking part?

It is unlikely that you will come to any harm as a result of taking part in the study, and no special arrangements have been put place for compensation. If you have concerns about the way you are approached or treated during the course of the study, please contact either Sandra or her supervisor Professor Alastair Macdonald at The Glasgow school of Art (0141 353 4715) or alternatively you can contact the National Health Service through the normal complaints mechanisms which will be available to you. If any malpractice or neglect is identified whilst participating in the research it is professional practice to report this.

Will my taking part be kept confidential?

Any information which is collected about you, or that you provide during this study, will be kept strictly confidential. In any audio and video recorded material, your personal details will be removed so that you will only be identifiable by a project number and the researcher and her supervision team only will have access to your details. All information will be held securely for a period of 10 years, as required by Glasgow School of Art. However, any audio and video-recorded information from you will be destroyed once the project is completed.

What will happen to the results of the study?

When the results of the study have been analysed, a PhD thesis will be prepared to present at The Glasgow School of Art and also reports will be prepared for publication and presentation at conferences. A summary of the results of the study will also be available to you if you wish; Sandra can discuss this at the final of the workshop.

Thank you for taking the time to read this information.

If you like to find more about the study please feel free to contact me

Sandra Neves
PhD student at The Glasgow School of Art

Tel. 0141 353 4442
Email. s.neves1@student.gsa.ac.uk

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**SCHOOL:
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Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Exploring lived experiences during mealtimes in rehabilitation

Consent Form for Stroke Survivors (Interview)

Please read the statements below. If you agree, please initial each box and sign at the bottom of the page.

1. I confirm that I have read and understand the study information sheet (dated .xxx)

and I have had the opportunity to ask the researcher questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw

at any time without giving any reason, without my legal rights being affected. ☐

3. I understand that relevant sections of data collected during the study may be

looked at by individuals from the Glasgow School of Art, from regulatory authorities

or from the NHS Trust, where it is relevant to my taking part in this research.

I give permission for these individuals to have access to my records. ☐

4. I understand that I will take part in one interview as part of the study and

that the interview will be audio-recorded. ☐

5. I understand that any information I provide will be treated in the strictest confidence.

This information will be held securely for 10 years at the Glasgow School of Art and

will only be available to the researcher. Information will be destroyed after this time. ☐

6. I give permission for the information I provide to be used for research purposes

(including, reports, publications and presentations) with strict preservation of anonymity. ☐

1

475

7. I agree to take part in the above study.   ☐

---   ----------------   --
Full name in BLOCK CAPITALS   Date   Signature

---   ----------------   --
Researcher   Date   Signature

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**SCHOOL
OF DESIGN
THE GLASGOW
SCHOOL OF ART**

Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Mapping ideas to redesign the mealtime experience in rehabilitation

Consent Form for Stroke Survivors (Workshop)

Please read the statements below. If you agree, please initial each box and sign at the bottom of the page.

1. I confirm that I have read and understand the study information sheet (dated .xxx)

and I have had the opportunity to ask the researcher questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw

at any time without giving any reason, without my legal rights being affected. ☐

3. I understand that relevant sections of data collected during the study may be

looked at by individuals from the Glasgow School of Art, from regulatory authorities

or from the NHS Trust, where it is relevant to my taking part in this research.

I give permission for these individuals to have access to my records. ☐

4. I understand that I will take part in one workshop as part of the study and

that the interview will be audio/video-recorded. ☐

5. I understand that any information I provide will be treated in the strictest confidence.

This information will be held securely for 10 years at the Glasgow School of Art Ethics and

will only be available to the researcher. Information will be destroyed after this time. ☐

6. I give permission for the information I provide to be used for research purposes

(including, reports, publications and presentations) with strict preservation of anonymity. ☐

1

477

7. I agree to take part in the above study.

--   ----------------   --
Full name in BLOCK CAPITALS   Date   Signature

--   ----------------   --
Researcher   Date   Signature

478

**SCHOOL
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Sandra Neves
167 Renfrew Street
Glasgow, G3 6RQ
Tel: 0141 353 4442

STUDY TITLE

Mapping ideas to redesign the mealtime experience in rehabilitation

Consent Form for Rehabilitation Professionals (Workshop)

**Please read the statements below. If you agree, please initial each box and sign
at the bottom of the page.**

1. I confirm that I have read and understand the study information sheet (dated .xxx)

and I have had the opportunity to ask the researcher questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw

at any time without giving any reason, without my legal rights being affected. ☐

3. I understand that relevant sections of data collected during the study may be

looked at by individuals from the Glasgow School of Art, from regulatory authorities

or from the NHS Trust, where it is relevant to my taking part in this research.

I give permission for these individuals to have access to my records. ☐

4. I understand that I will take part in one workshop as part of the study and

that the workshop will be audio/video-recorded. ☐

5. I understand that any information I provide will be treated in the strictest confidence.

This information will be held securely for 10 years at the Glasgow School of Art and

will only be available to the researcher. Information will be destroyed after this time. ☐

6. I give permission for the information I provide to be used for research purposes

(including, reports, publications and presentations) with strict preservation of anonymity. ☐

1

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7. I agree to take part in the above study.   ☐

--   ----------------   --
Full name in BLOCK CAPITALS   Date   Signature

--   ----------------   --
Researcher   Date   Signature

2

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Appendix E: Phase 1 – Topic guide to interview healthcare professionals

ABOUT YOUR ROLE

1) **What is your role and specialism within stroke care and rehabilitation?**

2) **What training and qualifications have you had?**

3) **How many years have you been working in this area?**

4) **Where do you see and work with stroke patients?**

5) **Can you briefly describe a typical consultation(s) / session(s) with a stroke patient?**

6) **What, in your opinion, are the main impacts of stroke on patients that you treat, for each of the following?**

- What is the neurological impact?

