Humanising Services: A new transferable leadership strategy for improving 'what matters to older people' to enhance dignity in care

Executive Summary

Background: The research was led by academics at the University of Hull (Kathleen Galvin, overall Chief Investigator (CI)) and Fiona Cowdell, local Principle Investigator (PI) and Bournemouth University (Caroline Ellis-Hill, local Principle Investigator (PI)). Within two purposively selected diverse care settings, a dermatology out-patient clinic in Hull and a stroke rehabilitation unit in Bournemouth, a tripartite humanising team comprised of older service users, healthcare staff including nurses and two researchers (Carole Pound and Claire Sloan) have engaged in a 'humanising improvement' process, with the aim of developing a transferable strategy for improving 'what matters to people' in order to support enhancements of dignity in care.

Aim: Eight humanising theory-led action research sessions were conducted in each location over the period of one year with the aim of answering the following question: What are the transferable benefits of a new participatory leadership strategy for improving the human dimensions of human services?

Project stages: In the first stage of the study both groups, facilitated by academic partners, learned about a new humanisation theory (Galvin & Todres, 2012) and explored the eight humanising dimensions (Todres et al., 2010), relating them to their own experiences of humanisation and dehumanisation in each setting which created new understandings and insights relevant to each setting.

During the second stage, group members carried out a humanised care assessment of the setting, drawing on each group member's experience of practice in their setting. This stage involved listening to and collecting examples of both humanising and dehumanising practices and then deciding how to take a humanising approach forward. An explicit theory application strategy was used in Hull, and an implicit strategy using 'Appreciative inquiry' at Bournemouth. Both are compared in a cross site comparison of the application of the theory to improve what matters to older people.

The third stage focused on implementation of actions that would enhance care practices that focus on the human dimensions of care and the development of transferable strategies for other care settings beyond the life of the project. A humanised care plan within each setting was initiated and dissemination materials and activities were created and engaged in with the purpose of sharing and transferring the study experience of the group participants to other health care staff in the setting.

Outcomes: As had been anticipated, differences in the locations, contexts, health conditions experienced and needs of the service users as well as the approaches taken by the two humanising improvement action research teams produced interesting contrasts in both processes and outcomes. In both instances group members were actively engaged in application of the humanisation framework, led by patients' own experiences and journeys,

which enabled them to participate in decision-making about enhancing care in humanising terms. A transferable leadership strategy is offered in the form of a suite of materials developed as part of the project, including a humanising care toolkit, DVD film of team project experience, with one teams' humanising journey in detail, and a humanising care assessment tool in the form of a validated questionnaire. These were developed with transferability in mind to be utilized in future dissemination and to help develop and extend the life, reach and applicability of the work. Of particular note is our aim to offer a transferable leadership strategy through this suite of materials: 'Humanising Care Toolkit' and the production of the 'Humanised Care Assessment Tool'.

Transferable outcomes from this project are intended to enhance impacts on practice and educational curricula. The overall strategy used included engaging diverse service user groups within in-patient and out-patient health service and service providers in order to ensure benefits would be transferred widely. The present report details the processes and outcomes of the project, provides a Humanising Care Toolkit that includes a process guidebook (manual) and film (DVD) aimed at sharing humanising care improvements and indicating transferable steps that can be employed. The development of the Humanised Care Assessment tool and piloting are described in detail with suggestions for its use. The project has culminated in two service user led dissemination events and development and piloting of a humanising care assessment tool in the form of a questionnaire. The findings and outcomes contribute to pathways and directions for practice in enhancing dignity in care.

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Acknowledgements

Section 1: Introduction

Something is missing in contemporary health and social care. Patients and services users are telling us in different ways that they do not feel fully met as human persons in the way that care is organised and practised (Patients Association, 2009; 2012). Further, the experience of dignity is closely linked to an understanding of what makes people 'feel human.' Conversely, what leads to dehumanisation and therefore loss of dignity needs to be understood and acted upon in meaningful service improvement (Galvin & Todres, 2014).

Based on a new conceptual framework through which humanly sensitive care can be achieved (Todres, Galvin & Holloway, 2009) the Humanising Services project was implemented in two NHS settings, in Hull, Yorkshire and Bournemouth, Dorset. A theory led participatory strategy to support health care staff working alongside older service users and academics was employed. Humanising care improvement teams in the form of theory led action research groups (ARGs) in both locations met with the purpose of 1) exploring an understanding of the eight dimensions of the humanisation framework (HFW) (Galvin and Todres, 2009) 2) assessing or evaluating the current practises of the unit in terms of humanised care and 3) creating and implementing a plan for specific action that will develop leadership to support improved dignity in care for service users (SU).

This report starts with an overview of how the Humanising Services project was implemented in two different settings, an in-patient stroke unit at The Royal Bournemouth and Christchurch Hospital (RBH) and an out-patient dermatology unit at Hull Royal Infirmary. The background and rationale for the study follows including a description of current approaches to care generally being utilised and rationale for introduction of a new framework to enhance a more humanised approach.   A review of relevant policies and literature supporting the need for a focus on human dimensions of care is summarised and links to threats or restoration of dignity in care are made. The aims and objectives of the study are presented and the research method explained. An evaluation of the findings follows including descriptions of processes and outcomes within each site as well as a cross site comparison. The findings and outcomes are discussed in relation to the research objectives and, finally, a conclusion is presented suggesting transferable strategies for delivering dignity through a focus on 'what matters to older people' in humanising terms.

Section 2: Lifeworld led humanisation

The research is based on the theoretical and practical work of Galvin and Todres (2013). Advocating an approach to care that is founded on a phenomenological, lifeworld-led approach (Todres et al., 2007; Dahlberg et al 2009; Galvin & Todres, 2013), eight dimensions of humanisation and dehumanisation have been identified and are useful to practice (Borbasi et al., 2013). These are not detailed lists of 'dos' or 'don'ts' or abstract generalities such as the need for more 'user/customer focus' or 'choice'. Rather, they are eight bipolar dimensions, that act as points of emphasis presented as a theoretical framework, about

what can make a person feel 'more' or 'less' human. The use of such a framework can be used as a sensitising tool to help nurses, along with other health care staff, and patients and service users to assess care and to effectively guide actions to improve services with the overall aim of enhancing dignity in care. The table below summarises the eight human dimensions of care, each with their corresponding form of dehumanisation. Together the dimensions delineate what needs to be attended to so that patients and service users experience care as meeting their needs as human persons. Conversely, forms of dehumanisation present threats to dignity of patients and service users as human persons, however it is important to note that each dimension is considered as *an emphasis* along a continuum. Each of the dimensions will be discussed in further detail on page 9.

Figure 1: Conceptual Framework

Conceptual Framework of the Dimensions of Humanisation

Forms of Humanisation	Forms of Dehumanisation
Insiderness	*Objectification*
Agency	*Passivity*
Uniqueness	*Homogenisation*
Togetherness	*Isolation*
Sense – making	*Loss of meaning*
Personal journey	*Loss of personal journey*
Sense of Place	*Dislocation*
Embodiment	*Reductionist body*

Section 3: Background and rationale: Why a humanising approach?

Research into health and healthcare has achieved substantial advancement in knowledge and improvements in care through its focus on interventions, treatment and cure. However, there is increasing evidence in the media and from qualitative research in particular, that the human dimensions of care can be obscured by a sometimes necessary technological and specialised focus. As long ago as August, 2009, a published Patient's Association report, *Patients … not Numbers, People … not Statistics,* questioned standards of care on a human level. We all want care to be efficient and effective, but it is not difficult to see how easily the human dimensions can get lost or obscured. For instance, the inherent division between 'mind and body' and between the 'body and society' has resulted in emphases that often include only the treatment of physical symptoms with regard to what are labeled as physical diseases. The intimate connection between the self and body that can easily be lost has been highlighted by Bullington (2006) who describes the embodied human being as living in a meaningful context or lifeworld which is rarely considered within medical or sociological research. Leder (1992) helpfully states, "When the body falls sick,

we are left not simply with a broken machine, but with a world transformed, a disease undermines our sense of self and autonomy, our relations with others, our habitual experience of space and time" (p.5). In her seminal text, Toombs (1993) evocatively describes the different perspectives of patient and physician and underlines the need for a lifeworld perspective in practice to reconcile these first person and third person views. Further, we know very well that physical diseases affect more than the physical body (Wahl et al., 2002). We therefore argue that to enhance humanly sensitive practice and provide a foundation for dignity in care, healthcare professionals need a beginning place that illuminates understandings, concerns and experiences of older adults that has its foundation in the lifeworld. The lifeworld for the purposes of this report refers to a particular view of the person as humanly living in the seamlessness of everyday life that includes temporality, spatiality, embodiment, sociality, or being in relation to others. This philosophical underpinning also includes a holism about the nature of care, here caring practice is mindful of restoring patients to all their possibilities and connections within their lifeworld, even in limited ways, and this can be achieved by attending to 'what it is like' for the older person, and for the purposes of this present project by specifically attending to eight humanising dimensions of care as directions for practice.

These eight dimensions are: **Insiderness:** Practices that connect with people's 'inward sense' of how they are, and which avoid making people feel excessively like 'objects'. **Agency:** Practices that enhance peoples' sense of being an active participant in their care or service use and that avoids practices that reduce human dignity. **Uniqueness:** Practices that help a person feel that they are being seen as individuals, and not only as a category or a diagnosis. **Togetherness:** Practices that address the need for belonging and for finding familiar interpersonal connections, so that a sense of isolation is reduced when facing challenging conditions or circumstances. **Sense-making:** Ways of communication and information-giving so that people don't just feel like a 'cog in a wheel'; **Personal journey:** Practices which help people to retain a sense of their own history and continuity. **Sense of place:** Practices that enhance the physical environment around care and the service so that people can feel more 'at home'. **Embodiment** (living as this body): Practices that help people to expand their horizons beyond narrow definitions of themselves, thus enabling more supportive personal identities.

Although these dimensions may seem abstract on first reading they can be translated into very practical questions. We will show through this project that they can be applied in practice using two different strategies and that they make sense to both service users and health care staff when they have had some time and facilitation to consider them within an experiential context (See Section 6). For now, we provide illustrative examples of questions that may be asked of service users: **Agency:** What would make you feel that you have more of a say in your care. Alternatively, what practices have made you feel that you do not have enough of a say in how you have been treated? **Sense of place:** What would make you feel 'more at home' in the places that you receive service? **Sense of journey:** What would make

you feel that your 'care' and the way that you are treated is 'joined up' with what has happened with you and the services you have received in the past? **Togetherness:** What would make you feel less isolated and more connected with the people who matter to you when you are having services provided by this setting?

Further, the humanising care framework offers *directions for practice* that can respond to meeting human need in highly specific ways that we believe offer a practical step forwards from the six values of Care, Compassion, Courage, Communication, Competence and Commitment, "the 6C's" (DoH, 2012). The 6C's were developed drawing on the phenomenological work of Roach (1987) who theorised professional caring values and outlined five attributes for caring in Canada. These concepts were developed further in a vision and strategy by the UK Chief nursing officer, who outlined a strategy for building a culture of compassionate care based on six values of Care, Compassion, Courage, Communication, Competence and Commitment. We argue that a meaningful step forward can be achieved by a) a distinctive focus on 'experience near' forms of humanisation and forms of dehumanisation given by the framework b) provision of actionable pathways to enhance care, beginning with patient experience and sensitised by humanising theory. The theoretical framework also has potential to reconnect practitioners to the values that motivated them towards caring work and which sustain their capacity to care. Therefore the present Humanising Services project responds to the Burdett Trust Empowering Dignity Programme by contributing new experience near understandings and by providing practical, transferable strategy for the implementation of a more humanised approach to healthcare.

As the focus of the research was to understand experience of older people in two distinct care settings, with two different health conditions, service users and health care staff, were invited from a dermatology out-patient clinic and a stroke rehabilitation unit to form a humanising care team that would meet as a series of action research groups. The inclusion of participants in two contrasting care settings enabled researchers to compare both similarities and differences in what aspects of humanised care are most transferable and most important to older service users.

The need for a humanising approach
We have found considerable evidence in the literature to suggest that a humanised care approach can enhance caring practices in both these settings: What follows is a short summary of evidence from both skin health care and stroke rehabilitation concerning the need for more humanly sensitive care.
In dermatology reports show that health care staff are inclined to treat patients with an emphasis on their skin condition alone rather than as a whole person (Young, 2005) and despite increasing knowledge about the need for more human care this problem persists over time (Nelson et al., 2013, Chisholm et al., 2016). This tendency to treat the skin disease

rather than the person is an example of a reductionist view of the body obscuring other human dimensions.

There is also established knowledge that long-term skin conditions can be all consuming. Qualitative studies involving people with three of the most common skin conditions all report troubling social and emotional ramifications in addition to physical signs and symptoms. People with psoriasis reported their condition as life changing, radically altering the self and contributing to a downward spiral in psychological health (Watson 2007) and impacting on many areas of their life (Pariser et al., 2016). Similarly within the experience of acne the visible signs of disease are hard to bear and impact negatively on self-perceptions and interpersonal relationships (Prior & Khadaroo, 2015). Eczema which persists into, or emerges in, adulthood can compromise quality of life, sexual relationships and choice of occupation (Katsarou & Armenaka, 2011). The focus on the skin rather than the human being can lead to impoverished consultations (Nelson et al., 2013) and can perpetuate the mismatch in disease severity when assessed by patient and clinician with the patient regarding their condition as more severe (Richards et al., 2004). Lack of sensitive human communication can lead to passivity, non-adherence and feelings of shame and isolation (Brown et al., 2006). Whilst the importance of seeing the whole person is increasingly recognised in dermatology care the majority of research continues to focus on physical signs and symptoms and tends to ignore the sufferer's personal experience of living with and through the disease.

Similar themes are evident within the care in stroke literature. A recent systematic review of stroke rehabilitation services concludes that there needs to be an equal focus on social and psychological dimensions as well as the physical for dignified care. Services need to be expanded to help a person focus on their recovery in their unique social world (Reed et al., 2012). Although outcomes for stroke survivors have improved greatly (Royal College of Physicians, 2014), patients and their carers still ask for more individualised approaches to care. They call for consideration of the whole person within the context of their rehabilitation and less emphasis on physical needs (Morris et al., 2007; Stroke Association 2015). During the in-hospital phase of their care, for every description of a physical need (elimination, eating and drinking, personal hygiene) patients gave lucid accounts of potentially dehumanising impacts (humiliation, distress, lack of dignity, recovery and confidence). Consistent features of positive experiences included stroke survivors describing how the physical, psychosocial and relational dimensions of care were integrated and coordinated around their particular need (Gallacher et al., 2013). Further, a review of qualitative studies investigating in-patient rehabilitation reported negative experiences in all cases and included disempowerment, boredom, frustration and personal goals not reflected in therapy. Stroke rehabilitation research would benefit by taking into account the lived experiences and preferences of stroke survivors (Luker et al., 2015).

Older people in particular are disadvantaged by care which lacks understanding of what it is like to live after a stroke. Nurses are considered as critical elements and key figures influencing the quality of the patients' recovery in hospital (Strull et al., 1984) however nurses and health care staff can often fail to see beyond discharge. For elderly stroke patients, to be treated with respect and dignity seems to be a core element influencing satisfaction with rehabilitation. 'Being treated with humanity' in services was identified as one of the five main subcategories of respect and dignity indicating that a range of cognitive and affective factors influence the process of patient satisfaction. Emphasis on functional recovery for elderly patients needs to be expanded with an approach also emphasising psychosocial aspects (Mangset et al., 2008).

Despite our ageing population and the fact that older people are a core group in receipt of services form the National Health Service (Age UK, 2016) there is extensive evidence that this group is consistently excluded or marginalised from health care research (McMurdo et al., 2011, Clegg et al.,2015). Justification for such exclusion is twofold. Firstly older people are frequently and unfairly often labelled as 'vulnerable'; one view that has been argued as a socially constructed concept without agreed definition (Alexander, 2010). When used as a *label,* it brings to the fore the ethical implications of research with some investigators believing that older people are in need of protection (McMurdo et al., 2011) which in turn, can lead to a paternalistic approach by gatekeepers in which older people are routinely denied the opportunity to participate in studies. The counter argument is that it is unethical to simply exclude older people without good reason as this may deprive them of the benefits of participation (Alexander, 2010) and it also represents a barrier to effective translation of research into clinical practice. For instance, in very practical terms, given that many new therapies will predominantly be used by older people it is important that they are not disadvantaged by being offered treatments that have only be tested with younger people (Mody et al., 2008). The second reason is often simply a lack of knowledge about how to engage older people in the research process. There is a growing literature on how older people may best be recruited and retained in high quality, ethically sound studies (Auster & Janda, 2009); following such guidelines will guide essential and meaningful engagement of older people throughout the research process. Further, there are nuances about empowerment, agency, passivity and even exclusion that are particularly relevant here. A lifeworld perspective provides a deeper context within which empowerment can still be cared for. This is not just a strategic emphasis of 'more choice' but rather when people are ill or frail they need to be seen in both their agency and their illness because they can feel unmet as humans by interactions and practices that emphasise one at the exclusion of the other.

Given this evidence we are interested in older peoples' ideas about what matters to them in human terms by drawing on our humanising theory and then finding ways to translate ideas into practice in partnership with them. In summary, we aimed to show how, by using a new framework for humanising care, 'what matters to older people' could be illuminated.

Further, by using participatory research we offer transferable knowledge and a leadership strategy for other settings. A theory-led action research approach, utilising tripartite teams of service users, health care staff and academic researchers, aimed to both maximise understandings, as led by everyday experiences of the settings, and secondly to investigate transferability of strategies for improved healthcare, all informed by core dimensions of what it means to be human.

Section 4: Aims and objectives

The main research question that framed the study was: What are the transferable benefits of a new participatory leadership strategy for improving the human dimensions of services? The **overall aim** of the project was to use new theory to contribute to a better understanding of what matters to older people to enhance dignity in care and to investigate the transferable benefits of a new participatory strategy for improving the human dimensions of health care services.

Specific objectives were to:

- Investigate what healthcare experiences and practices are important to older people in making them feel human
- Introduce and explore together a new, eight dimensional conceptual framework based on humanisation theory
- Identify the human aspects of care and practice that could be developed within a dermatology outpatient clinic and a stroke rehabilitation unit within a targeted 'humanising improvement initiative', led by new theory
- Plan, implement and assess a humanising services improvement process in each site
- Highlight similarities and differences in the two research settings, offering a comparative analysis to add context to the findings
- Identify transferable processes that have potential to enhance dignity in care for older people in other human service areas
- Produce dissemination materials, including a Humanisation 'Toolkit' (Guidebook), for the purpose of sharing our understandings of 'what works' in humanising service with other practitioners and settings
- Two transferable outcomes, informed by the theory-led action research process have been achieved: a film (DVD) that shares stories and experiences of the participants was produced as an addition to the toolkit and a questionnaire, 'The Humanising Care Assessment tool' was created to be used as an instrument for groups planning to conduct similar project.

Section 5: Methods

Research Design

Action research methodology, sensitised by humanising theory was utilised to a) achieve a participatory form of reflection, and discussion of care in humanising and dehumanising terms b) to facilitate decision-making in establishing what kind of humanised changes could be achieved and c) to reflect on what impacts this might have on dignity in care. It was also selected in the hope that a participatory strategy would provide a strong basis for sustaining any changes implemented beyond the life of the project. In this project, tripartite Action Research Groups composed of approximately ten service users, service providers and academics met in two different locations during the study. This facilitated a strong focus on participatory principles. The study was purposively designed as a theory led action research project purposively testing out application of a new theory of humanisation.

Context and participants

Two clinical settings were selected for use in the project, the dermatology outpatient department in Hull Royal Infirmary and the stroke rehabilitation service at the Royal Bournemouth and Christchurch NHS Foundation Trust. The two different locations and types of services provided opportunities to compare and contrast various aspects of the humanising process which are discussed in the evaluation section of the report.

Each theory led action research group was composed of four to five service users, three to four service providers and two researchers. The number of service users was chosen to ensure that people receiving services did not feel 'outnumbered' by staff members. The size of the group, ten to twelve, was consistent with best practice in running action research groups. Maximum diversity in relation to participants' experiences of using and providing the service was sought. Purposive sampling was used alongside the inclusion and exclusion criteria for selecting participants. All service users were aged sixty-five and above, medically stable and able to participate in group conversation. Practitioners were individuals currently working in or familiar with the clinical setting and able to attend meetings in working hours. Each action research group meeting was coordinated and facilitated by two researchers. Further details regarding participants can be found in Section 6 of the report.

Study Overview

Bournemouth site – Acute stroke Rehabilitation

5 service users | 6 service providers

4 researchers

9 x 90 minute Action Research Groups

Hull site – Skin health outpatient department

7 service users | 3 service providers

3 researchers

8 x 120 minute Action Research Groups
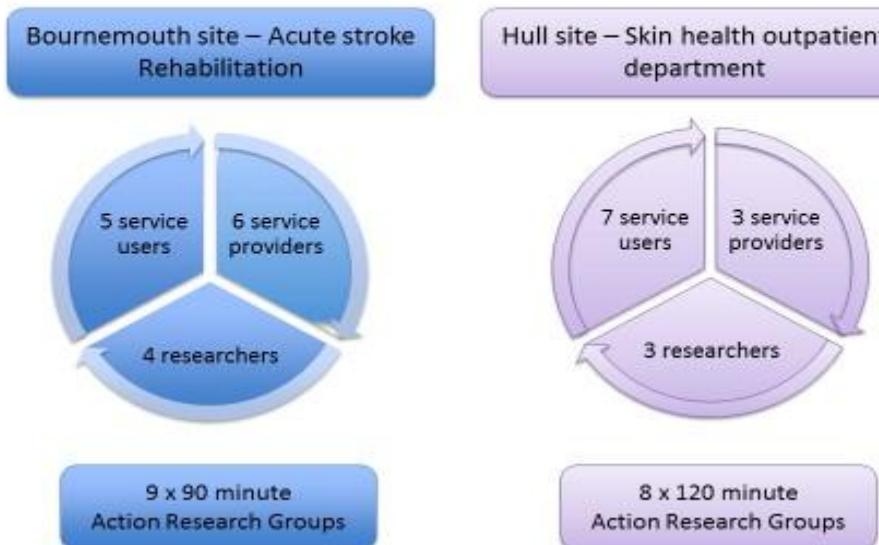
Research Governance

Ethical and research governance approval was secured from the Faculty of Health and Social Care, University of Hull (appendix 1), and the Proportionate Review Sub-Committee of the NRES Committee North East – Sunderland (REC Reference: 14/NE/1046; IRAS project ID: 150621) (appendix 2) and the NHS study sites (appendix 3).   Prior to giving written consent, participants were given an information sheet about the study explaining their right to withdraw at any time without giving a reason and that participation would not affect their continued access to treatment in any way. Those interested were invited to attend a question and answer session to learn more about the project and the proposed activities. The collaborative, relational requirements of action research where participants work together in groups required that researchers establish ground rules relating to confidentiality which were reinforced at each meeting. In the case of any group member becoming distressed while discussing negative experiences of healthcare, they were encouraged to take time out from the group meetings and provided with access to local sources of support and counseling.

As participants at both sites included older adults, researchers in contact with participants in Hull and Bournemouth had enhanced Disclosure Barring Service certificates. Research associates working in Hull had honorary contracts with Hull and East Yorkshire NHS Trust which allowed them to work in the dermatology department at Hull Royal Infirmary. Researchers working at the Royal Bournemouth Hospital were granted research passports to cover the duration of the project. Research and development approval was given by the

Royal Bournemouth and Christchurch NHS Foundation Trust and the Hull and East Yorkshire NHS Trust.

Data were stored and used in accordance with the NHS code of confidentiality (2003), the data protection act (1998) and university guidelines. The research team reported on progress at regular intervals to a steering group, to the project sponsor, the University of Hull at six monthly intervals and annually to the Board of the Burdett Trust for Nursing who were the main funder for the project.

Access to the Setting

Access to the sites was arranged in collaboration with the lead consultants. Dr. Shernaz Walton (Hull Royal Infirmary) and Dr. Damian Jenkinson (Royal Bournemouth Hospital) facilitated the research to engage fully with the clinical care teams at the respective sites.

Access to the Participants

The local care team was the initial point of contact providing individuals with a participant information summary sheet. Individuals from the staff team and service users interested in joining the ARG were invited to a Question and Answer Session to find out more about the project and the proposed activities. This meeting was also an opportunity to explore any concerns about participating in the ARG meetings and find out what kind of support might be required to enable individuals to participate, for example timing of sessions, additional communication support, help organizing transport.

Following this meeting, or an equivalent one to one session if any potential participants were unable to attend, those individuals who remained interested were invited to take away and complete written consent forms. A full discussion of the processes involved in each theory led action research group is provided in Section 6.

Data collection and analysis

All meetings with participants took place at local NHS premises near the dermatology outpatient department (Hull) and the stroke unit (Bournemouth). There were always two facilitators present at ARG meetings to ensure one facilitator was able to support any member of the group who might become distressed or unwell. All ARGs were audio recorded and tapes were transcribed and anonymised at the point of transcription. The data also consisted of meeting notes, distributed to all group members and field notes taken by the researchers. The researchers carefully documented all aspects of process and decision-making in line with the aim to capture the way the humanising improvement process operated in both sites. Data generated in the ARGs was in the form of participant stories and experiences and transcripts documenting discussion and processes of decision-making. Researchers also kept field notes and research journals to support reflection on

settings, meetings and research processes. The following table 1a summarises the level one analysis (within setting analysis) and the level two analysis (cross setting comparison).

Table 1a: Summary of 'within setting' and 'across setting' analysis

	Level one analysis		
	Data source	Data analysis	In order to
A	Transcripts of meeting	Were reviewed and analysed qualitatively by researchers to identify what experiences were described by • older people • staff as humanising or dehumanising	Investigate what healthcare experiences and practices are important to older people in making them feel human
B	Reflections of researchers	Explored to identify how easy/difficult it was to explore the humanisation framework (HFW) together	Discover how easy/difficult it was to introduce and explore together a new, eight dimensional conceptual framework based on humanisation theory to service users and service providers
C	Group notes	Were used to assess a) how people decided what to do b) what supported this activity	Identify the human aspects of care and practice that could be developed at RBH and HEYH within a targeted 'quality improvement initiative' led by new theory
D	Group notes /reflection	Used to a) describe what happened re plans and implementation and outcome b) describe what needs to be in place for this to happen	Plan, implement and assess a humanising services improvement process in each site Evaluate the impacts and outcomes of the action research process in each site
	Level 2 analysis		

	Comparative analysis of B,C and D	To highlight similarities and differences in the two research settings, offering a comparative analysis to add context to the findings	
	Comparative analysis of B,C and D	Identify transferable processes that have potential to enhance dignity in care for older people in other human service areas	
	Dissemination		
	Humanisation Toolkit/ Guidebook and film DVD	Produce transferable strategy materials	Share our understandings of 'what works' in humanising service with other practitioners
	Development		
	An initial humanised care assessment tool/questionnaire piloted	To allow clinical areas to assess levels of humanisation in their settings	Potential outcome measure for future research in development

Recordings of ARG meetings were transcribed and the data were reviewed and analysed in an iterative process that allowed researchers to understand how people conceptualised humanisation and to identify next steps to be taken. This process also enabled the research team to identify how well and in what way experiences related to the eight dimensions of the humanisation framework. Key experiences that service users highlighted as having a significant impact on them were also analysed. For example, key stakeholders in the ARGs were asked to describe important moments of humanly sensitive care, or otherwise, concerns or important turning points within their healthcare journeys to help illuminate the human aspects of practice under discussion. Data concerning all aspects of the decision-making process about what really matters in relation to human aspects of care and practice and ways to make services more humanising were documented in each meeting. These data were subjected to reflective analysis whereby an assessment of the ease and relevance by which the humanising conceptual framework was translated into useful 'humanising practice' directions was undertaken. These data were of particular importance in delineating transferable aspects of the humanising improvement strategy.

Summary

Sections 1-5 have presented an overview of the Humanising Care project and described how it was implemented in two different settings, an in-patient stroke unit at The Royal Bournemouth and Christchurch Hospital and an out-patient dermatology unit at The Hull and East Yorkshire Hospital. The background and rationale for the study was given including a summary of current approaches to care being utilized and rationale for introduction of a new framework to enhance a more humanised approach. A review of relevant policies and literature was presented supporting the need for a stronger focus on human dimensions of care. The aims and objectives of the study were outlined and the research method explained.

Sections 6-9 will provide an analysis/evaluation of the findings including descriptions of processes and outcomes within and across the two research sites. Transferable strategies for delivering dignity in care that could prove valuable for other practitioners or service teams are presented in terms of what worked well, lessons learnt and challenges to overcome. A detailed description of the suite of materials produced including a toolkit, (process guidebook), film (DVD) and humanised care assessment tool is presented. The concluding section summarises the research outcomes in relation to the original aims and objectives of the project.

Section 6: Analysis and evaluation

This section of the report firstly describes each research setting in terms of background and context followed by a brief summary of the recruitment to tripartite Action Research Groups and the participatory process. A description of these Action Research Groups (ARGs) in both settings is given including where and how often the groups met, attendance issues, the role of the researcher and introduction of the humanisation theoretical framework. Details of how each session in Bournemouth and Hull was facilitated are presented in a summary table. 'Within setting' outcomes are highlighted and impacts at the service, individual and institutional levels discussed. Finally, a 'cross setting' comparison is offered regarding similarities and differences in the two sites to underpin additional conclusions about transferability.

The Royal Bournemouth and Christchurch Hospitals Trust Stroke Rehabilitation Unit

Background and Context: first contacts, the setting, shadowing, study recruitment

Initial contacts with the stroke rehabilitation unit included a meeting with the Stroke Research team and consultant stroke physician where details of the study were explained and discussed. Each of these individuals helped facilitate introductions to other key staff.

Additionally, an initial meeting was set up to introduce the study to the two main managers of the stroke rehabilitation service.

The stroke unit is a complex service involving many interacting services including the Emergency Department, Acute Medical Unit, Hyper Acute Stroke Unit, Acute Stroke Unit, Early Supported Discharge (ESD), Day Hospital and Community Service. The experience of service users inevitably includes contact with many aspects of hospital and community life. Given the relatively short time scale of the study and the need to have a clear location for theory application and any potential service improvement initiatives, a narrowing of focus was necessary. Service providers based in and funded by the Acute Service and ESD were finally selected to participate in the study. This provided a good opportunity to apply the theoretical framework to key points of transition and to investigate services that were offered both in the hospital and at home within the community.

A period of shadowing allowed the RA to familiarise herself with the setting and to build relationships with a range of staff working on the unit and the ESD. By talking about the study to service providers and the onsite research team, the RA began to identify potential participants and facilitators in the recruitment process. It was also a good way to observe a wide variety of meetings that took place on different days and interact with staff who worked part time as well as to 'get a feel' for the fluid, fast-moving pace of the unit. The shadowing process was facilitated by the enthusiastic engagement of the consultant, the preliminary meetings with the key managers and the knowledge and ideas of the research team based on the unit who were helpful in making suggestions and facilitating introductions. The existing strong research and service improvement culture of the stroke care service was encouraging, the RA experienced staff openness to the project and willingness to help recruitment, as the teams were familiar with research processes for accessing samples of staff and service users   As one senior nurse who was a key referrer to the study said, "anything that improves quality of care because that's what the service is all about."

Recruitment and participation

Recruitment to the ARG, laying the foundation for engagement with the humanising theory and a humanising assessment began during the shadowing days. Informal discussions which included brief descriptions of the project were engaged in with key staff members. A one page information summary of the research was distributed to key staff and anyone who expressed a desire to know more about the project. Staff members on the stroke rehabilitation unit and ESD were also invited to attend a 'Thoughtful Thursday' session where the research team talked to approximately twenty staff about the project and what the ARG would entail. Thoughtful Thursday is a weekly 30 minute in-house learning event held on the unit. During this specific preparatory meeting potential participants were encouraged to think about what makes *them* feel human, and why humanising care might need researching. Explanations were given about how the project team aimed to ensure

that a range of voices of those with rich experience of using and providing stroke services would be at the heart of the focus on humanising stroke care. As a result of this session and the distribution of a summary of the session to staff who could not attend, we were able to recruit six staff members representing nursing, therapy and discharge coordination (see table 1).

The ethical process required that the RA could not approach patients/service users directly. Therefore the information sheet also proved to be a useful to help service providers give basic information about the study to potential service user recruits. A fuller information sheet was provide to those who expressed an interest in the study (Appendix 4).

Table 1: Service User Recruitment in Bournemouth

Service	Approached	Recruited	Declined or unable to attend
Stroke Rehabilitation Unit / Research team	3	1	2
Early Supported Discharge team/ Research team	10	2	8
Day hospital/ community team	7	2	5

Recruiting service users was slower than anticipated. Despite the high number of older people passing through the stroke care service, many were considered too frail or pre occupied with their immediate post-stroke recovery to have the time or energy required to attend the ARG (which was planned for future dates). Some people were necessarily excluded due to marked cognitive or communication disability. A number of those approached talked of having too many appointments to deal with and for some, for instance, the day and timing of the ARG clashed with outpatient appointments or regular social commitments. Several of those approached said they lacked the confidence or energy to travel alone to the hospital and to manage ambulation in what was considered 'long hospital corridors'. As can be anticipated, this was particularly the case for people with more marked physical disability who lived alone. We were mindful to remain sensitive to the issues of inadvertently marginalizing older people from research throughout our recruitment process.

Because stroke is a devastating event that disrupts the lifeworld we were particularly mindful of the need to recruit older people who had comprehensive experience of the service in their own stroke journey. Ultimately, by working closely with key members of the stroke unit and ESD team, we were able to recruit five service users who had direct experience of being cared for in the stroke rehabilitation unit and through ESD. One participant, who was in recovery several years post-stroke also had experience of using community stroke services. Another person, who had experienced a stroke nine years

previously, was now visiting the unit weekly as a volunteer and had experience of carrying out feedback sessions with patients and their relatives. Participant details are provided in table 2.

Both service providers and service users who expressed an interest in participating in the study were invited to an hour long 'Question and Answer' Session. These events enabled the researcher to share further detail about the study and to model some of the methods that might be employed in the action research groups. The sessions also gave potential participants a chance to get to know the facilitators and other recruits and provided an opportunity for them to check their understanding of the project and its requirements before consenting to participate. At the conclusion of the study recruitment period six service providers and five service users had agreed to participate in the study. Service providers included a registered nurse, a physiotherapist, a healthcare assistant, two speech and language therapists and a discharge coordinator who had formerly worked as a rehabilitation assistant. The service users included a volunteer (experience of stroke nine years ago), a retired illustrator (experience of stroke two years ago), a housewife (experience of stroke one year ago 2014), a retired salesman (experience of stroke 2014) and a retired woman (experience of stroke 2014). A research associate and an additional member of the research team were also present at every ARG to help facilitate the group.

Table 2: Action Research Group Participants from the Stroke Unit/ESD

Participant *	Background / role	No of groups attended
Elizabeth	Emergency admission. Two days on stroke unit then fourteen days using ESD	8
Sandra	Admitted via A and E. Overnight stay on unit then 14 days ESD	7
Linda	Stroke happened 9 years ago when she spent 3 months on stroke rehabilitation unit. Currently works as volunteer on stroke unit	8
Barry	Emergency admission then six weeks on unit with swallowing difficulties	9
Paul	Stroke happened approximately 5 years ago. Spent 4 weeks on unit then approximately three weeks ESD. Experiences residual communication difficulties	9
Jenny	Healthcare Assistant working on stroke rehabilitation unit	9
Andy	Speech & Language Therapist working on stroke unit	9
Laura	Physiotherapist working on stroke rehabilitation unit & ESD	8

Christine	Speech & Language Therapist working on ESD	8
Martine	Staff Nurse on stroke rehabilitation unit	4
Lisa	Discharge Co-ordinator – co-ordinating discharge of patients leaving stroke rehabilitation unit	6
CP	Researcher (RA)	9
CEH	Researcher (PI in Bournemouth)	2
FC	Researcher (PI in Hull)	6
CS	Researcher (RA in Hull)	1

*for purposes of this present report pseudonyms have been used for all service users and service providers to comply with ethical requirements asked of the team.

In this setting, we found it conducive to take an appreciative emphasis to facilitate the process of reflection, thinking, planning and acting in humanising terms. 'Appreciative inquiry' (Cooperider et al., 2007) encourages professional and lay researchers to work in participative, collaborative ways sharing stories and noticing positive experiences thus bringing an appreciative lens to the research process. It is well suited to practice based research and asks such questions as: What is working well and why? What would it take to get more of this? Engagement with participants throughout the research cycle encourages mutual learning and ownership so that the process of inquiry may itself represent a form of intervention for change, developing individuals and resources to sustain change (Ludema et al., 2006). Appreciative inquiry is well suited to practice based research and has been used for example to explore and develop care in acute nursing settings (Dewar and Mackay, 2010) and residential care settings (Dewar and Nolan, 2013).

The Hull Royal Infirmary Dermatology Outpatients Unit

Background and Context: first contacts, the setting, shadowing, study recruitment

At the start of the project in March 2014 an initial introductory meeting between the dermatology consultant, RA, HIF, PI and two senior nurses was arranged by the study PI. The purpose of this meeting was to introduce the research project to clinical staff, to familiarise research staff with the unit, to explain what the research was aiming to achieve and to begin recruiting staff and service users to participate in the ARGs. At the conclusion of this meeting the senior nurses were requested to facilitate a period of shadowing for the RA and HIF. Shadowing began the following week when Hull and East Yorkshire NHS Trust honorary contracts were in place.

The dermatology outpatient unit is set in a modern building erected around 2010 with an open atrium floor which overlooks another outpatient clinic (the ophthalmic clinic). There

are walkways to various clinical rooms around the balcony down to the atrium. The outpatients unit moved to Hull Royal Infirmary from the previous location which included an adjoined thirty bedded ward at the Princess Royal Hospital (PRH) in Hull which closed – the current unit has two inpatient beds which are situated in the ophthalmic clinic. Clinics held and named by dermatology services are: 'Plastics, Cancer, New Referrals and Follow-ups, Lumps and Bumps, Pediatrics, Biologics, Phototherapy, Day Cases, a Community Clinic and Theatre'. These clinics run 'back-to-back', constituting a very busy atmosphere. Clinical staff at time of initial contact included two full-time consultants, three specialty doctors, a Foundation Year 1 junior doctor and a registrar, four clinical nurse specialists, two band six nurses, two band five nurses, a clinical support worker (CSW) and auxiliary and clerical staff. Throughout the shadowing period, researchers were provided with access to all clinics within dermatology and to observe the day-to-day running of the unit. During the initial visits the RA and HIF were able to attend a staff management meeting, sit in on consultant- led clinics, namely clinics currently labelled as above, and also to spend time with reception staff. Staff were friendly and helpful and fully facilitated the presence of researchers in the outpatient unit. The research team were mindful to pay specific attention to the process of developing good relationships with unit staff in the shadowing phase of the research, for example, regularly checking if their presence was acceptable and not in any way obstructive, making sure that service users were comfortable with researchers observing clinics and that staff members were also happy for them to be present.

Recruitment and participation

Recruitment to the action research group began with staff during the shadowing days. The RA and HIF spent time on the unit observing and talking with staff in informal discussions about the project. After a brief absence, during which the ethical review was approved, the researchers returned to the unit and met with the Dermatology Consultant and Unit Sister. While there was some research taking place in the unit, generally staff running clinics where not closely involved. The RA was permitted to leave 'an advertisement' for the study to invite staff and also emailed all staff with study information and an invitation to join the study. In addition to distribution of information sheets and briefing emails circulated to all staff, staff members were given the opportunity to attend question and answer sessions about the study. Four staff members were finally recruited including three registered nurses and a Clinical Support Worker (CSW). The ethical process did not allow the RA to recruit patients and service users directly therefore service providers were asked   to initially approach possible participants in the first instance. Staff members were asked to contact potential Service Users and find out if they 'minded being contacted by a researcher that was carrying out some research in the department discussing patient experiences'. Once permission had been obtained, the RA telephoned potential participants to discuss further details of the study. For those interested in taking part, the information sheet described (Appendix 5) was distributed and an invitation to attend a question and answer session was

extended. Reasons for declining to participate included service users feeling that the study 'was not for them', the commitment of attending meetings would be 'too much' as they had other health problems and for some no specific reason was expressed. In all eight service users consented to participation the study, seven attended the clinic for psoriasis treatment, using Phototherapy and Biologics and one service user was receiving care from the Cancer clinic. Please see Table 3 for service user referrals.

Table 3: Service User Referrals

Clinic	Referred	Recruited	Declined
Phototherapy	2	2	0
Cancer	3	1	2
Biologics	7	5	2

Health care staff and service users who wished to participate in the study were invited to attend an hour long Question and Answer Session. The purpose of this event was to enable the researcher to share more detail about the study and answer questions regarding understanding of the project and its requirements before consent was taken. Two different times were offered and consequently most of the service users were able to attend. None of the service providers could attend at either time due to their busy clinic schedules.

At the conclusion of the recruitment period four health care staff and seven service users had agreed to participate in the tripartite Action Research Group. Service providers included two specialist nurses (Cancer & Biologics), a senior nurse and a CSW. Service users included four males and three females all over the age of sixty-five. Most service users were accessing the dermatology service for a long term condition (psoriasis) however one male service user was referred to the study through the skin cancer service. In addition, two researchers and the HIF were also present at ARG meetings to facilitate the group.

Table 4: Action Research Group Participants from the Dermatology Unit

All Hull service users are aged over 65 and retired.

Participant	Background / role	No of groups attended
John	Accessing the dermatology service for 15 years 'on and off', for psoriasis treatment. He has been using phototherapy and receiving topical treatments.	8

Edward	Accessing dermatology service for psoriasis for 40 years - using both in and out-patient services. He received topical, treatments, light therapy and now accesses the biologics clinic.	7
Linda	Accessing dermatology services for psoriasis for 41 years, using both in and outpatient services. She received topical, treatments, light therapy and now accesses the biologics clinic.	8
June	Has been using the service for approximately 6-7 years, for psoriasis. She accesses the biologics clinic	5
Shirley	Has been using the service for 3 years for psoriasis. She accesses the biologics clinic and has used light therapy.	7
Thomas	Accessing dermatology for skin cancer services	8
Arthur	Has been accessing the service for 49 years for psoriasis. He has been both an in-patient and an out-patient. He has received most treatments (topical, light treatments, and medication) and he is currently accessing the biologics clinic.	8
Staff 1	Specialist nurse Biologics	7
Staff 2	Specialist nurse Cancer	5
Staff 3	Clinical Support Worker	6
CS	Researcher (RA)	8
CP	Researcher (RA)	4

FC	Researcher (PI in Hull)	3

*pseudonyms have been used for all service users and service providers to comply with ethical requirements asked of the team

The Processes of the Humanising Care Action Research Groups (Bournemouth and Hull)

Meetings and locations

The Bournemouth ARGs met a total of eight times from November to June (2014-2015) with approximately one month between meetings. An additional meeting was added at the end. Each session lasted for a period of one and a half hours. In Hull, groups met a total of eight times from October to May (2014-2015) and each session lasted for two hours. Friday afternoon just after lunchtime handover was selected as the best time for most of the participants to attend in both settings.

At Bournemouth, finding an accessible room in the hospital that was available for repeat bookings was a challenge but eventually, with support from the RBH Stroke Research team, a seminar room was found. It was a relatively large, quiet and airy room which easily accommodated the group size and provided two large tables for group work. It was well located near the stroke unit which was important for access by staff based on the unit. A degree of separation from the unit was also considered helpful as the conversations would potentially involve confidential discussions which critiqued some aspects of care. On the dermatology unit in Hull a large, bright and airy day room was available to use for the ARG's. However, as the room could be booked for treatment, it was necessary to check availability the day before each meeting to make sure the room could be used.