- What is the physical impact?

- What is the social impact?

- What is the psychological impact

- How do you decide when people are ready to move on to another care stage?

ABOUT THE STROKE PATHWAY

My understanding of the stroke pathway is shown in the diagram.

7) **Is this how you see the stroke pathway? If not, how would you draw this? Are there any stages missing?**
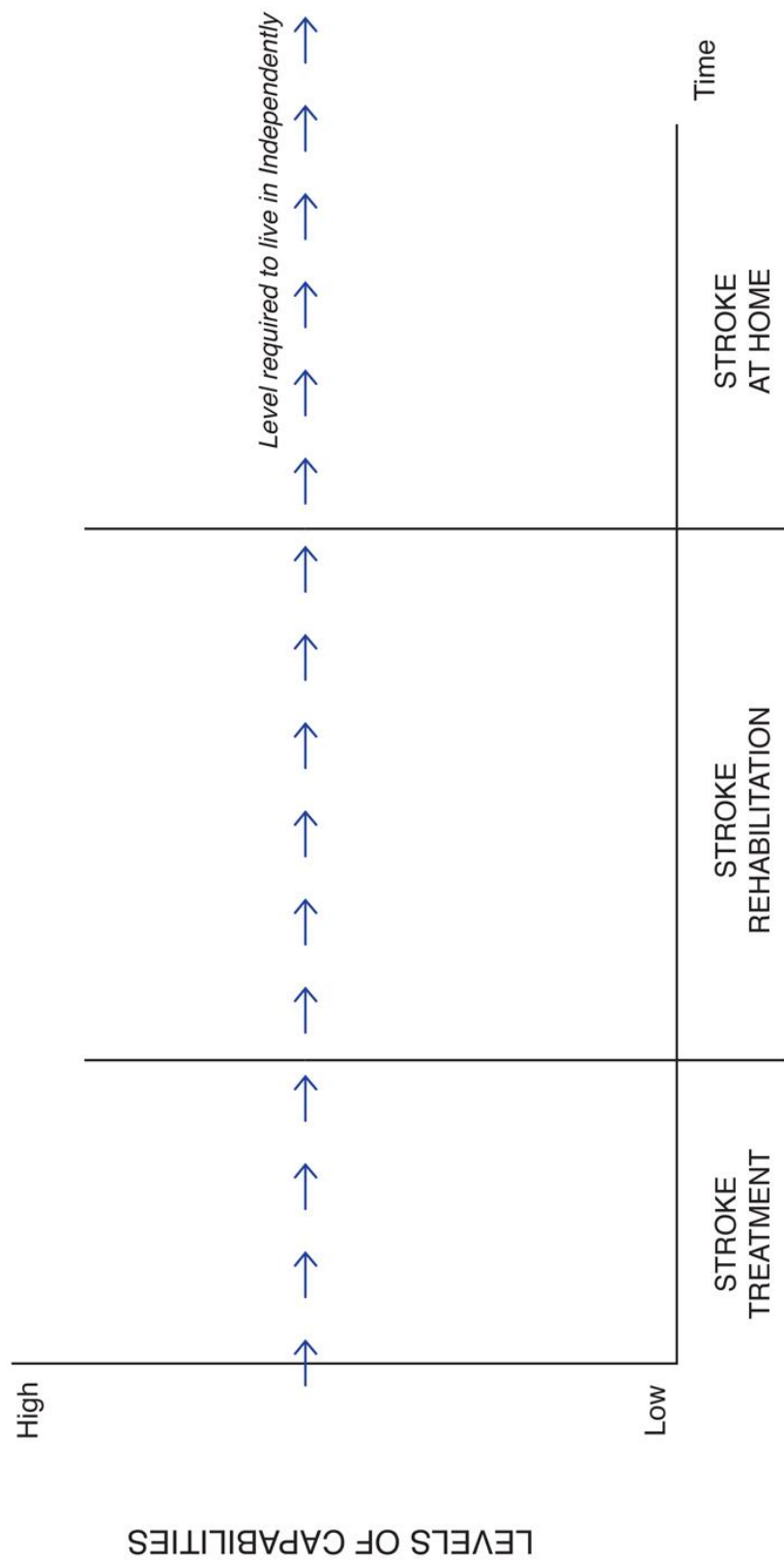
8) At what stage(s) in the stroke pathway do you see patients?

9) **What types of assessment are used to allow a patient to move from the stroke treatment to rehabilitation and from rehabilitation to home?**

10) **How do you define independence?**

11) **What level of competence do patients require?**

MEALTIMES

12) **How do these stroke conditions affect people at mealtimes?**

- How is their particular condition assessed with relevance to eating and drinking?

- What proportion of patients need assistance?

- What kind of problems can patients have at mealtimes?

- What are the reasons for a patient needing care assistance to eat?

- Can you give me an example?

- How do you try to minimise these problems?

- What difficulties do patient have with eating?

- What techniques and/or methods do you use to minimize swallowing / eating difficulties?

- What causes them to lose appetite and interest in eating?

My understanding of the texture of food is shown in the graphic.