Engagement with Action Research Groups

Attendance at the groups varied over time. In Bournemouth, the RA was always present and there was usually a second research team member present although this was not always the same person. Service users attended fairly regularly occasionally missing a session due to illness or   another commitment. For service providers attending consistently was more challenging. They were often required to attend to matters on the unit causing them occasionally to arrive late or leave early from the group meetings. Sometimes they were not able to attend at all.   However, there was also one case of a service provider coming in on her day off to attend the ARG as she found it to be such a meaningful and positive experience. In Hull, attendance for service users was excellent. For staff members, there were generally two of the three members of staff present at every meeting, due to service pressures, for one session only one senior nurse attended. Reasons included annual leave and clinical demands. The Researchers and PI were all present at the first two

ARGs. Sessions three and four were facilitated by the RA and PI. The remainder of the ARG sessions were led by respective RAs from Bournemouth and Hull as the ARGs consolidated.

Applying the Humanising theoretical framework

In order to investigate aspects of the ease or difficulty of applying the humanising framework in each setting, two different strategies were planned before the ARGs were convened. A predominantly implicit strategy was used in Bournemouth. This meant utilising a 'bottom up', lifeworld-led process, whereby elicitation of a) the experiences of living with stroke and receiving care b) experiences of delivering care in stroke services were prioritised. This included an analysis by the RA of how group participants understood and made sense of the humanising dimensions. The implicit strategy led to the use of varied materials and equipment as many of the sessions planned included hands-on activities that encouraged reflection and creative responses from the group participants. An overarching Appreciative Inquiry approach guided the hands on activity and group reflections. In Hull, purposively, an explicit strategy was used, whereby the framework was delineated and translated through examples from everyday life and practice. The process introduced the group to 'what makes an experience humanly sensitive' one dimension at a time. A formal presentation guided the group with discussion of each dimension in turn.

One objective of the humanising services project was to determine how the humanisation framework could be effectively introduced, understood and applied by the ARG participants. Participants from both groups were able to engage with the framework, although we used contrasting approaches. In Hull, in the early stages this involved familiarisation with the dimensions and humanising concepts language with a pointing out of examples from shared group experiences. Here the theory led the discussions. In Bournemouth sharing of experiences was focused on most in the early stages and then at a later stage the language of the framework was introduced to the group applied to the shared examples. Here the experiences led the discussions with reflection on the theory at a later stage in the process. Both strategies worked for slightly differing purposes: The explicit strategy revealed that service users and health care staff could engage with the theory and provide rich everyday examples, as led by each of the dimensions. However, after several sessions had been completed, some activities and materials used in the Bournemouth groups were implemented in Hull as they had proved to be very effective to enrich reflective group processes and facilitated a discussion of what was valued in the outpatient service with a view to sustaining outcomes in the setting. The implicit strategy framed by Appreciative Inquiry, aided the group in identifying humanising practices and because the group were in a reflective mode from the beginning they were also able to point to dehumanising practices later on in the process. This also facilitated action planning and longer term activity. The main activities and their purpose for each ARG in Bournemouth and Hull is summarised in the table below. A detailed discussion of processes is provided in Section 7.

Table 5: What We Did within Our Action Research Groups

Hull Dermatology Unit	Bournemouth Stroke Rehabilitation Unit
ARG 1 **Introductions and introducing the HFW** Discussion of the HFW as a large group. HIF introduced the dimensions, provided an example and then discussion was invited from the group. Covered: Agency, Uniqueness, Togetherness, Insiderness	**ARG 1** **Laying the foundation:** establishing a sense of group security, respect and togetherness, sharing everyday stories and impressions about the human side of care, getting to know each other as patients, professionals, researchers
ARG 2 **Discussion of the HFW as a large group.** Same format as group 1 only this time examples of the dimensions were created using service users examples from previous week. Covered: Personal Journey and Sense making	**ARG 2** **The experience of care following stroke:** sharing experiences of giving, receiving and researching stroke care – what it is like on the inside and outside
ARG 3 **Discussion of the HFW in a large group.** Same format as ARG 2. Covered: Sense of place, Embodiment, Objectification and Reductionist Body	**ARG 3** **The eight humanising dimensions:** introducing a framework for understanding care that keeps a focus on what it is to experience situations, events and interactions from a human perspective; a framework for understanding humanly sensitive care
ARG 4 **Discussion of the HFW as a large group.** Same format as ARG 2 and 3. Covered: Passivity, Homogenisation, Isolation, Dislocation, Loss of Meaning and Loss of Personal journey	**ARG 4** **Action planning:** identify a humanising service improvement area for unit/ESD, something that really matters to older people; what would it look like, how would we measure it?
ARG 5 **Evaluation: Appreciative Inquiry** Moving to the evaluation using appreciative inquiry. Groups were asked to discuss what they valued about dermatology. A' blob task' was done to assess how group members felt about the ARGs so far; small group discussions on: What do you value about dermatology?	**ARG 5** **Connections to the RBH:** identifying experiences of what is dehumanising and humanising in stroke and preparing going home/ESD care

ARG 6 **Evaluation of learning and appreciative inquiry** Fitting exerts from the 'what we value' discussion into the HFW – measuring how the groups could work independently with the HFW	**ARG 6** **Humanising service improvement:** building on humanising theory and learning to date, starting to think about a relevant service improvement initiative, getting more of the good stuff e.g. knowing what's happening, gentle explanations, two-way relationships between staff and patients, a kind and welcoming culture
ARG 7 **Narrowing down the humanising intervention:** card activity that represents a humanising experience of care, feedback from last week's discussions, identifying three most important ideas, narrowing down a humanizing intervention	**ARG 7** **Highlighting humanising moments**: What do patients and staff really value on the stroke unit and the going home/ESD service? Mapping these experiences to the eight theoretical humanising dimensions. Identifying projects and people to support humanizing care within the stroke services
ARG 8 **Concluding the group and agreeing the format of feeding back our findings to the unit staff.**	**ARG 8** **Keeping humanising care alive and extending it to other areas:** planning production of a DVD to disseminate the telling of humanising stories and giving examples of humanising moments, developing a guidebook for others to use, extending humanisation learning through dissemination meetings
	ARG 9 **Summary and future plans**: (an additional meeting) finalization of plans for the DVD and guidebook, discussion of possible dissemination meetings and events, reflection on the ARG process and experience, thoughts for the future

All ARGs were audio-recorded and transcribed verbatim. The RAs reviewed the transcriptions thoroughly, anonymising identifiable participant information and began the process of reviewing the data for stories and experiences relating to the eight dimensions of humanising care. In reviewing the transcriptions, notes and reflections were made regarding group activities, group process and dynamics and participant responses to the activities, humanisation themes and lifeworld-led facilitation. Things that worked

particularly well and challenges encountered were also considered and documented. A more detailed description of ARG processes in both research sites is presented in Section 7 of the report.

Project Outcomes (Bournemouth and Hull)

Outcomes resulting from the project have occurred at the level of the two services in Hull and Bournemouth and also at the level of individuals who participated in the ARGs. As the project concludes there are also 'ripple effects' that are evident at an institutional level. We now report on these three interacting levels of outcomes with examples from the project sites.

Perceived ease and difficulty of applying the theoretical framework

We did not experience any insurmountable barriers to the groups engaging with the theoretical framework. The following diagram summarises examples of practices that service users pointed to as humanising, as led by each of the humanising dimensions, for both sites. **Figure 1: Examples of humanising practices that older people from both settings indicated**

These are just a few illuminating ideas that our ARGs discussed, but there where many more. Our learning suggests that the framework application needs guided facilitation preferably an implicit bottom up process as outlined in our Humanising Care toolkit (Appendix 6) or an explicit guided exploration of the theoretical framework if this is not possible. However common to both settings the following were key: space to listen to lifeworld experiences, reflection on examples of the dimensions underpinned by shared experiences, discussion of implications in the setting. What was apparent in both groups was that participants were engaged, moved by experiences, able to link examples of experiences to humanising dimensions and were passionate about humanly sensitive aspects of care in the setting. As we anticipated, a lifeworld approach was powerful in bringing the dimensions alive in each setting. The dimensions that were readily engaged with early on included sense-making, sense of place, personal journey, and those that were worked through more slowly included embodiment, insiderness, uniqueness and agency. The degree to which dehumanising aspects of care where discussed was dependent on the stages of the group processes, and these emerged as the groups became comfortable working through the process. A specific focus on positive aspects of care within an Appreciative Inquiry framework particularly facilitated the group at Bournemouth.

The following Table 6 summarises discussion excerpts of how ARG group members responded to the application of theoretical framework to assess humanising aspects of practice.

Table 6: The meaning and transferable learning from two strategies to apply the theoretical framework:

Hull Explicit Strategy	Bournemouth Implicit Strategy	Meaning and Transferable Learning
Different ways of listening (Staff) *This could be dry – but [listening to experiences] have made it come alive (Service User)* *Because sometimes I find when patients aren't happy about their care, it's not necessarily about the diagnosis, it's about the way they were treated, sometimes it's those aspects of care that the patients aren't happy about and that's the human side... and I think that's what you're trying to put in in' humanising.'(Staff)* *...people do find it more difficult, so I was quite prepared, even though I wasn't sure which way we were going, to give it time and see. And yet in discussing it into different categories, yeah,[it was OK]' (Service User)* *...found that helpful because you understand from the other side (Staff)*	*It's like therapy (Service User)* *...reflecting from last time, answering to Betty to say it did feel really good to sort of sit down and [hear experiences] and that felt almost therapeutic. (Staff)* *Great way to get people to think about and express their experience, and definitely a lot that I will take forward for a long time (Staff).* *I like the discovering what... especially like with the patients, what their experience was like, because you don't know that, you just... it's something new that you don't know you don't actually experience that from (Staff)*	**Listening to lifeworld examples from Service User stories was moving and deepened understandings. It was helpful to Service Users and staff.** **Time, space to listen, to talk honestly about inner lifeworld perspectives rather than a more external view of goal setting, unit processes, physical outcomes was helpful.** **The language of the theory was perceived as difficult at times but became clearer through using experiences.** **A process of gathering a range of words to express each dimension was a helpful reflection.**

So some of these have a reason and they can bring it out - but I didn't know what they called them (the humanising dimensions), obviously, you've got a name for them but we didn't have a name for them (Service User) *… you had to revisit some of them over again, though, because it was almost as though we got to learn what the dimensions were, your experiences, where those experiences fit into those dimensions, so they kept coming up a lot (Service User)* *It has been useful, particularly to get the human side of care over, it's almost as though you're putting values into headings that people can relate to and what a difference that has on somebody else. Because I was once told the smallest action you can do in a day can either make or break somebody's day; you know, a crossed word with somebody or you can upset that person (Staff)* *HFW is deep and complex and this is appropriate because life is complex- need something that has a depth – but need to transfer it into something meaningful without making it meaning less (RA).*	*I think it's nice having it on a continuum because as we've had in this discussion, some people want to be unique/ don't want to be unique, want to be alone/ don't want to be alone so to be able to place yourself somewhere on some of those is quite useful, rather than doing it binary (Staff, Service User added agreement)* *I think the HFW was useful in putting it into words why that would be humanising of dehumanising, [then thinking through in our own words and language] helped to think about the different reasons why something could be humanising or dehumanising*	**Sharing Service User experiences gave opportunity for staff to reflect on what it was like for older people, an inside view, and this was in contrast to the professional more external organizational view.** **Understanding the nature of the theoretical framework made sense to Service User and health care staff although it took time and needed a facilitated process.** **The continuum of dimensions and HFW terminology helped groups reflect on what that dimension might look like in practice/ in everyday life.** **The application of the framework helped ARG members get in touch with their core values and this was welcomed.**

Specific local impacts

a) Tangible impacts at specific service level that can underpin a transferable strategy
Within stroke rehabilitation at Bournemouth the ARG decided that for the project to have a longstanding tangible effect on the humanising practice within the stroke service there was a need to raise awareness of what humanising care is and operationalise ways to notice, value, and encourage more staff to embody humanising ways. The ARG prioritised a range of ways to engage greater numbers of staff to include:

- Feedback sessions through pre- existing regular staff meeting: 'Thoughtful Thursday' learning programme
- Establishing a network of Humanising Champions
- Creating a '*Tree of Humanising Care'* as a visual presence, each of the roots represented a humanising dimension , each of the leaves represented a noticed and remarked upon moment in humanising care
- Developing a short film (DVD) to share illustrative stories of humanising care that would contribute to a transferable leadership strategy

Within dermatology outpatients clinic at Hull similar strategies were developed by ARG participants to enhance the transferability of the project that included:

- Developing a *Humanising Notice Board* to highlight significant 'humanising practices' that had been noticed on the unit with a view to valuing the application of the framework and sharing with wider teams
- Service users had pointed to the need to for greater sense of togetherness with the service, to avoid a sense of isolation especially during relapse in skin health. Therefore the ARG team have begun to investigate the use of a dedicated telephone line so that Service Users could maintain ongoing continuity if they experienced a skin 'flare up' in between scheduled appointments. This was also a reflection of mutual sustained relationships between staff and Service Users who respected and valued their expertise, there was an expressed need for a sense of continuity.
- Attempting to develop 'a huddle' with regular times to allow staff to come together as a team to discuss and plan further humanising aspects of care. This was to overcome the fragmentation that was a feature of busy clinics running in parallel with little time for team members to come together *"These groups could mean that [as we all work in various clinics] on the time when we come together for the meetings we could highlight what had happened or what we need to change or what had gone on and how we dealt with it rather than wait a month and think"...[a month has passed].(Staff)*
- Preserving the skills of the specialist nurses: The service users articulated how they highly valued the specialist nurses' skills (both holistic understanding of the impacts of a skin condition on the person in addition to specialised technical skills and knowledgeable practice): *"I thought I was someone special coming here – but since coming to the groups realised that all are special. If staff treat everyone like this they must be worn out". (Service User).*
- There were concerns that as these particular nurses were coming up to retirement there needed to be a way to pass on and preserve their specialist skills gained from an entire nursing career in dermatology. Such skills were noticed by Service Users. *"Nothing has been too much bother – could be receptionist or specialist nurses, they not afraid to bring someone else in and say I think it is X – share their expertise". (Service User).*
- The integration of humanly sensitive care with specialist technical knowledge was something the team did not wish to see lost to the next generation of nurses, providing an indication of the value placed by Service Users on these 'softer skills' in combination with clinical skills: *"… a warm greeting or a welcome smile can make such a difference to the consultation – getting the feedback of experience from the patients". (Staff)*
- It was suggested that the specialist nurses could be shadowed (although it was noted that this could be difficult due to the service demands leaving few staff ever free to shadow). However, final study outcomes included an initiative whereby both the 'biologics' and cancer specialist nurses have plans in place for a job share with an allocated member of staff to transmit and preserve skills. In addition, the specialist cancer nurse is teaching dermatology clinical staff once per month to share her specialist skill with a key focus on the humanising aspects of care.

The detail and implementation for each of these initiatives were developed collaboratively through discussions in the ARG. After the ARG meetings finished some of the carry-through of the service change activity were agreed through short action planning sessions with the Humanising Champions and RA at RBH, and the RA and Dermatology clinic team at HRI, including service managers who were essential to facilitate changes. Some illustrative detail concerning the planning, content and reach of specific initiatives with longer term impact in mind is provided on pages 22-25: For instance the 'Thoughtful Thursday' feedback sessions, roles and induction of humanising champions and sharing of best humanising practice.

b) Impacts at individual level that evidence the potential to enhance service culture

Both service providers and service users who participated in the ARGs commented on aspects of personal transformation that had occurred through participating in the project and engaging with Service Users, healthcare staff and researchers to collaboratively explore humanising care ideas. Researchers participating in the groups also noted personal change. Such cultural impact and change through shifts in personal perspectives is a defining feature of action research methodology and was noticed in tangible ways by health care staff. Change in skills, practice and behaviour noted and valued by **health care staff included:**

- **Increased awareness of the wide ranging and challenging impact of stroke for people who seem to have minimal or no ongoing practical or physical issues e.g. the fear of going home and leaving the hospital** (this insight pointed to by staff was linked to a greater sense of understanding insiderness and uniqueness)
- **Increased attention to how to provide information, e.g. providing information in more relational ways and encouraging everyone to be a part of 'gentle explanations'** (this insight was linked to a greater understanding of sense-making)
- **Increased attentiveness to the time people take to take to absorb information (understood as allowing time for a Service User to make sense of what was happening to them**: sense-making) and providing more opportunity for Service Users to ask questions (linked to an understanding of agency)
- **Increased awareness of the long term impact of small dehumanising incidents and experiences** (although these were often 'little things' they led to strong feelings of isolation and dislocation for Service User)
- **Increased confidence in noticing and commenting on the humanising practice of others** e.g. commenting on the way a nurse gave a little more time and communicative support to make sure a patient with difficulty communicating chose the flavour of yogurt *that they really wanted* (this was seen as striving to meet uniqueness,)
- **Enhanced relationships with peers** in the ARG group through knowing them a little better (a sense of staff togetherness): *"I learnt we are a team – used to have the ward – now we work as a team [in this new setting]– secretaries etc. – full team makes a really good service. Enjoyed working with Service Users and Staff –'It's an equaliser'.*
- **Increased understanding of why some, even simple, interventions are really worth pursuing as a way to humanise experiences of care** on the stroke unit (e.g. how Togetherness, Sense-Making and Personal Journey were all enhanced through a

lunch group) (Bournemouth*) 'Also the patients in the [lunch] club were good you know, you could just build a relationship without words…it was quite good…no very good' (Service user)*

- **An injection of energy and motivation through staff reconnecting with a focus on the human side of care**: "… *what an interesting session today. I genuinely cannot think of a time recently that I have learned so much, so insightfully expressed, that has made so much sense. It was one of those sessions that, for me, completely rejuvenated what we are doing, and why we are doing it. To have been on the ward and been around that busy atmosphere, and to have been in ESD working to fit everyone in - to hear what a difference, in both good and bad ways, that has made is truly fascinating and thought-provoking. I feel very privileged to have been involved in that session: it really has brought back to me what it is all about - and I can't tell you how valuable that is to be reminded of that".*

- **Increased awareness that it's the small things that make a big difference to service users – thus we can extrapolate that more attention may be given to these small things that really matter in clinical practice**: : "*…making time for patents – so important to then – smile – they know that member of staff has made more time for them. – Only a few moments- doing a little more than 100- 101 % makes a difference – I got this from listening to Service Users experiences".*

- **Increased focus on the person behind the diagnosis or care task**: "*…sometimes you can focus on the task rather than the person so I think we need to be reminded constantly it's not the task it's the person you are caring for - whatever treatment you are offered it's the patients that you are treating that is more important - so fair enough, we all have lots of jobs to do, we like to do them timely - but not to focus so much on the importance of the task but the person you are caring for.".*

- **Increased awareness gained through sharing of Service User experiences, increased awareness of the difficulties of living with** a skin condition on a daily basis and the impacts on the everyday life of the person. This was valued and seen to increase empathy by a stepping into what it is like to live with a skin condition. An increase in understanding from the Service User perspective is likely to enhance care: '*It was a positive, humbling experience listening to people who have suffered a long time'.*

- **Increased confidence in 'being good at humanising', feeling that skills in being humanly sensitive are valued and are visible**. *''If I knew somebody particularly liked strawberry yoghurt, say, and then I got them strawberry yoghurt it would make them feel like I was treating them like a part of a sort of individual.'*

- Development of a sense of pride and value of caring work from attending the group: '*Just to say...your presentation was excellent, it certainly put dermatology on the map. Thank you to you and all your team, sorry for not always having the time to commit but you made us proud. Thank you, from all the dermi bunch.'*

- **An appreciation of how staff had enjoyed being with the service users in a different, more equal way**: "*again thinking about both sides of the equation being a service provider and a service user, erm you know, feeling yeah, that you've just got a say, or that we're trying to give our patients say in what happens, … is difficult because we were talking about how there's, like, lots of research studies out there now trying to look at the pathways of general Mrs X who had a stroke, that did this to her and therefore where is she in ten years' time. And can we, you know, just*

micromanage her and get her out as speedy as possible, you know and its … I just kind of feel like sometimes going too much that way takes away from people's uniqueness".(Staff)
"...when you look after somebody you look after them as though they were your own family, you know, what would they want, what would they need, and you want to give the best, and I think those are the values and core values that make your very being yourself" (Staff).

c) Impacts on knowledge, understandings and response to the experience of stroke care and skin health care noted by service users included:

- Better and deeper understanding of the complex, diverse impacts of stroke (this was linked to sense-making)
- Feeling increased safety and being less frightened (this was understood in terms of insiderness, uniqueness and finding a sense of place)
- Feeling energised by the company and the people (a new found sense of togetherness)
- Increased understanding of the complexities of the stroke care unit (sense of personal journey through the illness, treatment and discharge)
- Development of a better relationship between service users and providers: A dermatology service user commented that he had a good relationship with his clinician beforehand but now it was even better, it had made him think about how much he trusts the judgement of his clinician (this was linked to agency and passivity).
- Service users valued being able to access and give feedback to service managers, with support of ARGs, that included a particular dedicated focus on the experience of living with a long term skin condition, which is not usually at the forefront of discussion with service managers (this is linked to embodiment and agency). In addition, the group within dermatology reported that a focus on the human dimensions of service, as led by everyday experience underlined the need for specialist skills and brought the value of such skills to the surface.

d) Impacts at institutional level

Through formal dissemination events undertaken in both sites the project aimed to influence at a broader institutional level. There has been interest at Board and Senior Management level within both settings, as people are signposted to the potential of a focus on humanising care by those who have attended and been engaged by the project's events. Some staff are now championing the project's cause in their locale. For example, in Bournemouth a dissemination event co-presented by the RA and Humanising Champions, senior nurses and team managers in the Older Persons Directorate illustrate some potential connections to improved patient experience and staff engagement. In particular the Bournemouth group wished to emphasise humanising leadership development and the support of it, find ways to value and celebrate those health care assistants who were noted to 'embody humanised care'. The group felt strongly that humanising leadership was meaningful in everyday practice terms and relevant to all levels of the organisation, from

the practice interface, to organizational values and strategic mission. This group's actions focused on strategies for humanising leadership development, through a kind of buddying system. This included development of ways to nurture and engage staff in cultural change, reflective practice, and continuing professional development, using techniques that reflected humanising values: 'humanising' techniques (that are creative, embodied). Across both sites there was a strong desire to enhance older people's experiences through raising awareness of what a humanised approach to care means, and how a focus on the human dimensions of care can guard and support excellent dignified care. In Bournemouth this was reflected in the need for *a Humanising Care Tree* in every department, (further details on page 42) and in Hull, the request to service managers for some clinic reorganisation to facilitate a staff *Huddle* each day and strategies to inform other staff about humanising examples. In both settings, the humanising framework was pointed to as a way of contextually understanding the substance of complaints, and providing a way of articulating and acting on root causes of complaints, that were often times directly linked to potentially dehumanising practices. It was noted in both project ARGs that a focus on the humanising dimensions of care may be a practically positive way to engage with improving practice in the light of complaints.

Cross site comparison of characteristics of dermatology outpatient service in Hull and stroke rehabilitation service in Bournemouth

There are a number of similarities related to the context of both settings that are important to draw out as a background for participatory project work that engages partners from NHS services and service users in enhancing humanised aspects of care. These include the nature of the specialist settings that deliver specialist services for older people, and which include a high level of expertise constituted by clinical teams. They were both high pressure NHS environments that operated within complex environments of change, policy drivers, local NHS Trust and national imperatives. Both settings and their staff have recently undergone service restructure and relocation, there was a sense of nostalgia for former times and former organisational models in both sites. The project was very successful in terms of the action research process in both settings, both settings engaged groups of service users who consistently attended and participated over a nine month period. As might be expected there was a mix of personalities and a range of perspectives and approaches to personally managing a long term condition, be it a skin condition or recovery from stroke. Both conditions have long term physical, psychological and social impacts and these aspects are perceived to be poorly understood by the general public. Further, service users in both settings and with both conditions talked at length of the stigma they experienced and were easily able to point to potentially dehumanising aspects of living with their long term condition on an everyday basis. It was evident that in both settings service users valued their relationships with staff and were highly respectful of the skills, competence and caring

behaviours that they had experienced before the onset of the project. It was very evident that staff were highly committed to the project in both sites, staff made great efforts to attend groups even though services were busy and staff rotas had to be covered, sometimes this included them generously attending ARG meetings on their days off. It is an important feature of the humanising services project that the application of the humanising theoretical framework was attempted in typical conditions for each setting, in other words, for purposes of transferability, that the global characteristics of both settings that are shared and are similar are noted. It is of equal importance that key contrasts between the settings are also understood, for the purposes of making a robust case for transferable potential of the humanising theory to more diverse settings beyond this present project. What follows is a summary of key contrasts between the two settings.

Key differences across the two sites are summarized in Table 7 below.

Table 7: Summary of key differences across Hull and Bournemouth sites

Hull Dermatology Service	Bournemouth Stroke Service
Condition and service users	
• Condition requires access via GPs with some delays and gatekeeping • Most service users have lived with skin condition for many years • Illness trajectory typically long term condition with treatment, improvement, periodic flare ups • All service users still in contact with service • Typically service users are ambulant and independent	• Condition requires rapid access to service typically via emergency route • Most service users have only recently experienced stroke (months- years) • Illness trajectory typically one off acute event followed by rehabilitation and re-enablement. • All service users now discharged from service • Many potential recruits unable to participate due to ongoing complex physical, cognitive, communication issues or transport difficulties
Service providers	
• Typically providers in the ARG have had long term contact with ARG service users (up to 40 years) • Less diverse mix of staff members in unit and ARG • ARG members tend to be more mature (2 semi-retired) and have worked on unit for many years (max range 25years)	• Typically providers in ARG have had minimal or no contact with service users in ARG (days-weeks) • More diverse multi-disciplinary staff mix in unit and ARG • ARG members tend to come from younger age group and have worked for less time on unit (1 -13 years range)
Place/clinical setting	
• Out-patient service offering long – term access and re-referral	• In-patient unit with short term community support

• More emphasis on nursing and medical care – greater sense of medical dominance • Perception (from staff and service users) that dermatology is viewed differently compared to acute care • Nursing leadership in unit undergoing staff change • 1 research nurse leading mostly clinical trials.	• Multi-disciplinary staffing on the stroke unit. • Stroke Unit recognised as a beacon within other older people services in the Trust • Stable nursing leadership in unit and strong support for project • Strong research culture on unit with multiple research projects and clinical trials
ARG process and practicalities	
• 2 hour session timed to co-ordinate with staff lunch sessions and clinic times • Service users very consistent in attendance but committed staff participants need to work hard to juggle rotas and leave to attend • Explicit process used to introduce humanising dimensions • More verbal presentation of dimensions and educational style in weeks 1-4 • More use of large group process	• 90 minute session timed to account for service user fatigue and post lunch time staff handover • Service users and providers consistent in attendance though 1 staff member stopped attending after week 4 • Implicit process used to introduce humanising dimensions • More participatory process with use of creative materials in weeks 1-4 • Mix of small and large group work

Given the particular characteristics and nuances of each setting, it is clear from our project that a facilitated action research process, led by the theoretical framework can be sustained over several months in busy service settings, with high turnover and that are characterised by both inpatient or outpatient services. Further, we have found that that both health care staff and service users value their prolonged engagement in the process. Variation in group ARG processes allowed us to test out ways in which the humanising theory could be explored. An implicit process to translate humanising theory is highly effective, embedding insights within everyday practice and will lend itself to a diverse range of groups and settings. An explicit strategy is also useful where there may be a desire for more structure in the sessions, limited time or limited facilitation resources, but where groups are comfortable to work together through both dehumanising and humanising examples as led by everyday patient experiences. These issues will be further discussed in Section 7. There are a number of general outcomes that have emerged which include: Increased appreciation of the impacts of stroke and the challenges to stroke care providers of meeting each service user in a way that remembers and cares about humanising; increased understandings of what it is like to live with a long term skin condition and the importance of holistic specialist skills to support older people in this situation; increased skills in working

in a lifeworld led mode, in other words, leading developments in care within any setting directly led by patient's experiences of humanisation or dehumanisation; increased insights into the value of using and trusting embodied relational methods of learning as part of an ARG process.

An illustration of how ARG processes delivered specific strategies to enhance humanised care

The **Thoughtful Thursday Feedback Session** in Bournemouth was designed to inform other service providers what we had done and learnt in the project and engage a wider pool of staff in being aware of humanising care and the consequences for patients of being on the receiving end of dehumanising care. We did this by sharing short stories of humanising care linked to the humanisation themes and also the impacts of humanising (or dehumanising) care on patient experience. One part of the session involved a scripted re-enactment of a story shared in the ARG. This involved a person newly admitted to the ward asking for and being denied in a curt manner a cup of tea. After the service providers from the ARG had acted out the scenario, the patient who had experienced it talked about the impact it had had on her. She gently but powerfully linked her emotions and memories to different humanising dimensions (isolation, loss of sense-making, passivity) in the same way that the service providers could highlight those dimensions linked to more positive stories of care.

Illustration – Email from an ARG member after Thoughtful Thursday

So enjoyed today!! Good news - one of the team has just approached me and said they would like to become a second wave Humanising Care Champion! I have said fab, if they can be continuing to lead on identifying, highlighting, and feeding back the positive humanising qualities they see on the ward, and I will chat to the others about how we make sure such keen humanisers are formally identified going forward!

Many thanks - I have absolutely loved being involved in this project!

The idea for a **Network of Humanising Champions** originated in discussions in the ARG around a perceived need to model humanising behavior and encourage others to be curious about what humanising care is and ways that staff could be more sensitized to it. During a follow up meeting between the RA and the Healthcare Assistant and the sister in charge of the stroke unit we noticed the list of other unit champions on the ward e.g. the sepsis champion, the infection control champion etc. ARG members self-identified as Humanising Champions, and defined the role as:

- Being a role model for humanising care
- Noticing and commenting on moments of humanising care that they witness
- Encouraging staff and service users to have conversations about humanising care

- Encouraging staff and service users who have any concerns about humanising care to talk to a champion about it
- Keeping an interest in humanising care alive within the service e.g. by adding it to the agenda of other meetings or feeding back data from the tree of humanising care (see below) at future Thoughtful Thursday meetings

The issue of how we might nurture and grow more humanising champions in a context of constant change and staff turnover, led us to focus initially on each humanising champion 'talent spotting' and recruiting one new champion each. We are negotiating with the Stroke Service Improvement team sustainable ways to offer 'light touch' training and support to this growing team of champions. Staff members of the ARG also identified the need for a visual but interactive mechanism of illustrating humanising care. The group members designed and produced a **'tree of humanising care'**. The aim of this interactive tool was to inspire curiosity and conversation on the unit but in a way that would remain fresh and engaging in the context of busy ward life, staff rotations and the comings and goings of patients and relatives. The roots of the tree were fashioned around the eight humanising dimensions and the small noticed moments of humanising care were added to stick on leaves. They positioned the tree at the entrance of the stroke unit to give it maximum prominence. The ARG members intend to keep the concept fresh and engaging by regular review of the leaves of humanising experience and seasonally changing the images on which staff and patients are asked to note down these stories. Images of the tree are shown in figure 2.

Figure 2: The Tree of Humanising Care
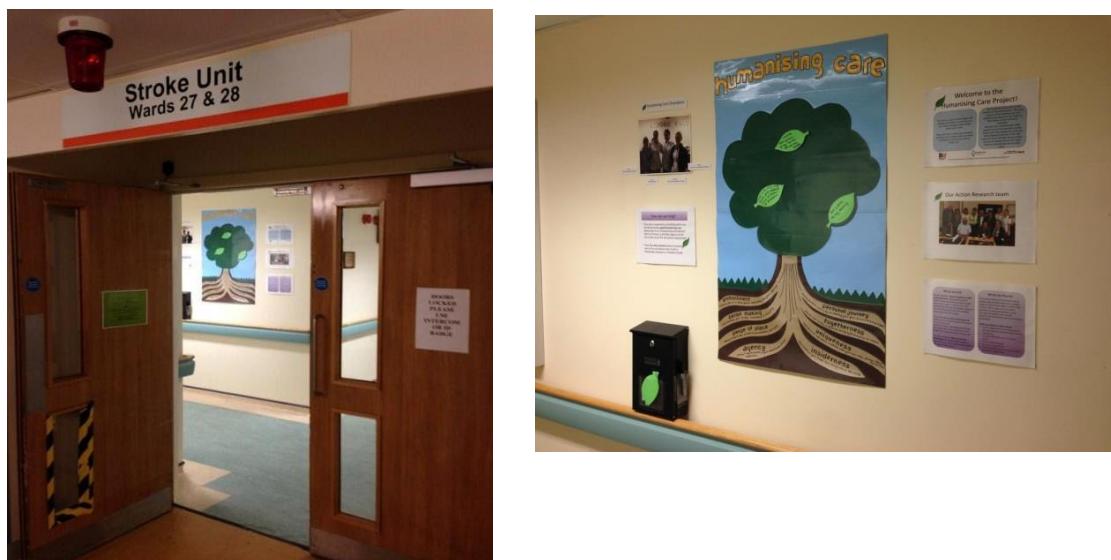
Both service users and service providers expressed a desire to **share some of the powerful stories of humanising care** and its impacts with a wider audience. Because everyone in the group had found the personal stories both engaging and evocative the group decided they wanted to develop a film available as a DVD which might be easily utilised within staff induction programmes or in house learning events. The aim of the film is to:

- Illustrate the different humanising dimensions, through personal lifeworld stories
- Support and enable current and future Humanising Champions to take a prominent sustained role in stimulating conversations and learning about humanising care
- Act as a lasting resource for the stroke unit and ESD in nurturing a humanising culture of care

Summary

Section 6 has offered a description of each research setting in terms of background and context and recruitment/involvement processes. Details of the ARGs were presented including where and how often the groups met, attendance issues, the role of the researcher in each setting, and strategies to introduce the humanisation framework. A description of what occurred at each ARG in Bournemouth and Hull is offered as a summary table. Outcomes, impacts and changes were discussed at the service, individual and institutional levels and, lastly, similarities and differences between the two research sites were highlighted in a comparative mode. In the following section, transferable strategies that could prove valuable in leading 'what matters to older people' for other service teams are presented.

Section 7: Transferability of the project and development of humanising care leadership strategies

A key objective of the study was to identify transferable processes that have potential to enhance dignity in care for older people in other human service areas. The transferable strategies are presented in main groups: how application of the theory underpinning participatory processes was implemented through a life world led process; transferable lessons learnt regarding the older people involvement processes, effective tripartite team processes and strategies to overcome challenges that were encountered. Finally a discussion of how transferable outcomes can be used to underpin a transferable leadership strategy for improving what matters to older people is offered. The impacts and outcomes of the project have contributed to resources that have been designed to lead and support care setting teams wanting to engage in a humanising care improvement project in the future.

Transferable strategies for theory application

1. The Tripartite Teams (ARGS)

A tripartite humanising improvement team comprising older service users, service providers and academics was utilised in each research setting. The aim of this approach was to enable older people, nurses and a range of health care staff to engage in discussion about care, and to engage in some planning and decision making that would make human perspectives more central in healthcare and treatment. The decision-making process was led by the eight dimensions of the humanising framework and informed by patients' own journeys and experiences. The key issues:

- ARGs comprised service users, service providers and researchers each with personal experience of engaging with stroke or dermatology care
- Most of the activities required equal participation though the researchers generally prioritised those of the older service users, followed by those of the service providers
- Researchers contributed their viewpoint and observations too – e.g. highlighting the tensions in the delivery of care for people in a system that has to prioritise process driven outcomes; pointing to examples of humanising care, and specifically sharing stories in the mapping (stories mapped to dimensions) exercise.

2. Defined steps in the application of the Humanisation of Care Framework

Each of the groups (working as a tripartite ARG) engaged in the following key steps:

Theory engagement: Introduction to the humanising dimensions, with a focus on positive humanising examples first, then moving onto negative dehumanising examples as the group were ready (depending on an implicit or explicit theory application process as discussed in Section 6). Discussion was encouraged that was lifeworld led, taking a core focus on service users experiences in dermatology or stoke rehabilitation relevant to the humanising dimensions. Through this focus on experience, what matters to older people in any setting

can be explored and a humanising context for future discussion can be set. In addition, this theory engagement process allowed a type of **Humanising self-assessment for the teams to reflect upon** and facilitated the development of a **Humanising improvement plan** with ongoing discussion of the humanising improvement plan and facilitation of actions that have been identified.

3. Lifeworld-led Facilitation

The Humanising care framework is embedded in a lifeworld-led approach to care. In the context of this project we discussed and developed activities, techniques, and facilitation styles which are consistent with a lifeworld-led approach. Transferable features of the facilitation approach include the following characteristics as summarised in Table 8 below.

Table 8: Characteristics of a lifeworld-led facilitation approach

Establishing lifeworld- led conditions	Attending to lifeworld- led activities	Challenges and Transferable learning
Using a room and surroundings where people felt comfortable and safe and where experiences were valued, not judged.	Engaging in activities which encourage equality, involvement and participation.	Sometimes we relied upon service providers to facilitate small groups, this could become more medically / professionally led than service user led
Striving to keep the atmosphere and tone relaxed and friendly by using humour, warm greetings, and not rushing goodbyes.	A focus on older peoples' experiences rather than a privileging of professional or medicalised perspectives.	A strong sense of confidence from each of the participants can be developed through the sessions so that they are not overly sensitive to potentially negative comments but able to embrace what the experiences mean in humanised care terms.
Making sure people know what was happening and what is expected (summarising, a clear but fluid agenda that prioritises their experiences).	Reflecting upon, being aware of and keeping in check professional or medicalised perspectives as discussion of experiences emerges.	
Keeping to time but avoiding rushing (planning time allocations in advance).	Choosing activities which reflect creative and embodied ways of knowing and participation rather than relying entirely on verbal description, patient 'reports' or feedback and organisational explanation. E.g. (stones and wool, cards, and road signs activities to help keep discussion open ended and not structured.)	Managing time in a way that allowed the space for something to emerge but without rushing to finish within time
Fostering a sense of respect and tripartite group equality (ground rules and facilitating to support equal opportunities to hold the floor and demonstrate experience/expertise).		Uncertainty is inherent in the process, this has potential to create a confusing sense of 'not knowing' and therefore needs ongoing clear description of how *the process* will develop over the coming weeks
	Encouraging maximum participation and collaborative listening and storytelling by organising into smaller groups and thinking about best ways to subdivide groups that will foster dialogue about older peoples' experiences.	
Creating a sense of trust through tone and gentle explanations and identification of humanised care practices and when group feel secure potentially dehumanising practices. An Appreciative inquiry		As with any group facilitation managing more dominant or talkative members of the group
	Introducing images (e.g. in card task) which represent lifeworld	

methods approach can create optimum conditions for this.	domains e.g. natural world, nature, connectedness, social relations, time, mood, people and the environment. Encouraging fun, creativity, exploration and a sense of freedom without knowing where it will take the group, so space is created within a target driven culture. Being courageous and honest e.g. raising issues witnessed in shadowing and emotional reactions to them, responding to older peoples' experiences whether positive or negative. Modeling an open, receptive and interested way of being Joint, equal decision-making as groups progress, particularly in planning service improvement phase Listening carefully to any suggestions expressed in between group work/ meetings and acting on them Checking in regularly with the groups to see how things are going for them.	Needs skills and experience of facilitation – e.g. being very comfortable with a process that is more organic, uncertain, opened and able to avoid a focus on aims and outcomes if the facilitation is anxiety making. Holding 'one's nerve' when introducing new and potentially unusual activities. Being prepared for emotional reaction and skilled/ confident in managing 'pivotal moments'. Teasing apart what is lifeworld-led facilitation (a focus on lifeworld experiences and what they mean in humanising or dehumanising terms) and what is good group facilitation e.g. creating conditions for service users to share their experiences and for service providers to reflect upon them. Spending a long time discussing experiences of care though the lenses of the HFW (4 sessions) might have felt to participants that we were '*going over old ground*' and perhaps not respecting their time, however it was important for the group to develop a sense of trust and this needs more explanation in advance. Readiness in the setting/system Preparatory work to ensure teams are open to/ want to explore humanised care ideas/ value lifeworld evidence.

In our experience a key characteristic of facilitators in this kind of theory application to practice initiative include confidence in the theoretical framework with understanding of its aims and ability to weather the uncertainty of others. Therefore it is important to attract motivated people to participate, to adequately prepare them for facilitation and also to provide tailored resources for facilitation (e.g. Toolkit and Film).

Within the context of lifeworld-led facilitation a number of motivating factors that were important to both service users and to health care staff emerged. Future projects may be able to draw upon knowledge that we have gained about these motivating kinds of factors. For healthcare staff this included a curiosity and desire to engage with service enhancement and with research. Staff reported that they found a participatory action research approach very attractive as it offered opportunity to work with and alongside patients in making a difference to care. This can be captured as an interest in participating in 'something a little different', this has been underscored by the engagement with creative tasks such as 'a cards task' (picking images and reflecting and discussing their relevance in relation to human dimensions of care, and feedback from participants that flags the value placed on the collaborative nature of the research and usefulness of modelling diverse techniques within group work. Such was the interest in the processes and opportunities of the project that several staff reorganised work shifts to attend or participated during their days off, generously helping overcome a potential 'shortage of time' barrier presented to the project team. Several staff were very engaged with and attracted to the 'being human' theme and all staff, even if at outset they were not attracted to humanising care ideas wished to engage with service users.

Clinical support worker (skin care) , 'Important that our patients feel…that the staff who are looking after them actually do listen to them…and for patients to understand our point of view regarding how we run a clinic, where and why'

Senior nurse (skin care), 'Always keen to learn about how patients see our service – what their expectations are and if we are meeting their expectations. If there are ways we can improve …so in a way it was connecting to the people I care about. At the end of the day [they] help me to improve the way I see patients and the care I deliver.'

Senior nurse (therapy) , 'I wanted to make a difference in the department'

Nurse (stroke care) That's what stood out for me. Usually you have a group where you discuss things and it's just…it's just nursing staff and therapists and professional staff and you don't see it from the patient's point of view.

Therapy Staff (stroke Care) 'I really enjoy the group, I like learning what we're learning here, I think it's a great aspect of healthcare to think about, like what makes care human, and I don't think there's enough time usually to think about it, so it's lovely to be here'.

Several service users indicated their interest and motivations for the sustained participation that was core to the project's progress. These included, wanting to 'do something for the community' and wanting to 'help others' [who shared what they themselves had been through], to 'give something back'. There were also expressions of

interest in lifeworld perspectives in wanting to share with others what the experience of for example, psoriasis, skin cancer, hemiplegia or disruption in confidence was like. Overall service users had strong wishes to contribute to research that might be useful for others. Most expressed an underlying desire for ongoing conversation with staff, wanting to ask questions about their condition and prognosis and give positive feedback including a desire to thank staff. After the initial ARG meetings all said how interesting they had found it listening to others, with experience of stroke or long term skin conditions, for most service users in stroke rehabilitation, engagement in this project was the first out of hospital contact with others living with stroke. Reasons for not being able to participate included, visual problems, being unable to walk the length of hospital corridors, requiring ambulance transport to negotiate transfers and three flights of stairs with no lift, fatigue, particularly following stroke. Some service users who declined viewed research participation 'for the general good', as a low priority compared to personal 'recovery' and keeping up with medical and therapy appointments. The Q and A session at the beginning of the project served as an important taster session and confidence builder, and was a deciding feature for some. It is important to note that in stroke rehabilitation language and communicative impairment is of course a potential barrier, however, even in this context the participants were sufficiently able to participate.

Transferable strategies for a theory–led action research process

The research team documented the processes used in each site. This was partly to review and evaluate what was happening in order to support a cross-site evaluation. It was also to capture aspects of the ARG process that might be relevant to developing the transferable leadership strategy - guidebook/Humanising Care toolkit and describing humanising care activities and processes for potential use in other healthcare settings. Two key aspects of transferability can be drawn out from 'what worked well'.

One key aspect that stood out as potentially important for transferable outcomes in particular was the tripartite model with inherent group decision- making processes. What worked well can be summarised as follows: Establishing from the outset that each of the 3 views, from service user, healthcare staff and academic were equally valid; clarifying at the outset, by talking through the type of research (participatory) that we weren't quite sure what would come out of our discussions and that we were interested both in the outcome and how we reached it (process); the '3 way wool and stones exercise' worked as a way to *really listen* to what we each did. Some group members expressed real surprise that there was an openness with freedom to focus on process and also fed back that they really enjoyed learning about each other's roles and particularly sharing of rich experiences – i.e. a mutual learning process.