13) **Is this how you see the stroke texture of food? If not, how would you explain this? Is there any type of food missing?**

NUMBER OF PATIENTS

30 25 20 15 10 5 0

| A | B | C | D | E | F |

smooth and purable

smooth and thin

smooth and thick purée

moist and some texture

soft moist

solid

TYPE OF FOOD

■ Treatment　　■ Rehabilitation　　■ Home
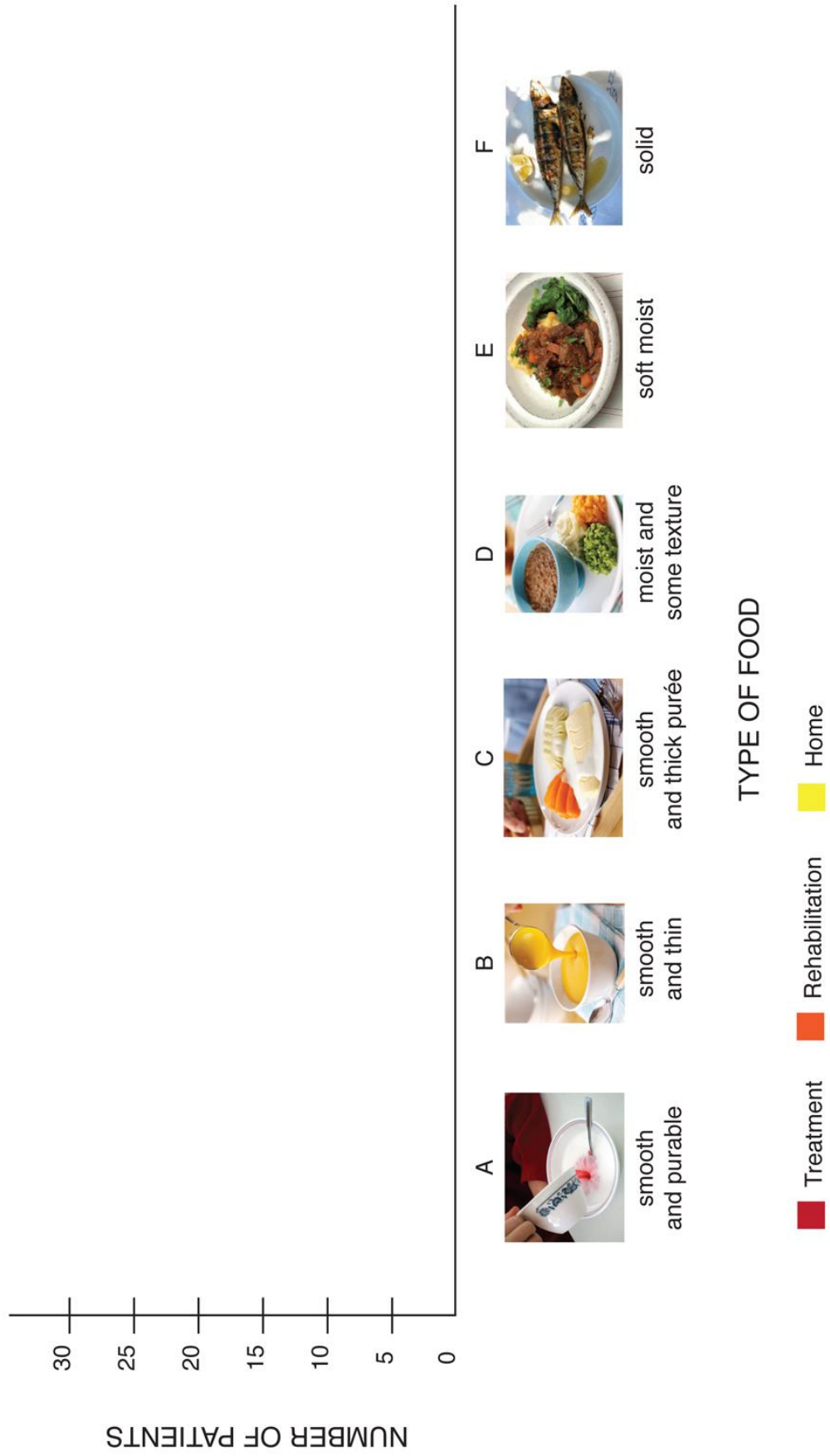
14) What type of food might patients eat?

- What is the number of patients who can eat solid food?

- How do you take into account patients' likes and dislikes about food?

- Do they express 'food memories' associated with certain food?

My understanding of the tableware standards is shown in the graphic.

15) Is this how you see the stroke tableware standards? If not, how would you show this? Is there any type of product missing?