A second key aspect was the application of the theory to lead group discussions. What worked well can be summarised as follows: Grounding discussions in personal experiences and inviting stories – this allowed time for group members to get to know each other but was a powerful way to link each other's experiences to the human aspects of care. A valuing of all kinds of knowledge emerged with honouring of different personal experiences and different kinds of expertise rather than a privileging of technical or medical knowledge alone. The theory led nature of the ARG discussions allowed a keeping of humanising dimensions in mind without having to 'overpower' or distract attention away from the experiences. This was a kind of back and forth movement between experiences and dimensions. Here, experientially grounded examples were vital to illustrate what each of the humanising dimensions pointed to. If the definition of a humanising dimension was 'read out', the group would look perplexed, but the examples aided understanding and helped groups to work beyond the theoretical language and to apply the ideas to experience near examples. Here, using the HFW as a lens or scaffolding for discussion in our experience facilitated a richer description of life world experiences at the human dimension level, rather than the more common focus of a general discussion on experiences of care. A lifeworld perspective with participants' everyday experience, was a coherent and useful starting point for the research. It allowed tripartite ARGs to develop deep understandings of the issues at hand and may have helped group cohesion, for instance there was no attrition in the sample of service users.

Transferable strategies to overcome anticipated research methods challenges

 As in any action research project, key learning has informed some transferable strategies to negotiate and overcome methodological issues. These methodological challenges are listed as follows:

- **Articulating what the research was about**: **making clear that everyone has a contribution:** a challenge in some of the initial conversations was providing people with 'something concrete' about the project. It required conversations that included description of the humanising dimensions of care framework 'in a nutshell' and a differentiation from the many other compassionate care initiatives. As outcomes specific to each site were emergent this presented a challenge to potential participants who sought an emphasis on specific pre-defined research goals. Our research approach with overarching objectives concerning 'what mattered to older people in enhancing dignity in care' meant that it was premature to articulate setting specific outcomes or service improvement benefits.
- **Overcoming unfamiliarity with the qualitative, iterative approach of the research** – participants, including service users, were more familiar with more commonly carried out quantitative study designs, and in one setting while research was taking

place, many staff were not involved or had little knowledge of the extent of research activity in the setting. In the other setting there was an established research culture.

- **Planning firm days and dates of meetings at the point of recruitment to the study** – needed because many staff are on rotation and know when and when not they are working on the unit many months in advance, this included co-ordination with part time staff. Recently discharged stroke rehabilitation patients, and dermatology outpatients often had follow up appointments and a sense of 'a lot going on' so were unable to commit to further appointments or general activities without a firm plan.

- **Working through uncertainty at the outset about numbers of people who might want to participate in tripartite ARGs**– strategies to cope in the event that a lot of people attended (e.g. would we be inundated with participants requiring us to select from a large pool of potential participants) or alternatively what plans are there if there is a struggle to recruit to the study?

- **Balancing a complex action research project in settings with a number of clinical trials underway and NIHR Portfolio adoption-** although this means teams are geared up to help with recruitment, they are generally already very busy and other studies sometimes necessarily take priority. Because the Burdett Trust for Nursing project was ineligible for NIHR Portfolio adoption, the team was explicit about not being able to prioritise time on study recruitment. It was necessary to check whether 'co-enrolment' was allowed and it would be valuable to explore future NIHR Portfolio adoption in service development work.

- **Finding effective incentives and processes to encourage medical staff to attend.** It was difficult to attract medical staff to participate due to work patterns and workload. Future projects could develop stronger researcher/medical staff relationships in shadowing phases and processes are needed to accommodate irregular timings due to shifts and rotations.

- **Finding ways to overcome the challenge of recruiting people from busy care settings** where many patients are in and out so quickly or are so ill while on the unit that there's not much time for anyone to get to know them; in dermatology, the very busy service left no room for reflective time as fed back by the Sister, 'no good time to run the research groups or have the information sessions'.

- **Finding ways to increase diversity of older people involved, which includes** e.g. older people with severe and lasting impairments, those who have experienced difficult transitions, for example hospital discharges to elderly care wards or care homes, and a range of family issues. Experiences of care might be quite different than those of the more able, who are in recovery or who are in remission from long term condition.

- **Using strategies to value good practice as this issue creates some difficulties at all stages of the process.** For example, when approaching a number of service users, some felt they had nothing to offer because their experiences of the staff and unit had been so positive. This required encouragement about interest in positive as well as negative

experiences. For some there was a reluctance to seemingly criticise any process when it was perceived that people had been 'so kind'. Appreciative Inquiry strategies offer support with this methodological concern.

- **Overcoming lack of visible interest from senior staff.** In our experience the support of senior managers and senior staff valuing the humanising care agenda adds to the sustainability of the service improvement work and strategies to make this support visible are important.

As in any participatory research a number of challenges were presented in learning about the humanising framework together, in negotiating a working through a humanised care assessment and in reaching decisions sensitised by the humanising care theory. These challenges in facilitation of ARG group decision-making processes are summarised as follows:

- At first, when discussing service improvement initiatives, the health care staff tended to jump back towards more common tasks and a professional framework that naturally tended to be more reductionist, for example a common response was to 'provide more information' rather than the group holding onto and 'staying with' ideas that had a more distinctive humanising and relational 'feel'.

- An appreciative approach, while powerful in helping the group work through a highly facilitative process, that focuses on humanising aspects of care risks over-looking the areas which really need improvement, and which may even be 'dehumanising', a balance has to be struck between these, as the group are ready (have reached a stage of readiness to explore areas that really need improvement).

- As in any group process managing more dominant group members who may have a louder voice when other participants are absent required ongoing facilitation.

- The decision making process within the ARGs was difficulty free but when our findings were shared with wider staff base, in one of the sites, there was a major barrier from senior staff that feedback 'We do that anyway'. This has potential to give the project work a low value within working culture, but also highlights importance of gathering evidence of the need for humanising care using examples of dehumanising care from service users' lifeworld examples. If this is difficult and sensitive a further strategy would be to use lifeworld evidence from published studies relevant to the practice area. Our findings point to the benefits of helping teams reconnect with humanising care values and harnessing the energising properties of this, so this is not an initiative on top of a range of other initiatives, it is rather a taking a step back to look again at what is important to teams and to what matters to older people. The service users in our project valued *the little things* e.g. a smile, clear gentle explanations, and were not adverse to the difficulties encountered and implications of professional concerns such as service targets.

- As in any action research trying to involve senior staff is an ongoing challenge, it is important that a range of staff participate—both front line staff to maintain humanising work and senior staff/organisational support to validate it. (Top down *and* bottom up involvement).

- *Readiness* in the system— the environment needs to be open to humanising care ideas and we suggest that using lifeworld evidence relevant to the setting, in addition to, locally obtained patient stories and experiences, making use of the film we have produced encapsulating the story of this present project and use of the humanising care assessment tool (HCAT), may have potential to sensitise settings and teams to these humanising care ideas.

- Minimising 'new initiatives overload'. We were able to show through our project that the application of the humanising care framework can be distinctive from other initiatives and can give teams tangible directions for practice. Because the work has its foundation in phenomenological philosophy, the project's characteristics allowed a focus on 'a way of being' with older people, rather than a 'doing more' and this was seen by staff and was valued to the extent that in both sites teams have taken steps to sustain discussions about humanising care.

SECTION 8: A transferable Leadership Strategy for improving 'what matters' to older people in improving dignity in care.

1. Humanising Care Toolkit: A process guide for transferability

Rationale and Content

The Humanising Care toolkit was developed as a flexible, practical resource to support practitioners to develop and nurture humanising care in their own clinical setting. The audience for the toolkit at this prototype stage are humanising champions, or individuals who have been supported through our research to assume leadership roles in noticing and nurturing humanising care. The toolkit ideas and activities will enable first generation champions to train, coach and support a new wave of humanising champions from all disciplinary backgrounds and all levels of the organisation. (For example, the next wave of humanising champions, identified as an outcome of this present project, within the stroke care unit will include nurses, healthcare assistants, rehabilitation assistants, occupational therapists and a ward administrator.

The humanising care toolkit consists of:

- A 60 page 'how to do it' manual equipping humanising care champions with background knowledge, activities and practical tips to set up, run and evaluate humanising care sessions and initiatives locally
- An accompanying physical resource bag containing creative materials, images and humanising care cards to support humanising care conversations and activities
- A film (DVD) illustrating application of humanising care ideas through talking heads explaining the background to humanisation theory, and sharing stories and insights about humanising care in practice, and what it was like for service users and healthcare staff

The toolkit manual which fully describes these components can be found in appendix 6 of the project report.

2. Film (DVD) rationale and content

The idea to design and produce the toolkit film (DVD) arose in the Bournemouth Action Research Group. Participants felt that a film (DVD) with real life stories from researchers, practitioners and older service users engaged in the study would be a powerful tool to resource further humanising care initiatives in the two pilot sites and beyond.

The film (DVD) comprises 3 sections with a total of 21 linked film clips:

- Part 1 presents the background to humanising care – why it is important and an introduction to the framework

- Part 2 presents stories of humanising care in practice – what it is and what it feels like from the perspective of both service users and service providers
- Part 3 offers insights from the project about ways practitioners, services and organisations might use humanising care initiatives to support service improvement, staff development and staff engagement.

The DVD will be freely available to humanising care champions who want to develop their own skills and knowledge in humanising care as well as provide training, support and coaching for their peers and colleagues.

3. A Humanised Care Assessment Tool (HCAT)

Rationale and Content

The humanising care assessment tool has been developed and piloted as part of the project. Currently there is no standardised way to assess or quantify the human aspects of care as delineated by the Humanised Care theoretical framework. To address this we wanted to begin the development of a measure of the human aspects of care that could be easily administered in the care environment. Such an instrument might be usefully applied in self-assessment of care settings (by for example 'humanising care champions') and may also be useful in further research in assessing the impact of the application of humanising care theory. The HCAT can be found in Appendices 7 & 8 of this report.

The Development of the Humanised Care Assessment Tool (HCAT)

In this section the development of an assessment tool designed to measure human dimensions of care is discussed. Currently there is no standardised way to assess or quantify the human aspects of care as delineated by the Humanised Care theoretical framework. To address this we wanted to begin the development of a measure of the human aspects of care that could be easily administered in the care environment. Such an instrument might be usefully applied in self-assessment of care settings (by for example 'humanising care champions') and may also be useful in further research in assessing the impact of the application of humanising care theory. Thus we began the development of a quantitative Humanised Care Assessment Tool (HCAT), based on the Humanising Care Framework (HFW) offered by Todres, Galvin and Holloway (2010) and articulated further by Galvin & Todres (2013). It was intended that this measure would be designed for use with Health Care Professionals (HCP). This next section describes the process of the HCAT development thus far.

Questionnaire Item Development

If a working culture more often attends to humanising behaviours, it can be extrapolated that the work environment can provide more humanly sensitive care. Thus we decided to develop the items that characterised 'humanised care', informed by the eight dimensions to form a rating scale for a set of observable behaviours, which we argue can be underpinned

by humanising values. It is important to articulate the underlying 'construct' the items are designed to measure (DeVellis, 2012), and in this case, this refers to the values underpinning humanly sensitive care, rooted in phenomenological philosophy as articulated as eight humanising dimensions of care.

However, of course there are also social desirability issues with asking HCP to rate their own attention to 'humanising behaviours'. We considered that as the Francis Report (2013) had highlighted the importance of the working culture in which care takes place, focusing our questionnaire on the context of care in the environment rather than an individual's own perhaps assumed 'volitional' behaviour would be a helpful methodological development. Thus the stem question to frame our humanising care behavioural items needed to address caring culture in the work environment, i.e. a focus on caring practice and not individuals. To address this, example stem questions we initially considered were *'my colleagues think it is important to…'* (e.g. *'support patients to have a say in their care or treatment')* and *'I feel able to'*. However, after much discussion, we settled on the stem question of **'my work environment enables me to'**. The research team agreed this stem question usefully located the measure of humanising care behaviours within in the care environment. Also we considered that 'my *work environment enables me to' was* a more abstract question than some of our other initial stem questions, it was an 'experience near' question. For instance, we thought stem questions such as '*I feel able to'* would require more abstract pondering of one's feelings, and thus could make items more difficult to answer and therefore less experience near.

Numerous items describing behaviours exemplifying all 8 dimensions of humanising care framework were needed to provide adequate sensitivity for the questionnaire. As our Action Research Groups (ARGs) had engaged in extensive and detailed discussion of experiences of humanised care, the transcripts from the ARG provided the starting point in looking for examples of humanised practice to derive items. The process of item generation involved our 4 members of our multidisciplinary research team (e.g. occupational therapy, nursing, psychology, and speech therapy) dividing up ARG transcripts and scanning these for examples of humanised care. These examples were then collated and refined and subsequently discussed at length by the wider research team.   The purpose of these discussions was to further refine phrasing (e.g. avoiding double barrelled items, Johns, 2010) and to discuss the relevance/applicability of each item to the 8 dimensions of the HFW (Galvin & Todres, 2013). Additional items were also generated through these discussions to yield a total number of 114 items to describe: Sense making/loss of meaning (e.g. '*update patients on treatments regularly',* n = 11), Personal Journey/ Loss of personal journey (e.g. '*offer support to patients moving through a system they are unfamiliar with*', n = 15), Homogenisation/Uniqueness (e.g. '*use patients preferred name'*, n = 7), Togetherness/Isolation (e.g. '*make sure patients know who you are',* n = 14), Insiderness/objectification (e.g. '*try to see the person behind the illness or condition'*, n = 9),

Embodiment/ Reductionist view of the body (e.g. *'avoid using clinical language where possible'*, n = 14), Dislocation/sense of place (e.g. *'be aware of the patients unfamiliarity with the environment'*, n = 14), Agency/ passivity (e.g. '*give patients the skills to manage their own conditions'*, n = 17). In addition, we wanted to create dummy items to observe if these items would be differentiated from the humanising care items, and check that there was variability in responses. Example dummy items included '*Be organised when booking annual leave'* and *'actively seek promotion'*, (n = 13). Please see appendix 7 for all questionnaire items grouped by humanising dimension, and a randomised item current version in development of the questionnaire (appendix 8). Questionnaire items were placed on a 5 point likert scale, asking respondents how often on an average day their work environments enabled various humanising behaviours. Likert scale responses were labelled 1: Always, 2: Most of the time, 3: Some of the time, 4: Rarely and 5: Never. Items with higher values indicated a less enabling work environment for a particular humanising behaviour. In addition, items were randomised using a random number generator (Randon.org, 2015).

Face validity testing of the assessment tool (FVT)

Face validity testing was undertaken with a group of Swedish Caring Science academics and a group of final year student nurses in the UK.

Specialist academic feedback: Due to the novel nature of attempting to offer a form of measurement within the context of lifeworld ideas about humanly sensitive care we wished to expose the questionnaire to rigorous face validity testing. We wanted to know how relevant and clear responders thought the items were, and to get feedback on the general face validity of the questionnaire content and design. To address this, the questionnaire was initially piloted with a group of 10 specialist Swedish Caring Science academics, experienced and knowledgeable in the ideas of lifeworld-led care and phenomenological perspectives in caring. The main purpose of receiving feedback on the questionnaire from this specialist group of academics, was to establish how relevant they thought the items were to the concept of humanly sensitive care. Specifically for the FVT procedure an adapted version of the questionnaire was designed that asked responders to circle how clear they thought the item read, and how relevant they thought the item was to the concept of humanised care. Also, a space was provided for any additional comments. The Swedish academics completed the questionnaire as part of a seminar session on humanising care with the co-author of the HFW, Prof Kathleen Galvin. Ten academics were present and each took around 25-30 minutes to provide feedback on the questionnaire. To note, although English was the second language of the Swedish academics, they spoke fluent English and their written English was of a publishable standard. Following the academics feedback a couple of small phrasing changes were discussed. For instance a number of responders had noted how the item '*Adjust your pace to get alongside that of your patient'*, was not clear, so we changed

this to *'adjust your professional pace to get alongside your patient'* to bring in the reference to the working environment.   In addition, for the item, show patients where they can find quiet spaces, this was change to 'peaceful spaces', as the Swedish researchers had pointed out that quiet can have positive or negative connotations. In addition one item *'where possible to help patients have some meaningful possessions close at hand' had* been missed off the questionnaire and another item had been duplicated (*Where safety concerns allow, adapt the environment to make it as homely/personal as possible*). This was rectified before administration to the English nursing students

Student nurse feedback

Ten 3rd Year students (8 female, 2 male) from the University of Hull BSc Nursing programme were recruited for FVT procedures. We thought 3rd year nursing students would have suitable experience, gained over a number of placements to answer items on how their current work place enables caring behaviour focused on human aspects. Student nurses were recruited during lecture time. They were provided with a short talk on the present project as an adjunct to a lecture on orthopaedics, at which all 3rd year students were present. Nineteen nursing students offered their contact details to participate in FVT, and on later contact 10 interviews were arranged on first-come-first-serve basis. We thought 10 interviews, would provide enough initial information (Guest, Bunce & Johnson, 2006) for us to establish if any recurrent themes were arising with regards to the clarity and relevance of any of the items.

Each participant was invited to attend a 1-hour interview, where they would complete the questionnaire alone in the first half of the interview. Then, participants were invited to discuss their answers with the researcher, and elaborate on reasons they may have rated items 'not clear' or 'not relevant'. Also the researcher asked for general feedback on the questionnaire content and thought about any social desirability issues immediately after the questionnaire was completed. These comments were recorded to assist with the face validity analysis.

Processing the Items following Face Validity Testing.

Following FVT all feedback from both Swedish academics and English nursing students were collated together. Items were initially selected for further examination if there were rated 'not clear' or 'not relevant' three times or more by the participants. These items were then selected for detailed discussion between 3 researchers with: specialist knowledge on questionnaire development (RW), specialist knowledge on the HFW (KG), and extensive involvement through all stages of questionnaire development, including the FVT interviews (CS). It is important to note that not only was the 'clear' 'not clear' ratings considered, but the additional comments as to why an item might not be clear or relevant was particularly useful at this stage.

There were a variety of reasons why participants had rated particular items either 'not clear' or, 'not relevant'. For example, some items were considered too general by responders as they were lacking in context, e.g. the Agency item: *'try to do what the patient wants'.* For this item we considered that as it was not possible to list all the circumstances that *'doing what the patient wants'* could apply in, we decided to drop the item from the questionnaire. Other items were considered too abstract by participants, e.g. *'adjust your pace to get alongside that of your patient'*, consequently this item was also dropped. Other items needed simple wording changes. For instance, the item *'my work environment enables me to notice my own feelings'* was changed to *'My work environment enables me to 'have the time to reflect on my own feelings'*. We thought by adding the context of time, and using the word reflect rather than 'notice' (which a participant had stated they preferred), this would reduce the lack of clarity reported.

Also we received feedback that some items had a lack of clarity as to who they were directed at. For instance, for the Sense-of-Place item: *'notice barriers to being made to feel welcome'*, responders did not know who this was directed at, patients or families. As we wanted to ask about both patients and families, but understood that some care environments may be more patient than family oriented, or vice-versa, we decided to create two items: (*'notice barriers that can get in the way of patients feeling welcome'* and *'notice barriers that can get in the way of families or visitors feeling welcome').* Conversely, we were able to reduce down item numbers in some domains by simplifying wording. For instance, three Sense-of-Place items asked about helping patients to stay in touch with important: 'places', 'people' and 'activities' from their everyday lives respectively. We were able to reduce these three items down to a single item '*Find ways to help patients to stay in touch with important things in their everyday life*'. Furthermore, although some items were considered 'not relevant' and 'not clear' by 3 responders, we made the decision to leave them in the questionnaire, to see how they could perform in future planned FVT. For example, we considered the item '*Care about the wellbeing of my colleagues'* relevant to humanising care, despite 3 participant's views that this was not relevant.

The FVT process also involved reflection on the general feedback we received from participants who had completed the questionnaire. This feedback was on the whole very positive. For example, we received comments such as: 'I *think the questionnaire is useful and highlights areas where staff already do that, and other areas where it makes you think you could improve on that'.* Other comments included *'most items address essential aspects of nursing'* and also, *'I enjoyed completing the questionnaire - at first I thought over 100 items is a lot, but I think it's very detailed and covers everything to do with care'.* Any negative feedback focused mostly on the similarity of some items e.g. *'Some items felt like they were repeating'*. We have addressed the issue of similarity of wording in some items, by either dropping items, changing phrasing, or keeping them in the measure, with a view to changing the questionnaire structure. For example items such as, '*notice barriers that can get in the way of patients feeling welcome'* and *'notice barriers that can get in the way of*

families or visitors feeling welcome' could be placed in separate questionnaire sections headed 'families' and 'patients' to reduce the feel of repetitive questioning. In addition, to address our social desirability concerns, the researcher asked the student participants if they thought they would be able to answer the items honestly in a work environment. All students said they would feel okay to do this, if their anonymity was guaranteed. Thus confidentiality must be guaranteed for those completing the questionnaire, if results are to be considered valid.

To conclude, following this first stage of FVT, 10 items were dropped from the questionnaire, 5 new items were created, and phrasing changes were carried out on 23 items, to yield a final number of 109 items: Sense making/loss of meaning (n = 11), Personal Journey/loss of personal Journey (n = 13), Homogenisation/Uniqueness (n =7), Togetherness/Isolation (n = 14), Insiderness/Objectification (n = 8), Embodiment/Reductionist view of the body (n = 12), Dislocation/Sense-of-Place (n = 15), Agency/Passivity (n = 16), Dummy items (n = 13).

Future research is planned to develop the HCAT further, and early indications are that the HCAT is an understandable and promising measure of aspects of humanising care.