NUMBER OF PATIENTS

25 20 15 10 5 0

A
Tableware standards

B
Tableware standards with adaptations

C
Special tableware

TYPE OF TABLEWARE

Treatment Rehabilitation Home
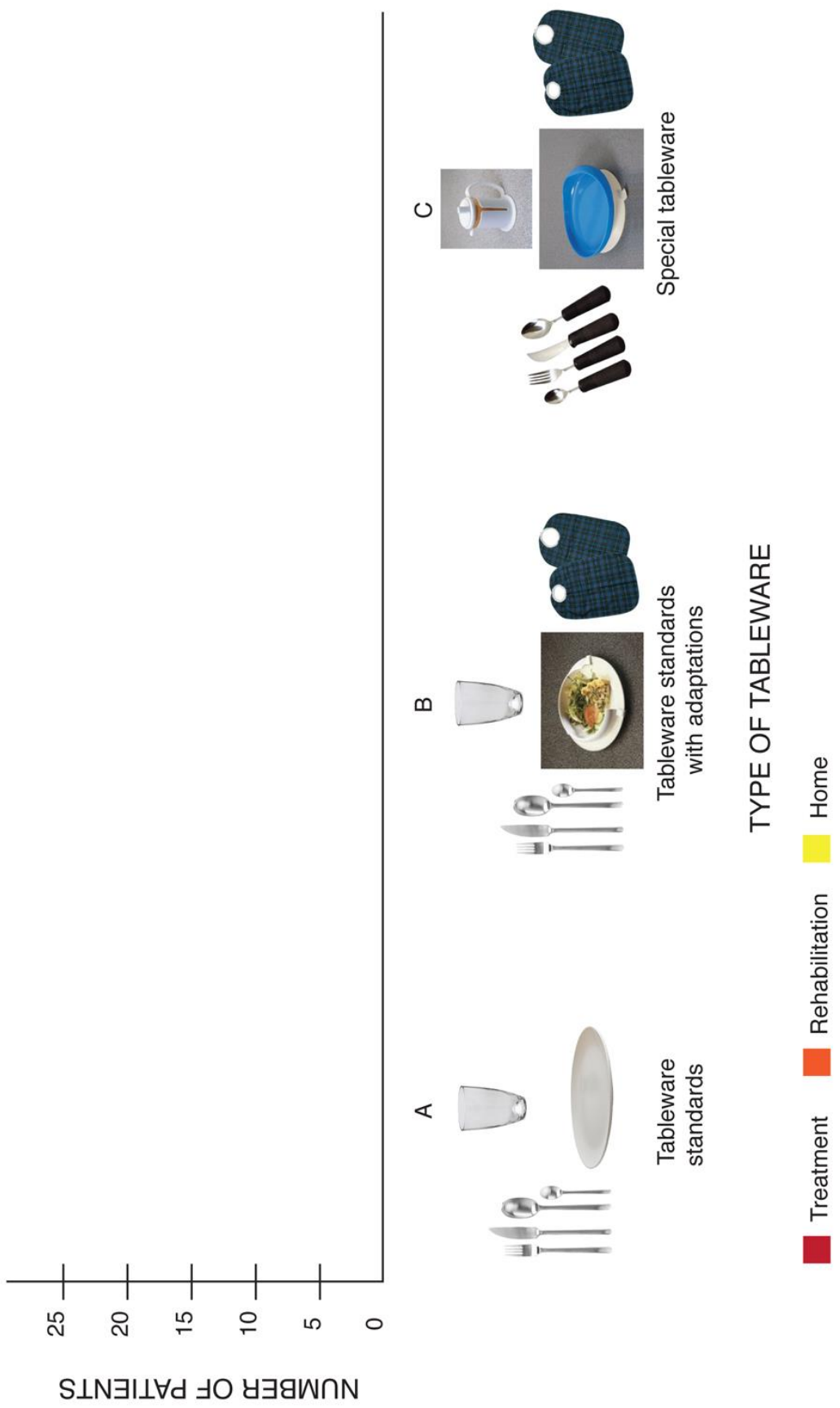
16) What type of design tableware/cutlery might patients use?

- How many patients use standard tableware to eat?

- How many patients need to use special tableware?

- Can you give me an example of tableware used by stroke patients?

- What do you think is the best way to help them to eat? Why?

- Do you know of any good examples of tableware – perhaps that you do not use but wish you could obtain?

17) How is rehabilitation important to help people eat?

- Who plans their meals?

- What guidelines are available in the kitchen to prepare meals for stroke patients?

- Are there certain strict procedures which staff who are preparing meals have to follow?

- How are social interactions stimulated at mealtimes?

OTHERS

18) Is there anything else you think important that we have not discussed?

19) It would be helpful to be able to observe stroke patients at mealtimes. Would this be possible and what would be the procedure I would have to observe?

Thank you

Appendix F: Phase 2 – Topic guide to interview patients

ABOUT YOUR STROKE

1. Can you remember how long you were in hospital?

2. What was the most annoying thing that you experienced during hospital mealtimes?

3. How did you deal with them?

4. Did you receive care assistance during hospital mealtimes?

5. Can you explain why you needed care assistance?

6. Did this change over time during your stay?

ABOUT YOUR MEALTIMES

My understanding of the mealtimes for patients in stroke rehabilitation in hospital is shown in the diagram. *(Show diagram to participant)*

AFTER

Eaten Food

DURING

Receiving Food

Eating Food

BEFORE

Waiting for Food

positive

negative

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I would like to talk with you about your experience during a typical mealtime in hospital, for example an evening meal, throughout 3 stages: BEFORE, DURING and AFTER THE MEAL.

5. Can you tell me the differences between the events of waiting for food, receiving food, eating food and after eating at your mealtime?
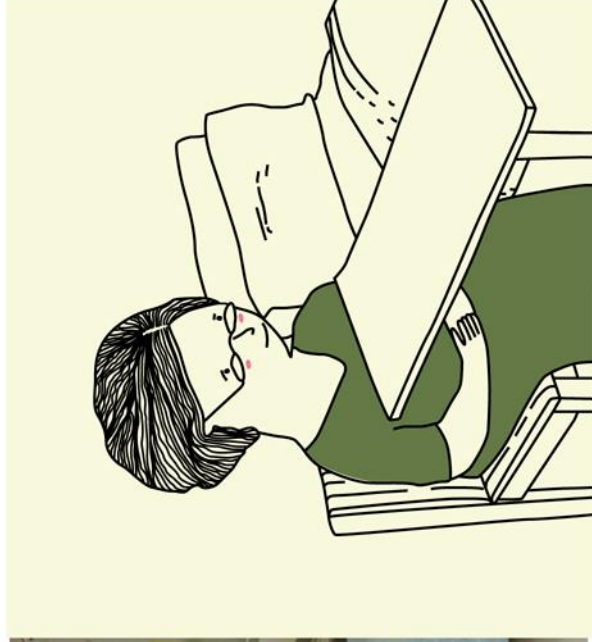
- What happened at each of these stages?
- How long did each take?
- What good or bad things happened during each stage of the mealtime?

BEFORE THE MEAL

My understanding of the type of environment you ate your food in is shown in the picture. *(Show picture to participant)*

BEFORE

Waiting for Food

6. Is this similar to the ward environment you were in, in hospital? If not, how would you describe this?

- Where were you sitting to have your meal? Why?

7. In what ways was it an attractive or unattractive place to eat?

- Did smells affect your appetite?
- What kinds of smells were there?
- Were these smells consistent or inconsistent throughout each of these stages?
- Did ward noises affect your appetite?
- What the sounds did you heard?
- Were these sounds consistent or inconsistent throughout each of these stages?
- Did what you saw around you affect your appetite?
- What were you seeing and/or looking at while you were waiting for food?
- Were these sights consistent or inconsistent throughout each of these stages?
- Did you know what meal you were getting? If not why?
- Did you receive care assistance at this stage?
- Can you explain why you needed care assistance?
- Can you tell me how the care assistant and/or ward staff assisted you throughout each of these stages?
- Did social interactions affect your interest to eat?
- What kind of social interactions did you have there?
- Were these social interactions consistent or inconsistent throughout each of these stages?

DURING THE MEAL

My understanding of the type of food you received at your mealtime in the hospital is shown in the picture. *(Show picture to participant)*

DURING

Receiving Food
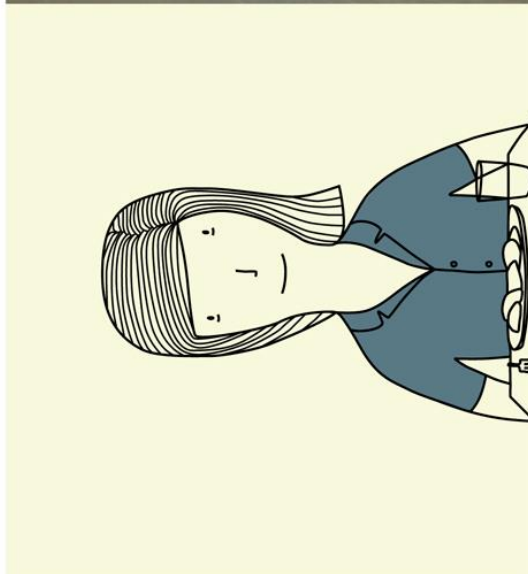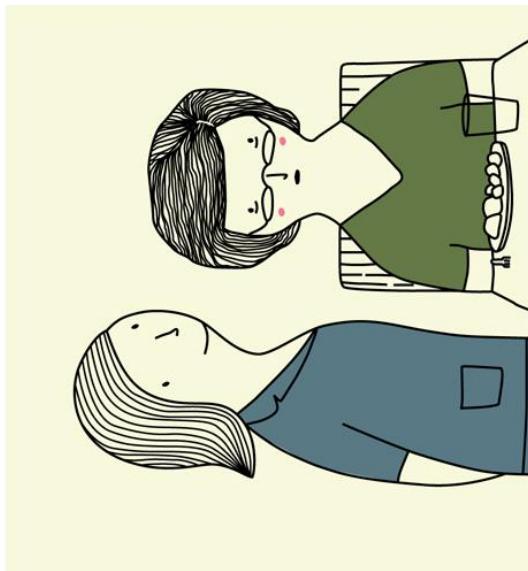
8. Is this what the food looked like? If not could you describe it?

9. How did you find the visual appearance of the food at your mealtime? Can you explain your reply?

- What was the shape like?
- What was the colour like?
- How was it arranged on the plate?
- What did you think when you saw your food for the first time?
- Did you express your likes and dislikes about the appearance of food to anyone? Why?
- Did the care assistant and/or ward staff take into account your likes and dislikes about the appearance of food?

10. Did this appearance of food stimulate your appetite, or not? Why?

My understanding of the way you ate your food at your mealtime in the hospital is shown in the picture. *(Show picture to participant)*

DURING

Eating Food

11. Can you tell me about the care assistance during your meal?

- In what ways did the care assistant help you eat?
- Did these ways of care assistance affect your interest to eat?
- Can you give me an example?

12. Can you remember any form of social interactions during your meal?

- How did you find the social interaction between you and other patients during your meal?
- Can you give me an example?

AFTER THE MEAL

My understanding of the way you finished your mealtime in the hospital is shown in the picture. *(Show picture to participant)*

14. Can you tell me what kind of thoughts came to mind after this mealtime in hospital?

- Did you see this mealtime as a good experience, or not? Why?

15. How did you see the best mealtime experience?

- What is the place like?
- What is the appearance of food like?

- What does this mealtime experience mean to you?

OVERALL

16. What in your opinion, are the positive aspects you experienced at mealtime during your hospital stay?

17. What in your opinion, are the negative aspects you experienced at mealtime during your hospital stay?

OTHERS

18. Is there anything else you would like to mention that you thought about whilst we have been talking?

Thank you for participating in my study and I very much welcome your input

Appendix G: Phase 1 – Sample coding and charting data in interview transcripts with healthcare professionals

Section 1: Developing a working analytical framework

Theme	The main impacts of stroke	The stroke care pathway	The mealtime in hospital
Sub-themes	Neurological (N) Physical (PH) Social (S) Psychological (PS)	Hospital (H) Day hospital (C) Home (HO)	Eating difficulties (ED) Team assessment (TA) Eating process (EP)

Section 2: Coding data

Coding		HP2_SPEECH THERAPIST	Notes
N N EP PS S EP	149 150 151 152 153 154 155 156 157 158 159 160 161 162 163 164 165 166 167 168 169 170 171 172 173 174 175	Well obviously the neurological impact is why they have swallowing difficulty to begin with because the majority of patients don't have anything wrong with their swallow beforehand it's interesting for me to, I find it interesting to find out what the CT results is where the stroke has occurred because obviously certain areas of the brain will effect swallowing more than others and it's useful for me, I, to know that detail. The neurological impact is great I mean it's massive but for some patients on the swallow side of things it's quite minimal and it's enough to be given advice on what to do, take little sips rather than big drinks you know and general advice, but often texture modification is required so it has a huge impact. Well obviously patients become dehydrated, they can lose weight, they have, it can affect their ability to rehab if they don't if they're not nutritionally stable. I'm trying to think, their fatigue levels, they're already very fatigued because they've had a stroke, they tire quickly so they've no stamina, it's all these things. Social impact, eating and drinking is a very social thing if someone's on a textually modified diet it looks different from what other people are getting. / They don't necessarily have a choice, where as other people are given a choice / because the kitchen prepares food that is suitable for them, it's not necessarily what the individual necessarily likes and I'm sure that's going to be a big part of what you're doing.	Swallowing difficulties require modified meals Patient fatigue HP aknowledging the mealtime as a social aspect Lack of choice