SECTION 9: Concluding thoughts: Empowering Dignity

In addition to meeting specific objectives as set out in Section 4, our overarching project outcomes offer a transferable leadership strategy for nurses, and other healthcare staff, to engage in a process of steps to applying a new theoretical framework for enhancing the human dimensions of care. This tried and tested process, applying new humanising theory within two different settings, we argue, can empower *dignity in care*. We offer practical directions to enhance dignity in care by responding to potential threats to dignity where humanised dimensions of care are obscured or are dropped out and even dehumanising. For instance: To experience unwanted isolation, to be rendered passive when one wants to be more active with a greater say and sense of agency; to experience a loss of personal journey and to feel dislocated from meaningful others, things, and places in ways that are not a necessary part of medical treatment or rehabilitation; to experience a sense of having to fit in unnecessarily or without explanation, and to interact with care services in language and practices that overly label, overly categorise, overly focus on signs and symptoms, and physical response to treatment and therapy at the expense of what the experience means for everyday life are all forms of potential indignities. Any attempts to refocus on the humanising dimensions of care can sensitise staff to attend and value these aspects of care, and in turn, guard against such indignities. Further, we argue that our transferable strategy led by new theory offers *concrete steps* for meaningful service improvements.

Service Enhancement Impacts of our project

There have been a number of significant impacts for individual staff members, services and organisations involved directly in the project. Learning from the study is also offering insights for organisational development and leadership projects in new settings.

In Bournemouth the outcomes of the study have been presented to the senior nursing team and the Board of the Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust. We are currently liaising with the Director of Nursing about ways the humanising care initiatives on the stroke care unit can inform practice on other wards within the Older Person Directorate. Sessions on humanising care using activities and items from the toolkit have been introduced within the Trust's Education and Training programmes including the rolling programmes for Health Care Assistants and nurse preceptorship.

We are also in discussion with the stroke care unit about facilitating a further humanising care group to train a new set of humanising champions and service users. This work will again draw on the materials developed in the project and inform the stroke unit's ambitions to model and showcase leadership in humanising care practice.

In Hull, the outcomes of the study have been presented to senior service managers and board members of the Hull Royal Infirmary. The dissemination event was undertaken by service users and the team. The Trust are exploring potential to develop a 'Friends and Families' feedback initiative to encompass Humanising Care dimensions and examining potential outcomes within managing complaints work.

In recognition of how the humanising care values can underpin and facilitate culture change members of the research team have also been approached to support a programme of organisational change at a hospital specialising in the treatment of people with severe neuro-disabilities. The research team have used the humanising care materials to support sessions for more than 40 members of the leadership team as well as the executive team and Board members. Building on experiences from the Burdett research study, the executive team are currently examining ways that the humanising care framework can underpin the hospital's strategy for developing best practice in humanising care and culture.

We are currently in discussion with *Belong Community Villages* who offer an alternative to conventional care homes. Older people live in self-contained apartments or supported households offering a family atmosphere enabling people to develop meaningful relationships. One Belong community is keen to clearly illustrate the difference in the care they offer and are interested in using the Humanising Framework as one method of evaluation.

Recommendations for future research

Together the Humanising Care toolkit (manual), with facilitation materials and film (DVD) and Humanised Care Assessment Tool form the basis of prototype resource which we envisage could form the basis of a national training package centred on the human aspects of care. Our future research aspirations are to:

1. Test and refine the Humanising Care Toolkit including evaluation of best ways to facilitate take up in a range of different settings.
2. Undertake further research to psychometrically evaluate the content of the Humanising Care Assessment Tool.
3. Grow a national network of *humanising care champions* in follow-up practice development and improvement/ research studies.
4. Develop a further research initiative to explore impact of application of humanising care framework on staff outcomes, including wellbeing at work measures.
5. Develop a further research initiative to explore impact of application of the humanising care framework on care outcomes, using the HCAT as an outcome measure.
6. Develop a cross county comparison of application of the framework in collaboration with international partners.

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Appendix 1

Claire Sloan
Faculty of Health and Social Care
University of Hull,
HU6 7RX

FACULTY OF HEALTH AND SOCIAL CARE

T: 01482 464680

E: j.dyson@hull.ac.uk

OUR REF: 119

31 October 2013

Dear Claire

Re: Humanising Services: A new transferable leadership strategy for improving 'what matters to older people' to enhance dignity in care

Thank you for submitting the above proposal to the Faculty of Health & Social Care Ethics Committee.

I am pleased to grant Chair's approval as per the Terms of Reference of the Faculty of Health and Social Care Ethics Committee.

We wish you every success in your study.

Yours sincerely

Dr Judith Dyson
Chair, Faculty Research Ethics Committee

Cc: file

Appendix 2

NRES Committee North East - Sunderland

TEDCO Business Centre
Viking Business Park
Jarrow
Tyne & Wear
NE32 3DT

Telephone: 0191 4283564

18 June 2014

Prof Kathleen Galvin
Professor of Nursing Practice
University of Hull
Cottingham Road
Hull
HU6 7RX

Dear Prof Galvin

Study title:	**Humanising Services: A new transferable leadership strategy for improving 'what matters to older people' to enhance dignity in care**
REC reference:	**14/NE/1046**
IRAS project ID:	**150621**

The Proportionate Review Sub-committee of the NRES Committee North East - Sunderland reviewed the above application on 16 June 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager Miss Kathryn Murray, nrescommittee.northeast-sunderland@nhs.net.

Ethical opinion

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.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned</u>.

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.

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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).

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").

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Copies of advertisement materials for research participants [General information summary & invite to Q & A session]	1	09 May 2014

Covering letter on headed paper [Covering Letter The Humanising Care Project]		04 June 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance certificate]	01	20 May 2014
Letter from funder [Letter from funder]	01	20 May 2014
Other [Question & Answer session additional information]	1	09 May 2014
Participant consent form [Consent form]	1	21 May 2014
Participant information sheet (PIS) [PIS Hull]	1	21 May 2014
REC Application Form [REC_Form_09062014]		09 June 2014
Research protocol or project proposal [Protocol]	1	26 May 2014
Summary CV for Chief Investigator (CI) [CV Chief Investigator]	01	20 May 2014
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Flowchart study entry and consent]	1	21 May 2014
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Flowchart Phase 1]	1	09 May 2014

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 HRA 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 HRA website http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

14/NE/1046	Please quote this number on all correspondence

K. Murray.

Mr Paddy Stevenson
Chair

Email: nrescommittee.northeast-sunderland@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
	"After ethical review – guidance for researchers" [SL-AR2]
Copy to:	*Dr Andrew Taylor, University of Hull*
	Mr James Illingworth , Hull and East Yorkshire Hospitals NHS Trust

NRES Committee North East - Sunderland

Attendance at PRS Sub-Committee of the REC meeting in Correspondence

Committee Members:

Name	Profession	Present	Notes
Mr Obi Iwuchukwu	Consultant Surgeon	Yes	
Mrs Debra J Lett	Manager Newcastle Brain Tissue Resource	Yes	
Mr Paddy Stevenson (Chair)	Research Operations Manager	Yes	

Also in attendance:

Name	Position (or reason for attending)
Kathryn Murray	REC Manager

Appendix 3

Research & Development Department
2nd Floor Daisy Build
Castle Hill Hospital
Castle Road
Cottingham
HU16 SJQ

16/07/2014

Dr Fiona Cowdell
University of Hull
Faculty of Health and Social Care
University of Hull
Cottingham Road
HU6 ?RX

Dear Dr Fiona Cowdell

Re: NHS Permission Granted for Research Application

Study Title	Humanising Services: A new transferable leadership strategy for improvin!'.l 'what matters to older people' to enhance di!'.lnitv in care
HEY R&D ref	R1682
REC Ref	14/NE/1046
CSP Ref	N/A

I am pleased to notify you formally that the above titled study has been granted 'NHS Permission for Research' by Hull and East Yorkshire Hospitals NHS Trust and may proceed subject to the conditions outlined in the enclosed conditions of approval document.

Approved current documents are fully listed on the Research Ethics Committee Favourable Opinion Letter(s) and have been reviewed as part of the governance review process.
Core documents as follows :

Document	Version	Date
Protocol	1	26/05/14
Participant Information Sheet	1	21/05/14
Participant Consent Form	1	21/05/14

__Please ensure that the most recent REC approved documents are used. Please notify the R&D Office if the versions above are in__correct.

Please inform HEY R&D when you have recruited your first patient.

The target date for first patient recruited:	15/08/2014

Great Staff - Great Care - Great Future

NHS 'Permission for Research' is granted on the understanding that the study is conducted in accordance with the requirements of the Research Governance Framework', the NHS Intellectual Property Guidance and all other applicable regulations and associated Trust policies. In undertaking this study, you agree to comply with all reporting requirements , systems and duties of action put in place by the Trust to deliver research governance. In addition, you agree to accept the responsibilities associated with your roles which are outlined within the Research Governance Framework.

Please read and sign both copies of the conditions of approval document enclosed with this letter, keep one copy for your records along with this letter and return one signed copy of the conditions to the R&D Dept. *Failure to do* so *may invalidate this NHS permission.*

I would like to wish you every success with this project

Yours sincerely

James Illingworth
Research & Development Manager

. ' The Research Governance Framework for Health and Social Care (RGFHSC}(2 "d Edition 2005) sets out the broad principles of good research governance

Re: R&D Ref- R1682 / REC Ref- 14/NE/1046 / CSP Ref- N/A

Humanising Services: A new transferable leadership strategy for improving 'what matters to older people' to enhance dignity in care

Conditions of NHS Permission for Research (Non-IMP)

THIS DOCUMENT SETS OUT IMPORTANT GUIDANCE FOR INVESTIGATORS ON THE CONDUCT AND MANAGEMENT OF NON-IMP RESEARCH WITHIN THIS NHS TRUST.

1.0   Research Governance

1.1 The study should follow the REC approved protocol

1.2 All REC conditions of authorisation that pertain to Hull and East Yorkshire Hospitals NHS Trust must be adhered to prior to the first patient being recruited at this site.

1.3 All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant.

1.4 All HEY R&D conditions highlighted in the NHS Permission letter must be adhered to prior to the first patient being recruited at this site.

1.5 Any suspected misconduct by anyone involved in the study must be reported in accordance with HEY Trust policy.

1.6 All relevant support services and departments must be consulted on and authorise their involvement in the research prior to any patient being recruited into the trial.

1.7 The Sponsor, REC and HEY Trust R&D Office must be notified, as appropriate, of any serious breaches or incidents (at this site or any other participating sites) as soon as the Sponsor or site is made aware of them

1.8 Where applicable for Non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

2.1   Study Delivery and Monitoring

2.2 The site must co-operate with the monitoring schedule and monitoring plan put in place by the Sponsor to demonstrate compliance with all applicable legislation and institutional policies.

2.3 Where applicable- as Chief/Principal Investigator you will ensure that you understand and have acknowledged all obligations placed on you in any trial agreement and agree to adhere to these obligations

2.4 As Chief/Principal Investigator, you will ensure that any indirect or direct obligations imposed on the research team from any third party agreements/service level agreements will be complied with.

2.5 Copies of all amendments with related approvals, applications and documents need to be forwarded to the HEY Trust R&D Office. Amendments must be approved by the HEY Trust R&D Office prior to implementation.

2.6 **Where HEY NHS Trust is the study Sponsor** – all changes to the study must be notified to the HEY R&D office prior to submission to the REC. It is the decision of the Sponsor (HEY Trust R&D Office) whether the proposed changes are deemed substantial or non-substantial.

2.7 Copies of REC annual progress reports must be forwarded to the HEY Trust R&D Office.

2.7 Copies of the end of trial notification and summary reports must be forwarded to the HEY Trust R&D Office within the regulatory timelines.

3.0 Participant Safety

3.1 Participants should receive appropriate care while involved in the study. As a matter of courtesy, all relevant healthcare professionals should be informed of the study and the likely impact on day-to-day activities. Any activity should not be at the detriment of routine care.

3.2 Where applicable, appropriate counselling must be available to patients taking part in the study.

4.0 Informed Consent

4.1 All potential subjects should have enough information to make a free and informed decision about participation.

4.2 Only those staff authorised and documented on the delegation log obtain consent.

4.3 Where required, an appropriate consent process, approved by the Ethics Committee is implemented for participants lacking the capacity to consent prior to the study commencing at this Trust.

5.0 Training and Human Resources

5.1 No staff member should be added to the delegation log without appropriate training. The R&D office must be notified of any staffing issues that may prohibit the Trust from fulfilling its obligations during the course of the trial.

5.2 All staff participating in the research at HEY must hold substantial or honorary contracts/letters of access with this Trust. Any staff not holding an appropriate contract of employment (or honorary contract) will not be indemnified by HEY Trust

5.3 All Health and Safety legislation (including Trust and University policies) must be adhered to during the conduct of the research.

5.4 Where applicable, the relevant Trust and University lone working policies must be adhered whilst conducting the research.

6.0 Data Protection

6.1 No patient identifiable data should be sent outside of the research team at Hull and East Yorkshire Hospitals NHS Trust (except where covered by the patient consent form)

6.2 Before a patient is recruited into the trial that the security of data transfer must be in accordance with the Trust policy on encryption and data access controls should be in place (individual user accounts and passwords).

6.3 No patient identifiable data should be held on laptop computers (except where encrypted as per Trust policy). No laptops should be loaned from commercial companies for the storage and transfer of research data. The R&D Office must be notified of any computer equipment loaned or given to the Trust for the purposes of the study prior to implementation. Laptops or home computers that have not been Trust encrypted must not be used to collect or transfer data as part of this study.

6.4 An appropriate mechanism must be in place in line with the Sponsors instructions, the study protocol and Trust policy to check for any patient deaths prior to sending follow-up questionnaires or contacting patients for follow up.

6.5 The integrity and confidentiality of clinical and other records and data generated by the study must be maintained in accordance with the Data Protection Act (1998) and associated HEY Trust Information Governance policies

7.0   Studies Involving Tissue

7.1 Any central labs used in the research must hold the necessary license/accreditation and local Pathology authorisation and agreement (where required) for any processing, storage and handling of tissue (including archived tumour blocks) and bloods must be in place prior to recruiting the first patient at this site. (Appropriate finance must be available to cover the costs of storage and handling).

7.2 You must be aware of, and adhere to, all obligations placed on you as Chief/Principal Investigator with regards to ensuring all guidelines and regulations are adhered to for the storage and transfer of tissue and blood samples outside of HEY as part of the study protocol. Where required, a Material Transfer Agreement must be in place for the transfer and storage of human tissue. You must adhere to the Sponsor's written instructions and SOPs regarding tissue and blood handling)

7.3 There must be an appropriate custodian of the samples supplied to the lead site by this Trust and this custodian should be duly authorised by the Sponsor.

7.4 Appropriate consent must be obtained for all translational sub study and genetics work within the limits of the REC favourable opinion.

7.5 Please note that samples may be held after the declaration of the end of the trial, for analysis or verification of research data for up to one year. After this period legal authority to hold any human tissue under the ethical approval for this project will expire. To ensure that any continued storage is lawful, either the tissue must be held on premises with a storage licence from the Human Tissue Authority, or an application made for ethical approval of another project before the favourable ethical opinion of the existing project expires. Otherwise the tissue would need to be destroyed in accordance with the HTA Codes of Practice.

8.0   Use of equipment (including loans)

8.1 You should notify the Trust R&D Office of any equipment loaned or donated to the research team for the purposes of the research to ensure that the Medical Physics team can check that the appropriate indemnity arrangements are in place prior to using the equipment.

8.2 Where applicable, appropriate agreement must be in place (prior to the study commencing) to cover the cost and potential additional resources as part of this research.

8.3 Where applicable, all decontamination and sterilisation procedures required (as per Trust and national policy and regulations) for the duration of this research must be adhered to. The research team should be made aware of any obligations in this regard prior to commencing the research at this site.

8.4 It must be confirmed that all medical devices being used as part of the study are not within the remit of the Medical Devices Directive and therefore do not require authorisation from the MHRA.

9.0   Funding

9.1 Funds must be held by the department to cover all identified costs. It is the responsibility of the Chief/Principal Investigator to notify the HEY R&D Office if any funding issues are identified.

9.2 Where relevant, all eligible service support costs must be agreed with the Local Clinical Research Network prior to any patient being recruited into the trial.

9.3 Where applicable, all excess treatment costs should be agreed with the appropriate Clinical Commissioning Group (CCG) as per Department of Health guidance.

9.4 The research site must hold the necessary funds to cover the cost of the archiving period stipulated by the Sponsor. Where archiving responsibility is delegated to the participating sites, this should be clearly documented and agreed in the clinical trial agreements for each site.

10.0   IRMER / ARSAC

10.1 All necessary IRMER regulations must be adhered to at the HEY site during the course of the research and where appropriate, local radiology review (IRMER, ARSAC and service capacity assessments) must have been undertaken prior to the study commencing at this site.

11.0   Adverse Event Reporting

11.1 All serious adverse events (SAEs) that in the opinion of the Chief/Principal Investigator are related* to the research treatment/procedure and unexpected* require reporting to the Ethics Committee and R&D within 15 days of the CI/PI becoming aware of the event using the NRES report form available from:
http://www .nres.npsa.nhs.uk/applications/after -ethical-review/safetyreports/safety -reports-for-all-other-research/#safetvnonCTI MPrepotingSAEs.
*Related i.e. the SAE resulted from administration of any of the research treatments or procedures; and Unexpected i.e. the SAE is not listed in the protocol as an expected occurrence.

11.2 All related and unexpected serious adverse events (SAEs) must be reported forthwith to the Sponsor REC and HEY Trust R&D Office (and other authorities specified in the protocol) as soon as you are made aware of them

Chief / Principal Investigator Declaration

As the Chief / Principal investigator I can confirm that I have read and understood the above conditions of approval

I can confirm that I understand and have acknowledged all obligations placed on me under the Research Governance Framework and all other applicable regulations, Trust and other external institution policies and procedures, and I agree to adhere to the these obligations

<u>Please sign below</u>

Chief Investigator / Principal Investigator (Print Name):

Chief Investigator / Principal Investigator (Signature):

<u>Date</u>:... . ...

<u>SIGN TWO COPIES OF THE CONDITIONS OF 'NHS PERMISSION FOR RESEARCH'.</u>

<u>RETURN ONE SIGNED COPY TO THE R&D DEPT. FAILURE TO DO SO MAY INVALIDATE NHS PERMISSION</u>

<u>FILE THE OTHER SIGNED COPY WITH THE NHS PERMISSION LETTER IN YOUR STUDY FILE</u>.

Appendix 4

The Humanising Care Project: How older adults' experiences of care can guide practice and enhance dignity

Participant information sheet

This information sheet is about some research being undertaken by the University of Hull and the University of Bournemouth in collaboration with local NHS services. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear please contact the research team for more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Whether you decide to take part in the research or not, will not affect your healthcare in any way.

What is the purpose of the study?

The purpose of this study is to investigate what 'human aspects of care' mean to older people. We are interested in the experiences of people who have used the Bournemouth Stroke Unit services and the experiences of people who work in the Stroke Services. We will look at how people have experienced human aspects of care and explore ways to enhance human aspects of care in practice.

Similar research is being carried out in Hull and in Bournemouth. This information sheet refers to participation in **Bournemouth.**

Why are you asking me?

We are asking you because we value your opinion and personal experiences of using or providing care in the stroke service. Your name was suggested to the research team by the local healthcare team. The study is particularly interested in the experiences of:

- People aged 65 + who have received services from the Bournemouth Stroke Unit
- People who work in the Stroke Unit at the Royal Bournemouth Hospital

Do I have to take part?

No, the decision to take part is entirely voluntary. We are giving you this information sheet in advance to give you time to think about any questions and give you time to decide. If you think you might like to be involved we hope you can come to a Question and Answer session at the hospital (see invitation). After the meeting we will give you a consent form to consider and sign if you are still interested. If you do decide to take part you can choose to withdraw at any time. You do not need to give a reason. This will not affect the care you receive either now or at any time in the future.

What will happen if I agree to take part?

If you agree to take part you will become an important member of an Action Research Group. This group will have about 10 members, 4-5 people who have experienced the services as patients, 3 clinicians and 2 researchers. This group will meet at the Royal Bournemouth hospital. The group will discuss how patients can be at the centre of health care and how human aspects of care may inform practice to enhance human dignity.

Group members (patients and staff) will share their own experiences of the stroke services. They will talk about experiences of being treated in human ways and perhaps times where they felt aspects of care and dignity were not handled sensitively.

The groups will review a framework to support humanising healthcare developed by some previous researchers. Together the Action Research group will review their own stories and experiences in relation to the framework. For example, the team might discuss:

- ways people can feel more in control of their treatment
- ways the environment has got in the way of feeling comfortable with procedures
- ways staff members can show that they really understand individual needs and are not just treating you as any other patient

Then the group will generate and prioritise some options for change. They will help develop a plan to enhance human aspects of care and practice in their setting. Carrying out this plan will be Phase 2 of this project.

Group members will need to:

- Come to a series of meetings, over 18 months, at the hospital in Bournemouth.
- Be happy to describe their experiences of receiving or providing stroke services in Bournemouth.

Action Research group meetings will last about 2 hours. We anticipate about 8 meetings in total.

Are there any other ways to be involved ?

In Phase 2 of the project we hope to involve more people who have used or who provide services. For example, we might hold some interviews or group meetings. We might ask people to help us with a survey of experiences. We are not sure yet what form this will take. Tell us if you are interested and we will let you know more when the Action Research group decides on the plan for Phase 2.

What are the possible disadvantages of taking part in the study?

Some people find it distressing to talk about experiences of healthcare. If you do, you can withdraw at any time. If you want, we can suggest where you can go to get help and support.

If you tell us about very poor care we will report this in line with professional guidelines. We will always discuss this with you before reporting incidents to other people/ managers.

What are the possible benefits of taking part in the study?

This is a research project. It is not therapy or treatment so you will not receive any direct benefit. However, some people enjoy sharing their experiences of services they have received or provided. You will have the opportunity to actively influence the improvement and leadership of services. This can result in benefits to future service users.

Will my personal details and information remain confidential?

Yes. We will keep your personal details and information private. We will remove your name from any transcripts of group discussions.

Expenses

We will pay all service users travel expenses to and from the meeting, and offer service users £10 for each hour to thank you for your participation.

Part 2

The next section contains more information about the research. If you are still interested in taking part in the research please read the following information before you make any decision about taking part.

What happens if I want to leave the study?

We hope that the members of the Action Research group will stay with the project for about 18 months. However you are free to leave at any time. You do not need to give us a reason.