Section 3: Charting data

<table>
<tr><td colspan="4" style="background-color: yellow; text-align: center;">The stroke care pathway</td></tr>
<tr><td></td><td>Hospital</td><td>Day hospital</td><td>Home</td></tr>
<tr>
<td>HP1</td>
<td>We're acute stroke ward (…) we see them from the very start (…) from within 4 hours of their stroke. (Line 86)</td>
<td></td>
<td>We have a team who take the patient home as soon as they can transfer they go to discharge and treat them from their own home they've got physios, OT's, speech and language and nursing in that team. (Line 74)</td>
</tr>
<tr>
<td>HP2</td>
<td>The patients who come into the hospital who are suspected of having a stroke have a differential diagnosis of stroke have a water swallow test, a water screening by the nursing staff and myself and colleagues train the nurses to provide the screen, screening assessment. (Line 48)

At an earlier stage I would say assessment and rehab can often begin right away, we use the early mobilisation model (…) CT scan (…) diagnosis (…) the rehab phase starts right away as soon as you put someone on recommendations. (Line 217)</td>
<td></td>
<td>Getting them home from here with the early supported discharge team the CARS team, that's the team of therapist that would go into the house and work with the patients (…) the intensity of therapy is much less. (Line 247)</td>
</tr>
<tr>
<td>HP3</td>
<td>They come into the hospital and they get their initial medical treatment involved (…) very quickly in sort of early rehab early mobilisation (…) getting them up getting them out of bed. (Line 113)</td>
<td>They can then be referred onto rehabilitation teams for home but that's not always appropriate for everybody. They can also be referred to our day hospital. (Line 118)</td>
<td></td>
</tr>
<tr>
<td>HP4</td>
<td>Initially (…) you've got acute stroke Treatment(…) medically they've got to Be stabilised (…)and then (…) they like to get them early mobilisation (…) acute can kind of overlap with rehabilitation. (Line 133, 137, 147)</td>
<td></td>
<td>We also have early supported discharge (…) where they go home maybe slightly earlier but they continue their rehabilitation at home and physios and occupational therapists will go into the home and they'll basically rehab at home. (Line 192)</td>
</tr>
</table>

Appendix H: Phase 2 – Sample of coding and charting data in interview transcripts with patients

Section 1: Developing a working analytical framework

Themes	Before (B)	During (D)	After (A)
Thematic colours	Sensorial		
	Physical		
	Social		
	Emotional		

Section 2: Coding data

Coding		P3	Notes
D	248 249 250 251 252 253 254 255 256 257	See I very very rarely ate, I won't say it looked like that 'cause that looks quite nice, but that was nothing like what I ever had I only ever had like a baked potato. But, but the actual receiving of this there was never anyone there with you throughout your food, / so that's a big difference. They just used to give you it and then go away again. ***How did you find the visual appearance of the food at your mealtimes?*** Not very attractive, not very attractive.	
D	258 259 260 261 262 263	***So what do you mean by not being attractive?*** Cause like when you get food and I'm quite a fussy eater as it is but I tend to when I get food if it doesn't look appealing then it's not appealing and a lot of the time the food was very very unappealing. / It was as if it had just been slapped onto a plate.	Unattractive/ Unappealing food
D	264 265 266	***So what was the shape like?*** It wasn't the shape, it was just like a big bundle slatted on the middle of the plate.	
D	267 268 269 270 271	***And what was the colour like, do you remember?*** Not really as I say the only kind of meal I every really tended to have was a, I used to try the baked potato. The only thing about it was the actual potato itself could have been a lot softer in order for people to eat it, / I found it quite hard.	Food texture Patient difficulties

Section 3: Charting data

	Before	**During**	**After**
P1	*The toilet was next door to my bed (...) Urine (Line 121)* *In bed (Line 113)* *I could not talk to the other patients. (Line 189)*	*Not appetising. It looked like a normal meal but not nice to look at. (Line 220)* *They fed me with a tea spoon. (Line 244)* *They would sit on a chair beside me. (Line 204)* *They did not talk while I was eating. (Line 206)* *I imagined I was eating. (Line 9)* *I could not eat like others. (Line 104)*	*The meal was recorded on a chart, what I eat. (Line 81)* *No interactions. (Line 266)* *None of them were better than the other. (Line 288)*
P2	*I could smell the soup (...) They were consistent. (Line 91, 96)* *I mean you could tell if it was a Monday or a Tuesday cause of the meals. (Line 98)* *In bed (...) Because I couldn't get up. (Line 69)* *where I was everybody was in bed you couldn't move, you couldn't get up. (Line 240)*	*I wasn't eating, I didn't lie there thinking oh I wish I could have that. (Line 246)*	*Jealousy (...)Because the rest of them have had something to eat and I haven't, I never had any food at all. (Line 199)*
P3	*It was quite bland(...) it didn't smell of roses (...) see they the disinfectant wipes and things like that (...) there's a really strong smell of that sometimes. (Line 154)* *We kind of usually they came in with, about fifteen, twenty minutes before(...) you would decide whatever you were wanting. (Line 54)* *There wasn't really (...) the other three women that were there but it never affected us eating (...) we used to have a little gab and that but that was it. (Line 234)* *You're always staring at the same people, you're always staring at the same four walls, it always seems to be the same food you're getting offered (...)it was always the same things you were getting offered. (Line 429, 435)*	*When I get food if it doesn't look appealing then it's not appealing and a lot of the time the food was very very unappealing. / It was as if it had just been slapped onto a plate. (Line 259)* *I had the left hand side but I still found that some of the meals were pretty difficult as in cutting (...) because I can't cut it or things like that. (Line10, 17)* *I just used to struggle with a knife, like a fork. They just used to bring the food out to you, leave you with it. (Line 70)* *Being so young I think you don't really want to have to ask somebody to have to cut your food for you. So I think the most annoying thing was that you couldn't get some meals and you were probably thinking about it when you were seeing it, oh no I can't eat that. (Line 12)*	*They would just sort of start going back round again an collect everybody's trays. (Line 82)* *Time to go to sleep (Line 379)* *I was never satisfied by meals. (Line 381)*
P4	*With my chair here and the toilet right there (...) In and out, in and out, in and out all day (...)It was just a smell of a toilet (...) it wasn't really a nasty smell (Line 299, 312)* *We were in our bed waiting, and when the trolley came round, and on the trolley there would be meals on it. (Line 100)* *Nobody, just talking(...) patients and nurses. (Line 381)* *There was a total lack of choice (...) the soup, it wasn't conventional and I don't like barley, that's what you got and I hate barley (...) I said what is this? The only thing you got. (Line 7)*	*See the roast potatoes you can't cut an inch, can't cut them with your knife see the skins in them solid. (Line 425)* *What really turned me was the so called mashed potatoes. (Line 442)* *I haven't got the strength in that hand and I tried to struggle with this hand I just couldn't, just had to get one of the nurses or whatever was serving the meals to help. (Line 252)* *You eat alone in your bed. (Line 129)* *I'd say to the nurse that meal was rotten. (Line 64)* *There was nobody really to complain to (...) They'd come round and say did you enjoy that meal or what? (Line 67)*	*The nurses just took (...) your dishes away, took your cups and saucers, cutlery and plates, they took them away. (Line 138)* *You were in bed you just stayed in bed. (Line 147)* *Sometimes I spoke, depends who the person, who's there some people weren't able. (Line 552)* *Thank god it's over and done with (...) Because the meals absolutely rotten, rubbish. (Line 677)*
P5	*It's not an attractive place to eat is in the hospital. (Line 201)* *I was in the ward, four in a ward and just sitting there. (Line 31)* *I spoke to them (...) Just everyday things. (Line 84)* *Just four women in the ward, talking and the television. (Line 299)*	*It was different colours it depended what it was (...) I got em... cauliflower cheese(...) And I couldn't get enough of it, it was beautiful. (Line 323, 329)* *I couldn't hold the fork (...) my hand shook, so I had to use my right hand with the fork because the minute I lifted that up it was going like that and the dinner was falling off the fork, so I had to sort of dig in with the fork. (Line 154)*	*They just came and took it away (...) They just asked me if I'd enjoyed it. (Line 95)* *Just started talking away again to the other woman that was in the ward. (Line 174)* *I enjoyed it. (Line 380)*

Appendix I: Phase 3 – Sample of coding and charting data in workshop transcript with patients

Section 1: Developing a working analytical framework

Magical game	
Thematic colours	Sensorial
	Physical
	Social
	Emotional

Section 2: Coding data

Coding		Magical game	Notes
	616	*S: ok we wait a little bit more. I know P1's prepared to*	
	617	*tell us her story.*	
	618	F: yeah, that's what I like.	
	619	*S: ok so can we start…*	
	620	S: yes	
	621	*S: To tell our stories?*	
	622	S: yes	
	623	*S: P1 you would like to be the first, I can see you are…*	
P1	624	P1_ F: she's anxious. An Indian restaurant, the smell of	Ambience (smells) (visual)
	625	curry and different smells from the kitchen, tables all	
	626	decorated with candles which are lit with different	
	627	colours and tables with placemats.	
	628	*S: good thank you. How about you P2?*	
P2	629	P2: I'm going on somebody's boat, with the barbeque on	Ambinece (smells)
	630	the back of the boat so you're getting the smell of the	
	631	smoked food and putting a couple of steaks on barbeque.	
	632	And then on the plate and inside the boat it's no very	Self-control
	633	comfortable but the plate on my lap and a glass of wine.	
	634	*S: oh that sounds a good story too.*	
	635	F: don't forget the wine.	
	636	P2: aye you've got to have some alcohol.	

Section 3: Charting data

P1	P2	P4
she's anxious. An Indian restaurant, the smell of curry and different smells from the kitchen, tables all decorated with candles which are lit with different colours and tables with placemats. (Line 624) *A family sitting round the table and the meal brought in, in different dishes(…) of different food(…)choosing an appetising dish. (Line 554)* *socially ideally for her would be the Grandson's playing their games and I laughing at them and helping them when required. Typical grandmother (…) listening to them listening to their wee jokes. (Line 694, 698)* *She has said the satisfaction of feeling full and feeling drowsy. (Line 701)*	*I'm going on somebody's boat, with the barbeque on the back of the boat so you're getting the smell of the smoked food and putting a couple of steaks on barbeque. And then on the plate and inside the boat it's no very comfortable but the plate on my lap and a glass of wine. (Line 629)* *Al-a-carte. (Line 556)* *I was out one afternoon and I come in and I was hungry and I popped my head round in the dining room and there was a local Sheriff, Sir Steven Young and saw me and gestured that he wanted to talk to me. So I went and sat down at the table and I was starving and (clears throat) and he was just saying his daughter had been out drinking in different hotels in the Peninsula and he wasn't very happy about it and I was trying to tell him that I knew who she was and she hadn't been in here drinking because she was underage and that was all (…) to go to the pub and get a drink and a fag. (Line 667, 686)* *I was thinking hurry up and get across to the pub (…) I was thinking(…)I wanted to be more sociable after the meal (…) interact with the other people (…) have a drink and a fag (laughs). (Line 709, 722)*	*Aye, going to McDonalds with my Grand weans (…) Going to the McDonalds for the afternoon (…)you can smell the chicken and chips and that (…) the people going about and other people talking (…) it was quite good. (Line 658, 671)* *See what's happening and going on around you (…) you can pick up what you want to on yourself, have your meal by yourself. (Line 574)* *Well eh my daughter in law and son and the kids and sometimes my daughter. (Line 708)* *You get a good tuck in(…) quite happy (…) em… enjoyed being there. (Line 642, 651)*