If you decide to leave we will ask you if you are happy for us to keep the stories and information you have given us up to that point. If not, we will delete all of your contributions to the research.

What if there is a problem?

If you have any concerns about the study, in the first instance you can ask to speak to the researcher in Bournemouth (Dr Carole Pound). If you are still unhappy you can contact the main project supervisor, Professor Kathleen Galvin (see contact details)

What will happen to the information and stories you record about me?

If you agree to take part we will digitally record the stories, experiences and ideas that you share with the researchers in the Action Research

meetings. These recordings will be transcribed into printed text. All personal details and experiences will be treated in the strictest confidence. Only the research team will have access to the data.

We will ask you for permission to use anonymised stories and experiences that you share with the Action Research group.

What will happen to the results of the research study?

At the end of the study the researchers will write a report for the Burdett Trust. We will present some of the findings at scientific conferences and in academic journals. We will also use the learning from the study to help other settings and practitioners to enhance dignity and human aspects of care. With your permission, we may use stories and direct quotes from Action Research group participants but we will not use your name.

Who is organising and funding the study?

The study is being organised by a research team at the Faculty of Health and Social Care, University of Hull, headed by Professor Kathleen Galvin. The team is working in partnership with Bournemouth University. The funding for the project is being provided by the Burdett Trust and the University of Hull.

Who is supervising the study and the researchers?

Professor Kathleen Galvin is supervising the study in Hull and Dr Caroline Ellis-Hill is supervising the study in Bournemouth. The project is run in accordance with NHS guidelines at a national and local level.

Who has reviewed the study

Hull University Research Ethics Committee has reviewed the study. We are in the process of submitting the details of the study to the NHS Research Ethics Committee. This Committee examines research proposals that involve patients and healthcare workers to make sure that the research follows good practice and protects the dignity, rights, safety and wellbeing of all study participants

Who do I contact if I want to take part or have any further questions?
If you have any queries, or would like any further information, please contact

Dr Carole Pound
Research Associate
Bournemouth University
Centre for Qualitative Research
Room 109, Royal London House
Christchurch Road, BH1 3LT
Email: cpound@bournemouth.ac.uk
Tel: 07821 374661

If you have any complaints, please contact:
Professor Kathleen Galvin
Hull University
Faculty of Health & Social Care
Cottingham Road
Hull HU6 7RX
Email: k.t.galvin@hull.ac.uk
Tel: 01482 463336

Appendix 5

The Humanising Care Project: How older adults' experiences of care can guide practice and enhance dignity

Participant information sheet

This information sheet is about some research being undertaken by the University of Hull and the University of Bournemouth in collaboration with local NHS services. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear please contact the research team for more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Whether you decide to take part in the research or not, will not affect your healthcare in any way.

What is the purpose of the study?

The purpose of this study is to investigate what 'human aspects of care' mean to older people. We are interested in the experiences of people who have used the Dermatology Outpatient Services in Hull and the experiences of people who work in the Dermatology Outpatient Department. We will look at how people have experienced human aspects of care and explore ways to enhance human aspects of care in practice.

Similar research is being carried out in Hull and in Bournemouth. This information sheet refers to participation in **Hull.**

Why are you asking me?

We are asking you because we value your opinion and personal experiences of using or providing care in the dermatology service. Your name was suggested to the research team by the local healthcare team. The study is particularly interested in the experiences of:

- People aged 65 + with long term skin conditions (who attend the Dermatology Outpatient Department in Hull)
- People who work in the Dermatology Outpatient Department at Hull Royal Infirmary

Do I have to take part?

No, the decision to take part is entirely voluntary. We are giving you this information sheet in advance to give you time to think about any questions and give you time to decide. If you think you might like to be involved we hope you can come to a Question and Answer session at the hospital (see invitation). After the meeting we will give you a consent form to consider and sign if you are still interested. If you do decide to take part you can choose to withdraw at any time. You do not need to give a reason. This will not affect the care you receive either now or at any time in the future.

What will happen if I agree to take part?

If you agree to take part you will become an important member of an Action Research Group. This group will have about 10 members, 4-5 people who have experienced the services as patients, 3 clinicians and 2 researchers. This group will meet at Hull hospital. The group will

discuss how patients can be at the centre of health care and how human aspects of care may inform practice to enhance human dignity.

Group members (patients and staff) will share their own experiences of the dermatology services. They will talk about experiences of being treated in human ways and perhaps times where they felt aspects of care and dignity were not handled sensitively.

The groups will review a framework to support humanising healthcare developed by some previous researchers. Together the Action Research group will review their own stories and experiences in relation to the framework. For example, the team might discuss:

- ways people can feel more in control of their treatment
- ways the environment has got in the way of feeling comfortable with procedures
- ways staff members can show that they really understand individual needs and are not just treating you as any other patient

Then the group will generate and prioritise some options for change. They will help develop a plan to enhance human aspects of care and practice in their setting. Carrying out this plan will be Phase 2 of this project.

Group members will need to:

- Come to a series of meetings, over 18 months, at the hospital in Hull.
- Be happy to describe their experiences of receiving or providing dermatology services in Hull.

Action Research group meetings will last about 2 hours. We anticipate about 8 meetings in total.

Are there any other ways to be involved?

In Phase 2 of the project we hope to involve more people who have used or who provide services. For example, we might hold some interviews or group meetings. We might ask people to help us with a survey of experiences. We are not sure yet what form this will take. Tell us if you are interested and we will let you know more when the Action Research group decides on the plan for Phase 2.

What are the possible disadvantages of taking part in the study?

Some people find it distressing to talk about experiences of healthcare. If you do, you can withdraw at any time. If you want, we can suggest where you can go to get help and support.

If you tell us about very poor care we will report this in line with professional guidelines. We will always discuss this with you before reporting incidents to other people/ managers.

What are the possible benefits of taking part in the study?

This is a research project. It is not therapy or treatment so you will not receive any direct benefit. However, some people enjoy sharing their experiences of services they have received or provided. You will have the opportunity to actively influence the improvement and leadership of services. This can result in benefits to future service users.

Will my personal details and information remain confidential?

Yes. We will keep your personal details and information private. We will remove your name from any transcripts of group discussions.

Expenses

We will pay all service users travel expenses to and from the meeting, and offer service users £10 for each hour to thank you for your participation.

Part 2

The next section contains more information about the research. If you are still interested in taking part in the research please read the following information before you make any decision about taking part.

What happens if I want to leave the study?

We hope that the members of the Action Research group will stay with the project for about 18 months. However you are free to leave at any time. You do not need to give us a reason.

If you decide to leave we will ask you if you are happy for us to keep the stories and information you have given us up to that point. If not, we will delete all of your contributions to the research.

What if there is a problem?

If you have any concerns about the study, in the first instance you can ask to speak to the researcher in Hull (Dr Claire Sloan). If you are still unhappy you can contact the main project supervisor, Professor Kathleen Galvin (see contact details)

What will happen to the information and stories you record about me?

If you agree to take part we will audio record the stories, experiences and ideas that you share with the researchers in the Action Research meetings. These recordings will be transcribed into printed text. All personal details and experiences will be treated in the strictest confidence. Only the research team will have access to the data.

We will ask you for permission to use anonymised stories and experiences that you share with the Action Research group.

What will happen to the results of the research study?

At the end of the study the researchers will write a report for the Burdett Trust. We will present some of the findings at scientific conferences and in academic journals. We will also use the learning from the study to help other settings and practitioners to enhance dignity and human aspects of care. With your permission, we may use stories and direct quotes from Action Research group participants but we will not use your name.

Who is organising and funding the study?

The study is being organised by a research team at the Faculty of Health and Social Care, University of Hull, headed by Professor Kathleen Galvin. The team is working in partnership with Bournemouth University. The funding for the project is being provided by the Burdett Trust and the University of Hull.

Who is supervising the study and the researchers?

Professor Kathleen Galvin is supervising the study in Hull and Dr Caroline Ellis-Hill is supervising the study in Bournemouth. The project is run in accordance with NHS guidelines at a national and local level.

Who has reviewed the study

Hull University Research Ethics Committee has reviewed the study. We are in the process of submitting the details of the study to the NHS Research Ethics Committee. This Committee examines research proposals that involve patients and healthcare workers to make sure that the research follows good practice and protects the dignity, rights, safety and wellbeing of all study participants.

Who do I contact if I want to take part or have any further questions?

If you have any queries, or would like any further information, please contact

Dr Claire Sloan Research Associate
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If you have any complaints, please contact:

Professor Kathleen Galvin
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Hull HU6 7RX
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Tel: 01482 463336

Appendix 6

The Humanising Care Toolkit

Sharing experiences and learning

Burdett Trust for Nursing

UNIVERSITY OF Hull

BU Bournemouth University
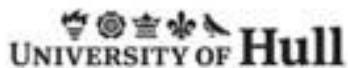
Hull and East Yorkshire Hospitals NHS
NHS Trust

The Royal Bournemouth and NHS
Christchurch Hospitals
NHS Foundation Trust

The Humanising Care Toolkit

This toolkit was produced as part of a major research project funded by the Burdett Trust for Nursing. All materials are the culmination of time, effort and collaboration between the project partners in Yorkshire and Dorset: The University of Hull, Bournemouth University, Hull and North Yorkshire NHS Trust, Bournemouth and Christchurch Hospitals NHS Foundation Trust. We ask that you respect our intellectual property and copyright, and our desire to stay in contact with users of the Humanising Care Toolkit by always asking permission before using the materials.

Acknowledgements

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Section 1: Introduction: About the toolkit

This toolkit is a resource to support health and social care practitioners to develop and sustain humanising care in their work setting. It has been developed and produced by a team of healthcare researchers, professionals and older users of NHS care who worked together on a research project, The Humanising Care Project. The project was funded by the Burdett Trust for Nursing and involved a collaboration between Bournemouth University, the University of Hull and 2 hospital settings, the stroke unit at the Royal Bournemouth Hospital and the dermatology outpatient unit at Hull Royal Infirmary. The study explored what really matters to older service users in relation to their experiences of dignity in healthcare. Working together with service users and service providers in Hull and Bournemouth we identified:

- What the service users really valued about the services they received
- What the service users and practitioners identified as important human aspects of care
- Ways service providers could practically support humanising care initiatives in their workplaces

Who the toolkit is for

We have developed the toolkit as a resource to support humanising care champions in different settings. A humanising care champion can be anyone who works in health and social care. Their main qualifications are:

- Feeling passionate about the human aspects of care and highlighting these on their unit
- Feeling able to notice, appreciate and raise awareness of humanising care when they see it
- Feeling confident to have conversations with colleagues and managers where they notice any dehumanising practices.

In this manual we will use 'participants' to refer to the colleagues or group members you are training or supporting in your role as humanising champions.

How to use the toolkit

We hope that humanising champions will either have participated in one of the Humanising Care workshops or have attended some humanising care sessions or special interest groups run by members of the Burdett research team.

As humanising care champions, you will be able to use the toolkit in a range of flexible ways to support yourself and your colleagues to think about Humanising Care. Different approaches will suit different settings. Some of the ways you may want to use the toolkit are represented in figure 1.

Figure 1

The toolkit encourages you to start by thinking about what being human and the human aspects of care mean to you. Each section of the toolkit contains ideas for practical activities and personal reflections. Try these out on yourself or with a colleague before you embark on using them to support others to develop their own thoughts and practices about humanising care.

What's in the toolkit?

The toolkit has 7 key components:

√ This manual for humanising care facilitators / champions

√ A DVD containing 21 film clips illustrating stories of humanising care gathered from service users and service providers in the research sites (A)

√   A start up set of images to support participants to reflect on being human (B)

√   A set of downloadable powerpoint slides (on memory stick) (C)

√   Useful handouts for group activities (on memory stick) (C)

√   A set of laminated humanising care cards (D)

√   Some start up creative materials for your personal kit – wool, stones, scissors (E)

For ease of portability, we have created a four-pocket canvas pochette to keep materials together. The pochette and core contents of the toolkit are illustrated below. We encourage humanising care champions to gradually develop your own personal toolkit, adding to, or replacing the start-up materials with images or creative materials such as wool, ribbons, buttons that fit with your own preferences.

(A) DVD with film clips

(B) Set of images – on the meanings of being human

(C) Memory stick with powerpoint presentations and handouts

(E) Creative materials

(D) Set of humanising dimension cards

Contents of the toolkit manual

There are **7 main sections** in this toolkit manual:

Section 1 tells you about the toolkit and how to use it.

Section 2 introduces some of the background and theory behind humanising care.

Section 3 encourages you to think about what you want to achieve with the humanising care toolkit and how you might go about facilitating conversations or workshops about the human aspects of care.

Section 4 focuses on tools, materials and activities that will help you explore humanising care initiatives with your colleagues in your work setting.

Section 5 offers some tips and examples for nurturing and sustaining humanising care initiatives.

Section 6 addresses issues of evaluating change and measuring the impact of your humanising care initiatives

Section 7 draws some threads of humanising care and practice together and offers some suggestions for further reading and resources

What the humanising care toolkit is and isn't

We know how tempting it is to have a ready-made tool to help practitioners develop new skills and practices. The humanising care toolkit is not an off-the-shelf recipe book or a set of prescriptive exercises. Good humanising requires time and space for personal reflection and conversations about what makes people feel more human with others. So we ask you to view the toolkit more as a flexible set of resources to support personal reflection and conversations with others. As noted above, we also encourage you to develop your own set of creative materials and images as you become more familiar with facilitating sessions with and for others.

The humanising care toolkit is….	The toolkit is not…
A flexible resource	A recipe book
A set of principles	Prescriptive exercises
Organic, alive and open to your ideas and materials	Static with an unchanging set of activities and materials
Experience driven	Performance and target driven
Focused on human experience	Focused on organisational processes and systems
Concerned with who you are and ways of being	Concerned solely with service processes and the tasks of doing

Navigation

The icons below are designed to help you navigate your way through the different types of practical activity and core resources.

Getting ready

DVD clip

Groupwork

Personal reflection
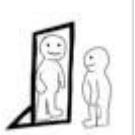

Handout

Training slides

Humanising dimension
Cards

Creative materials

Images

Section 2: What is humanising care?

This section will introduce you to the eight dimensions of humanising care and the humanising care framework, which is the underpinning for the practical activities in the following sections. It will also support you to think a little more about what humanising care means to you. Our study showed that the best way to prepare to run sessions with others is to start with yourself and consider ways to raise your own awareness about what makes care humanising and dehumanising.

Thinking about humanising care

Watch part 1 of the DVD. In the first clip Professor Kathleen Galvin talks about why it is important to think about the human aspects of care when we are providing complex services to people with a complex range of health and social care needs. She argues that sometimes, unintentionally, the focus on the human aspects of care gets lost or obscured by the drive to achieve targets or produce statistics or deliver specialised services.

The humanising care framework is grounded in European philosophy and a lifeworld approach to understanding human experience. A lifeworld approach to care encourages us to think about who we are as humans in time, place, mood, in our body and in the way we relate to others around us. In other words, it aims to take account of who we are and how we experience life in ways that do not stereotype and simplify but allow a space for the depth and breadth of human experience.

Being Human

Reflection

Think of your own life: What does being human mean to you?

Group activity

Look at the greeting card and postcard images in the toolkit. Gather together your own set of diverse images. Greetings and postcards, cards from art galleries and places of interest, or scenes from old

calendars all work well. Make sure you have a range that includes different moods, different places, scenes from nature and scenes involving people and animals, works of art and images that may suggest metaphors about who we are and how we live, serious cards and images that convey humour. Spread out the images on a table. Ask participants to look at the set of images – then pick one or two in response to the question: 'What does being human feel like for you?'

Tip: Don't get involved in thinking about healthcare at this point. Keep it general and focussed on what resonates with different people in relation to everyday life and everyday experience.

The human aspects of health and social care

 Group activity

Ask your participants think of a time when they or their close family members have used health and/or social care services. In pairs, share the following reflections:

- What did you really value about the human aspects of care?
- List some examples of when you felt met as a human being not just a 'patient' or a number
- What was it about what the care provider (eg GP, nurse, therapist, care staff) did or said or the way they behaved that made you feel more human

Feedback in the large group, generating together a list of what people valued, the impact good humanised care had on their experience (or that of their family member)

Do a similar exercise focussing on dehumanising experiences of healthcare. Some questions to ask:

- Does anyone have examples of when they did not feel met as a human in their health or social care experiences?

- What was it about the service or service provider that made you feel as if you were just a number or statistic or object going through a system?

- What words or behaviours or procedures made you feel neglected as a human? What was the impact on you of this experience?

The 8 dimensions of humanisation

Todres, Galvin and Holloway (2009) articulated 8 dimensions of humanisation to capture the depth and breadth of what it means to be a human and be met as a human in health and social care services. The 8 dimensions are represented in Table 1 with a short description of what the dimensions mean in relation to the human aspects of care.

Table 1 The human dimensions of care (from Todres et al, 2009)
See handout 1

Forms of humanisation	Forms of dehumanisation
Insiderness Care takes account of your feelings and how things are for you on the inside; attends to feeling uncertain or scared	**Objectification** Care that labels you and treats you as a person as invisible; treated as an object, without thoughts or feelings
Agency Having a say and a sense of control; free to make choices and decisions; asked for your opinion and treated as knowledgeable about your health and wellbeing	**Passivity** Passive recipient of care; no say in decisions; others decide for you; little or no control over what happens
Uniqueness Treated as an individual with your own particular likes, dislikes, preferences and priorities	**Homogenisation** Categorised into a group; not treated as an individual but with a 'one size fits all' approach
Togetherness Feeling connected to other people who share your experiences and interests; a sense of belonging and community	**Isolation** Isolated and alone with your experience; no one to share what you are feeling and experiencing

Sense Making Understanding what's happening; care that helps you make sense of your condition, treatments and recovery	**Loss of meaning** Hard to make sense of your care, what's happening and why; feeling lost and bewildered
Personal Journey Care and treatment that helps you find continuity; connecting your past with who you are now and future hopes and aspirations	**Loss of Personal Journey** A lack of continuity with who you are as an individual; care that is short term or feels disconnected from you and your life
Sense of Place feeling familiar & 'at home'; Environments, surroundings, architecture, culture that help you feel relaxed and at ease	**Dislocation** Feeling uncomfortable and alien; displaced; feeling out of place or in an alien context that doesn't fit with or feel familiar to you
Embodiment Care and treatment for you as a person and in your bodily connections with the world; attending to mind, body, mood, relationships. Being alive to the world and what your body is telling you.	**Reductionist Body** The whole focus is on medical diagnostics and symptoms and the impact of your condition on your physical body. Geared towards fixing a body part.

The dimensions are not either / or concepts but represent dimensions with a spectrum of possibilities for humanising care. At any time a person may be exposed to practices that are more humanising / or dehumanising along each dimension.

Aren't the human dimensions just a variation on person- centred care?

Certainly good humanising care will have a lot of overlap with great person-centred care or compassionate care or humane, holistic care. However, humanising care based around the 8 humanising dimensions or values offers something additional and something distinctive.

Person-centred care can be quite generic and therefore it offers few suggestions for how to change practice. Because the 8 dimensions are clearly articulated they offer a vocabulary as well as a set of values to support change in practice. Both person-centred care and humanising care puts the patient at the very centre of the care experience. But because person-centred care channels all the focus to the 'sick person' it can fail to attend to the service provider as a human too. Humanised care is about human centred care, which values the service provider as well as the patient.

Feeling human in the workplace

Reflection
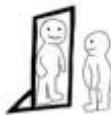
What enables healthcare providers to feel met as a human being in their workplace and in the care encounter?

Using the 8 dimensions of humanisation in care and practice

We hope that the framework with its 8 dimensions will act as a backdrop or a sensitising framework against which to think about humanising (or dehumanising) experiences of care in your practice and setting. They are not a checklist but a set of principles and values to hold in mind when you are looking at whether care is responding to people in human and humanising ways.

A few tips when looking at the 8 dimensions for the first time:

√   Don't worry if you can't remember all 8 dimensions

√   Start with the dimensions that feel more familiar or most relevant in your practice

√   Don't be put off by the language. We have purposefully kept some of the original terminology so that you can explore the language and make it your own.

√   Try to find stories and examples of the dimension rather than rushing to translate them into different language. Its easy to come up with generic, clichés which don't hold much meaning or sound familiar but mean different things to different people.

√	Don't worry if the stories that your group share cover more than one dimension
√	The dimensions are not an either / or but an interactive set of concepts.
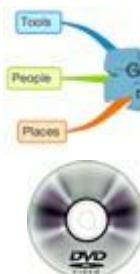
Getting Ready

Watch the film clip of Professor Les Todres (Part 1 - The 8 dimensions of humanisation) introducing and describing each of the dimensions.

- Do these dimensions make sense to you?
- Which dimension or dimensions really stood out for you …as a patient / as a service provider?
- Can you think of any of any stories or examples from your work place and work practices that relate to one or more of the 8 dimensions?

Illustrating the humanising dimensions

Here are a few examples of stories and experiences that our project teams in Hull and Bournemouth shared when thinking about the different dimensions.