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Appendix J: Phase 3 – Sample of coding and charting data in workshop transcripts with healthcare professionals

Section 1: Developing a working analytical framework

What if?			
Themes	Before (B)	During (D)	After (A)
Thematic colours	Sensorial		
	Physical		
	Social		
	Emotional		

Section 2: Coding data

Coding		What if?	Notes
B	100 101	P6: Like the smells of the food, you know you get the smells wafting through from the kitchen.	Ambience (smells)
B	102 103	P1: He's very enthusiastic isn't he, he's very enthusiastic about what he's cooking.	Empathy
	104 105	*Tell me about enthusiastic, what do you mean by enthusiastic?*	
B	106 107 108 109	P1: He's very passionate about what he put's in his food, he loves his spices and all things like that and he's very passionate about his taste. Everything has to taste good not just look good but taste.	Empathy
	110 111	*And around of her what things could happen you see that Jamie Oliver could provide to….?*	Ambience (visual) presentation
B	112	P1: Something nice to look at.	
	113	*Ok*	
	114	P1: As in him	
	115	*(Laughter from the group)*	
	116 117	*Do you have an example to give me, what kind of things, these nice things.*	
	118	P6: Not that you can put on tape	
	119	*(group laughter)*	
B	120 121	P5: I suppose good food, it doesn't make a difference really when it's good quality.	
	122	Yeah	
	123	P6: I guess you've got that expectation because it's him	

Section 3: Charting data

Before	During	After
P5: *Like the smells of the food, you know you get the smells wafting through from the kitchen. (Line 100)*	P1: *It's to look nice for you, you don't want it just all shoved in a bundle in the middle of the plate, you want it presented well so that everything complements each other. (Line 248)*	P5: *You can sit at the table. (Line 325)*
P1: *Something nice to look at. (Line 112)*	P1: *and they all have the same presentation so it's very pleasing to the eye, (Line 256)*	P6: *You can sit and have a cup of tea or whatever afterwards you know at your leisure you know. (Line 326)*
P5: *I suppose good food, it doesn't make a difference really when it's good quality. (Line 120)*	P6: *It's that's thing that when you eat there is so much happens before you put that first bite in your mouth it's about the smells and it's about if something comes down and it's on your plate and it's just presented really nicely. It's laid out really well. (Line 258)*	P1: *If they ask if you enjoyed it then, feedback. (Line305)*
P5: *It's the interaction. (Line 142)*		P2: *I suppose you'd be chatting about "oh yours looked nice and how did you enjoy it." (Line 307)*
P1: *They take in what they person that they're cooking for, what they like. (Line 202)*	P1: *It would be like a nice environment, a comfortable environment. (Line 215)*	P1: *"gis a bit" (Line 309)*
P5: *You'd be hoping that he was going to come out and say hello to you. (Line 137)*	P6: *A comfy chair, I hate it when you go to a restaurant and kind of half way through the meal you're like, back's killing you. (Line 219)*	P1: *Chat to Jamie about what he's doing at the weekend, a wee chocolate. (Line 328)*
P1: *He makes everything a joke, he makes things funny by the comments that he makes when he's doing the cooking. He involves people as well. (Line149)*	P5: *I think to be knowledgeable About what they're serving you, to be happy. (Line 246)*	
P5: *And yeah he can be quite amusing and he's so enthusiastic about the food that he talks about it's not as much about making jokes for him it's about "wow look at this"(Line 175)*	P1: *it's there personalities makes it pleasurable as well and the way they're dressed as well. (Line 280)*	
P5: *He's very enthusiastic isn't he, he's very enthusiastic about what he's cooking. (Line 102)*	P1: *They all have the same passion though. (Line 255)*	
P1: *He's very passionate about what he put's in his food, he loves his spices and all things like that and he's very passionate about his taste. Everything has to taste good not just look good but taste. (Line 106)*	P1: *You enjoy it more. (Line 263)*	
P5: *He's got a good sense of humour too though hasn't he. (Line 140)*	P3: *You kind of go "oh wow." (Line 265)*	
P1: *It's his personality. (Line 147)*		

Appendix K: Phase 1 – Consent form for healthcare professionals

Project title: Enjoy your meal: design tools and strategies for stroke patients

Before you read this consent form please make sure you have read the enclosed 'Project information sheet: the initial meeting with stroke specialists' and asked the researcher any questions you may have.

This form is to ensure that everyone taking part in the research fully understands the following:

1) I confirm that I have read and understood the Project information sheet for this research and I have had the opportunity to discuss this project and ask (questions).

2) I understand that my participation is voluntary and that I am free to withdraw from the research at any point without giving any reasons.

3) I understand that I can withdraw all or part of what I say during the research. I'm free to do this without giving any reasons.

4) I understand that this research will be published in reports, journals or in other forms that will be widely available and that my contribution will remain anonymous.

5) I have been informed that what I say will be kept safe and secure in accordance with the Glasgow School of Art Ethics Policy.

6) I agree to my interview being recorded by a recorder.

7) I agree to take part in an interview for this research.

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Name of volunteer   Date   Signature

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Name of person taking consent   Date   Signature