Dimension	Illustration
Insiderness	Staff ask how you are and care about how you are feeling on the inside *'the fear never left me, until I had the team come to help at the flat, every day for two weeks, taking me for little walks. I thought I would never go out ever again on my own or the bus. It was their encouragement - took the fear away'* *'They knew I'd been feeling a bit down. And the next day they asked me 'how are you feeling today, I hear you were a bit down yesterday'*
Agency	Staff treat you as an expert in your condition and let you take the lead on solving some problems, e.g see Brian

	telling the nurses the best ways to secure an NG tube *'I sit and look at the monitor that they monitor my blood and, say, I was this one doing and I was that one doing, it's … you're a partnership when you're in there – patient and professional.'*
Uniqueness	Feeling special and that your own issues and preferences are attended to rather than just receiving what the system prescribes *'I think they treat the patients here as people, equivalent to their own thing, rather than a number. You're actually a person.'* *I quite like that one [uniqueness] because I think every patient should be looked at individually … I want to be, you know, be a mum, a wife, that's my individual thing*
Togetherness	Feeling connected to other patients or to staff members as human beings *'It's very reassuring, a smile'* *'I found it interesting to hear other people's stories'*
Sense Making	The way staff don't take it for granted that you know what's happening. Gentle explanations repeated little and often. *'then I saw Dr J, and his team, told me what would be happening, changed me to from an aspirin to something else which gave me a bit of confidence …then I met some of the team on the stroke unit who came to tell me that they would be coming to see me when I was at home, et cetera'*
Personal Journey	Continuity of care and staff who care about who you are not just what you have. *'Its comforting knowing that you're seeing the same specialist nurse, you're not going over and over the story.You're life story of psoriasis'* *'I really like it, they know exactly you, and they've known you for a long time'*
Sense of Place	People care about making you feel comfortable and welcome *'you come in and everybody's friendly and the nurse comes up and says, "Oh this way, please," you know, "Have a seat, I won't be a minute," and you relax'*
Embodiment	Feeling alive to and connected to people and the world

17	through your body. Experiencing and noticing bodily reactions e.g. excitement, passion, feeling lucky, feeling troubled. *'sitting and listening to other people I feel really lucky that I got off lightly'* *' I looked forward to seeing them [the early supported discharge team] I really did…it was like friends coming to visit'* *'this is when I was told I could go home [points to floating stone] so that reminded me of a boat and I felt I was sailing'*

These first sections have been about the principles of humanisation and humanising care. Its important to think about what these mean to you before you embark on training or experiential sessions with others. The next 2 sections of the toolkit will look at ways you can facilitate conversations or groups with others about the meaning of humanised care.

Section 3: Getting started

This section will help you think about what you *want* to do and what you are *able* to do with your colleagues. It will help you think through how to go about some of the groundwork before you embark on humanising care activities with your colleagues. For example, it will cover issues such as ways to recruit people to your session, the practicalities and principles of facilitating humanising care groups, and ways to engage with the experiences and stories of service users.

Running Humanising Care sessions in your workplace - Practicalities

In our research study we took a strategic approach to thinking about how we could start, continue and sustain conversations about humanising care in 2 discrete settings. Because we wanted to explore in depth what humanising care looked like in the two research sites we set up:

- Preliminary information meetings to tell the staff working in the site about the project and to start the process of looking for others who might want to join us in the study
- A series of 8 monthly group meetings with staff members and service users who joined the humanising care project group
- Follow up meetings to feedback to other staff who had not been directly involved

In follow up work in these and other settings we have run:

- Short taster sessions – 15-30 minutes to get a wider group of staff to think about the human aspects of care generally
- One-off 2 hour workshops – to run practical sessions introducing the 8 dimensions and beginning to think about what they mean to individual staff working in their clinical roles
- Education sessions (30 – 90 minutes) within nurse and Healthcare assistant induction training about what makes humanising care

- A series of workshops (3-6 90 minute sessions) for staff and staff members who become humanising champions

- A rolling programme of sessions on using the humanisation framework to support leadership in culture change

- One to one coaching sessions where one humanising champion supports someone new to be more aware of humanising care in the workplace

Ways to use the toolkit

So, as we described in figure 1, there are a range of different options to facilitating sessions in your setting about humanising care.

Planning your humanising care sessions

What are you hoping to achieve with your humanising care activity?
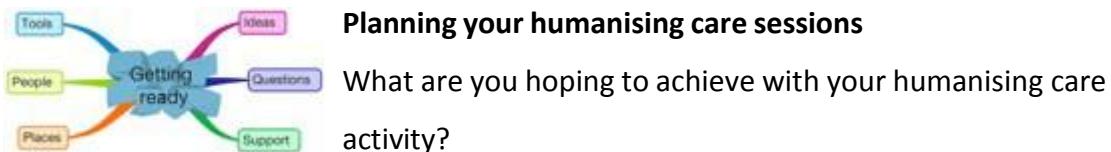
There is no hard and fast way to run the humanising care sessions. However you might want to think about:

- What is motivating you to champion humanising care in your setting? Why is it relevant to your setting?

- The caring context – how does humanising care fit into a wider culture of supporting humanising care in your workplace – what are the current challenges and priorities?

- How does humanising care seem similar and or distinct from other improvement initiatives in your setting? For example are there any connections with issues

raised in CQC inspections, culture change, person-centred care type quality improvements?

- If part of a training and / or induction programme what are the key learning outcomes relating to humanising care?
- If part of a programme of staff support and professional development what are the personal development goals for your peers and colleagues – what do they hope to gain personally by being involved in humanising care projects or support communities?

Some other questions to consider regarding the scope, scale and support for your plans:

√ Are you targeting a ward, a particular setting or client group or are you hoping to have a wider impact on culture?

√ Who is supporting your initiative – at a local level, at a managerial level

√ What will help staff who sign up to your initiative to participate regularly and consistently e.g. occasional time out from clinical duties, flexibility with rotas, CPD incentives?

√ Who will support you in your role as humanising champion?

√ How will you access a network of support?

√ How might you share interesting findings with your peers and managers?

Tip: It feels important in humanising care work to start with yourself and try to influence others simply and one person at a time. Once your own awareness of what makes care humanising or dehumanising is heightened start modelling and creating space for conversations about humanising care in different ways. So first steps are more about awareness and modelling rather than trying to change everyone and everything in the system.

More practicalities to consider:

√ Will you be doing the humanising care work on a 1 to 1, small group or larger group basis?

√ Do you have a budget to support your activities, e.g. paying for refreshments; funds to support service user involvement

√ Where will you meet?

√ How many people will the room hold comfortably?

√ What's the best lay out for the room?

√ If you plan to use powerpoint/video where will this go?

√ Who will make and confirm the room bookings and carry out other administrative tasks?

√ If running workshop sessions, how many times will you meet and what is the schedule of meetings?

√ Who will be facilitating the meeting(s)?

√ How will you recruit people to participate?

√ Will you be working with service providers only or providers and service users?

√ How will people know where and when to come?

ü If running one to one sessions or on site coaching…

ü How often will you meet with your colleagues?

√ What are the expectations and commitments of you and your coachee?

√ How will you document or log your learning and examples in a flexible but efficient way?

Using stories

Encouraging service users and service providers to share stories about their health and social care interactions underpins all the different forms of humanising initiatives that you may want to undertake.

Why are stories important?

√   They are real

√   They provide the raw material from everyday lived experiences to think about what makes humanising (or dehumanising care)

√   They embrace the rich diversity of experience that doesn't over simplify or reduce the complexity of our human responses to illness and how to provide services

Stories don't have to be all positive or all negative. In our study we chose to focus on stories that illustrated the human aspects of care that patients really valued. We asked:

- What did you really value about the service you received

- How could you get more of that good humanising care?

This is an approach called appreciative inquiry. Appreciative Inquiry is about noticing and valuing what's good, and not taking it for granted. Highlighting humanising experiences and asking people to talk about what it was that someone did or said that demonstrated humanising care, how those human aspects of care felt to the patient, what it was that they really appreciated about the care and the person providing care are key to initiatives focused on humanising care.

Stories of humanising care and practice

     Part 2 of the DVD has stories from service users and stories from service providers. Watch a selection of these as preparation for your sessions. Think about ways you and your team could build up a resource of your own humanising care stories.

Involving service users in your session

Taking time out to listen to first hand stories and experiences from service users was a key component of the success of our study. We strongly advise finding a way to recruit a handful of service users to participate in your humanising care project. If

you have time and an involvement budget you may be able to get service users to take part in your sessions. If not you may need to access and use their stories in different ways.

Finding different examples of patient experience

Your unit may have a user forum or access to people from local voluntary sector support groups.

If you are unable to invite patients and service users to your sessions, here are some good sources of material that provide access to patient stories:

- The Humanising Care toolkit DVD (Part 2 – Stories from service users) Healthtalk online – a website with video and audio stories of patients and their friends and relatives talking about their experience of different conditions and care. http://www.healthtalk.org/peoples-experiences

- Patients Voices – a series of short digital stories, where images, words and music support a person's story of illness, disability and receiving healthcare. http://www.patientvoices.org.uk/stories.htm

- Patient groups websites – often a section of support group websites will be dedicated to personal stories and experiences.

How to involve service users

If you wish to involve patients and service users in your project we strongly advise that you look at the INVOLVE website (http://www.invo.org.uk) . INVOLVE aims to help researchers and practitioners involve patients and service users ethically and responsibly in their projects and activities. The website has a wealth of resources looking at recruitment, resourcing and the practical issues you will need to think about to support lay people to be involved in authentic and productive ways.

In our study we chose to involve service users from the start and on equal terms with service providers. Questions we needed to ask ourselves included:

√   How will we cover service user travel costs?

√   How will we recompense service users for their time and expertise?

√   What timings work well for both service users and service providers?

√ How long can service users tolerate in a group and being sensitive to the particular impact of their condition?

√ What criteria will we use when recruiting service users?

√ How will we explain what the project is about and what it requires service users to do?

You can see an example of our recruitment materials in handout 3
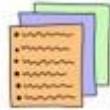
> Tip: Photos and stories can be an important way to share your learning and experiences with others outside the group. If you are hoping to use stories, experiences, photos from your groups and conversations with service users and staff you will need to think about asking for their consent. It's best to think about this at the start of your initiative. Check with your department or Trust if they have any particular requirements or consent forms that you can use. Think about how to keep the identity of your participants anonymised if required.

Benefits of involvement in humanising care groups

What might service users gain from being involved in humanising care project groups and initiatives?

In our research study we asked patients and service users what they felt they had gained from being involved. Here are some of their responses:

It's nice to meet everybody (Brian)

What stood out for me was having the nurses from the wards to hear their opinions as well as all of ours as well, that was really good and interesting for me… And I found that helpful because you understand from the other side (Sandra)

Yes, I've enjoyed it as well, I found it interesting to hear other people's stories and… Yes, it's good. I thought it might be boring but… (Laughter). I'm honest. It was far from that so (Lynn)

What might staff members gain from being involved in humanising care project groups and initiatives?

Here are some of the benefits staff members involved in our humanising care project groups talked about:

I like the discovering what... especially like with the patients, what their experience was like, because you don't know that,... it's something new …when you're on the ward you try your hardest to like talk to people, I try hard to talk to people … the patients on the ward, and find out how they feel, but erm you haven't got really that amount of time to sit down and talk as much as you'd like to because you're always conscious that you've got something else to do and someone else that needs your attention. (Andy)

what an interesting session today. I genuinely cannot think of a time recently that I have learned so much, so insightfully expressed, that has made so much sense. It was one of those sessions that, for me, completely rejuvenated what we are doing, and why we are doing it. … to hear what a difference, in both good and bad ways, that has made is truly fascinating and thought-provoking. I feel very privileged to have been involved in that session: it really has brought back to me what it is all about (Chris)

It did feel really good to sort of sit down and use the materials to talk about it …that felt almost therapeutic (Andy)

I'm feeling so much more confident now since coming to the group. Its helped me realise what I'm good at and that I'm not <u>just </u>a healthcare assistant. (Jenny)

I'll miss seeing the lovely ex-service users each month, it's been a great reminder that life goes on and has influenced my practice greatly (Laura)

Humanising care in your setting

Reflection

Before embarking on your humanising care initiative take time to reflect on some of the experiences you have witnessed or been involved in at work. Sometimes it's hard to reflect on what's happening when you are directly involved in an activity or are very used to the way things happen. Take 5 or 10 minutes just to sit quietly and observe what's happening in an area of your clinical environment.

- What stands out?

- What are the sights and sounds and smells that you notice around you? Who is involved?

- What are people doing and saying?

- What do you think someone new to this environment might be thinking or feeling?

- Try to view an event (eg a medical procedure, a ward round, a family visit from the perspective of different people – what different stories might they tell of the same event?

Getting ready to run a group – Thinking about humanising groupwork

If you plan to get together a group of peers or colleagues to run a humanising care workshop or sessions you may want to think a little more about how to run your groups. There are lots of good resources to help you think about ways to facilitate groups. For example, Elwyn et al 2001 provide a rich resource of ideas for how to facilitate small groups in healthcare, education and research.

As with all good groupwork you will need to think a little about:

√   The broad aims and boundaries of your group – what the group is and is not, what the focus of your conversations will be, responsibilities and reporting, aspects of confidentiality, ground rules

√ Group process – how groups come together and go through a process of forming, norming, storming and performing; what can you do to ensure your group works well together

√ Facilitation – what style of facilitation is appropriate to the aims of your group and what you hope to achieve; how can you introduce ideas and materials but encourage the group to take ownership of ideas and learning

√ Group dynamics – developing some techniques to help manage tricky scenarios such as group members who dominate or are very quiet or hard to engage

A few props and materials that we have found useful in our groups
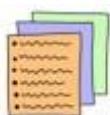
Ground rules

It is well worth just agreeing between you some basic ground rules, particularly where service users are involved and may have little experience of working in groups. Most often covering these in session 1 is sufficient. But if any tricky issues arrive you can quickly revisit the ground rules in future sessions.

Example of ground rules for humanising care groups – see also Handout 2

Listen – allow each person time to talk

One person at a time

Everyone is different - respect different points of view

No rights or wrongs

Avoid jargon – ask if you don't understand

Confidentiality – keep what we share in the room in the room

Start and finish on time

Let [facilitator] know if you can't make it

Other- Anything else you think we should add?

Forming, Storming, Norming, Performing and Adjourning/Ending

Tuckman (1965) describes 5 key phases in the life of a group. These can be useful to consider when planning group work. As group facilitator you will need to be aware of

what stage your group is at and the way the methods and activities you use can promote good team work so that the focus of your team's energy and attention stays with the humanising care theme rather than being distracted by challenging group dynamics. See Elwyn et al (2001) for more ideas and reading around group work.

Table 3.1 The 5 stages of group process after Tuckman (1965) and some useful methods

Stage	What's happening in the group	Methods that help
Forming	Group comes together Tentatively getting to know each other	Allow good time for introductions Ground rules Identity focused ice breakers – who people are, likes/preferences
Storming	Differences and conflicts may surface in beliefs, values and behaviours	Facilitator acknowledges difference and makes space for different individuals. Use of small group work, pairs and triads as well as large group work. Consider who to pair with whom
Norming	Group members negotiate differences and behaviours settle so that group can address group aims	Facilitator validates the differences between people but ensures all views included. Clarification how different experiences fit the humanising care brief of the group. Reiterating purpose of the group.
Performing	Group members take on clear roles and shared ownership of work	Facilitator keeps overview of dynamics and performance, encouraging and supporting participation and co-ownership of ideas
Adjourning / Ending	Group ends but individuals may take on follow up roles	Clarify from outset when group will finish. Celebrate achievements

Being clear what the group is and is not

Sometimes it can be useful to spell out what the group is not as a way to keep the focus on humanising care and avoid drifting into other discussions. Table 3.1 shows an illustrative list you may want to use or amend.

Table 3.2 Focusing your humanising care sessions

What the humanising care group aims to be …	What the humanising care group is not …
A group focused on the human aspects of care	A generic patient satisfaction group
A place to highlight specific features of humanising care and their impacts	A group to tell the staff how wonderful they are
A place for conversations about the human aspects of care	A general coffee and chat group
A place to appreciate what's working well and why	A place to moan
A place to think about ways to get more of the good stuff	A monitoring or inspection group
An organic group where ideas spring from all participants	A group controlled by the service and a service agenda
A group where all participants have an equal say and valid expertise	A therapy group where the service providers are considered to hold most of the expertise

Lifeworld led facilitation

Before embarking on humanising care groupwork we ask potential facilitators to reflect on a particular style of group facilitation. Consistent with the underpinning philosophy of Humanising Care we call this lifeworld led facilitation.

Our lifeworld concerns everyday experience of life in relation to time, space, mood, our body and ways we interact with others. Lifeworld theory provides a context for making sense of human being and a methodology for reflecting on humanising health care (Todres et al, 2009). You can read more about this in Dahlberg et al 2009

or in the book Caring and Wellbeing – A lifeworld approach by Galvin and Todres, 2013.

Group facilitation in a lifeworld led style reflects the values of lifeworld led care. There are no rights or wrongs about what constitutes a lifeworld led facilitation style but it will aim to convey the following principles:

√ **Sensitivity to identity** and the uniqueness of each of the individuals in the group

√ Encouraging everyone, whether service provider or service user to participate **equally**

√ Valuing the **expertise** of every individual not just professional expertise

√ As a facilitator and as group participants, **being present** and able to hold a space to think about issues together, free from external pressures or the busy ward environment you have just left

√ As a facilitator emphasising a **process of learning together** and making your own contribution rather than being on the outside

√ Keeping a focus on **connectedness** and **aliveness** of the group

√ Encouraging an atmosphere of **serious playfulness**, eg using creative materials to explore complex or taken for granted experiences; ensuring there is space for humour and light heartedness

√ Experimenting with activities that encourage **understanding and expression through bodily rather than verbal means**, for example using visual or tactile materials

√ Allowing participants the freedom to explore **how things feel on an emotional level** rather than always focussing on the rational

√ An **openness to uncertainty** rather than a prescriptive approach to objectives and what the session might achieve

√ An approach to fellow human beings underpinned by **curiosity and respect**

√ A group process which reinforces **connectedness and kinship** in exploring healthcare whilst appreciating the rich diversity of individuals

Warm up group activities with a lifeworld-led style

In our Action Research Groups we aimed to start each group with an activity that:

- Focussed participants on the present

- Reinforced and modelled equality of everyone in the room

- Helped participants share something of their identity with the other people in the room – who they are not just what they do

- Set a light hearted but engaged and listening tone

Some activities you may find useful in getting everyone present and into the room:

√   A favourite TV programme or film or book

√   A highlight of the week

√   Something that made you laugh or cry today

√   Pick an image to represent…how you feel today, how you handle crises, your family dynamics (see Long and Wilson, 2014) for great collections of scenes and people

You could also **use the cards and creative materials** in the toolkit for a warm up centred on being in the present and being you. For example, you could ask group participants to:

√   pick a card or image that represents how they are feeling right now

ü   use the stones to choose 3 significant people in their day so far

ü   use the wool and stones create an image of their week so far

Experiences of groupwork

Reflection

- Think of a group that you have participated in recently.

- What is it that helps the group feel productive and useful?

- Is there anything that stops the group feeling productive and useful?

- What is it that helps people participate readily and equally?

- What stops people participating readily and equally?

You may want to think about:

√ The environment

√ The remit or aims of the group

√ The style of the facilitator

√ The participants and their behaviours

√ The group dynamics

√ Any explicit or implicit tone and values that exist in the group

Take each of the above areas –

Can you identify something that works well in helping the group feel more creative, productive, supportive?

Facilitating groups

Reflection

Think about your natural style as a facilitator

- Do you tend to prefer more or less control over what happens in a group?

- Do you have any concerns and anxieties about facilitating groups?

- Can you think of anyone who you feel has a different style of facilitation? Are they more or less controlling in their facilitation than you? Are you aware of any particular techniques that they use?

- From your experience in work based groups and meetings, note down some styles of questioning which seem to open up discussion, and exemplify curiosity

- Where could you get support to develop your range of facilitation styles?

This section has been about preparing yourself to facilitate humanising care sessions and conversations with others. The next section will describe in more detail what you might actually do when working with others to develop awareness of the the human aspects of care and practice in your setting.

Section 4: Facilitating sessions and conversations about humanising care

This section contains a selection of activities and ideas for facilitating humanising care groups and conversations. Because different humanising care champions will have different needs and requirements, depending on how long you have with your colleagues and your ambition for your humanised care work, we have grouped the activities under three main headings:

1. Experiences of being human; experiences of illness and care
2. Understanding the human dimensions and what makes care human
3. Promoting and sustaining humanising care in your setting

These are the key building blocks for addressing humanising care and practice in different settings. Pick and choose from the activities in flexible ways but try to work out ways to build on and reinforce in some way each of these three core elements.

Materials

The activities and ideas in this section require a range of materials. Some are in your starter toolkit. Others you may want to start collecting as you undertake more humanising care workshops and/or training.

Table 4.1 lists the activities and resources and which of the core components of humanising care that they support

Core component	Activity / Materials	Purpose
Experiences of being human; experiences of illness and care	1. **Images of being human** (cards and postcards)	Share impressions of what being human means to different individuals
	2. **A day in my lifeworld** (stones and wool)	Create and share your perspective on what you do/ how you feel
	3. **Journeys through care and illness** (routemap and road signs)	Elicit stories of living with a condition or illness, the highs, lows, transitions and everyday impacts
	4. **Stories of suffering and wellbeing** (personal stories from service users or story based resources such as healthtalkonline)	Highlighting what stood out about being met as a human in health and social care interactions
Understanding the human dimensions and what makes care human	5. **Background to humanising care and the humanising care framework (**Powerpoint slides and/ DVD Part)	Provide a quick overview of why humanising care is important and relevant in todays systems of care Provide an insight into the theoretical background to humanising care and why humanising care is distinctive
	6. **Introducing the 8 dimensions** (DVD part 1)	Introduce each of the 8 dimensions and how to use them when listening to stories
	7. **Stories of humanising car**e (DVD part 2)	Gain inspiration from stories of humanising care as told by people using stroke care services and multi disciplinary professionals providing stroke rehabilitation
	8 **Mapping stories to dimensions** (Humanising care framework)	Map short stories of giving and receiving care generated in your group to the 8 dimensions
Promoting and noticing	9. **Evaluating humanising care in your setting**	Reflect on how well your unit or setting is doing in

humanising care in your setting	(Humanising Care cards or framework)	relation to each of the 8 humanising dimensions
	10. **Appreciating what works well**	Notice and raise awareness of good practice in humanising care; identify ways to get more of the good
	11**. Acknowledging and noticing** – the humanising care tree (DVD part 3)	Inspire to develop local tools and initiatives for keeping humanising care alive in your setting
	12. **Initiatives in hospital settings** (DVD part 3)	Provide ideas for small scale humanising care initiatives in busy clinical settings

Getting to know the toolkit resources

Familiarise yourself with the toolkit

Explore some of the resources on the memory stick, DVD and in the toolkit bag

Pick an activity from each of the 3 sections to do with yourself and/or with a colleague

- What worked well?

- Any parts that were confusing or that you didn't understand?

- How confident would you feel to run the same activity with a small group of peers and colleagues?

- What might you need to think about if you were including patients and service users in your group as well as professional colleagues?

Experiences of being human; experiences of illness and care

These activities act well as warm ups and a way for participants to share something of their own experience as well as getting to know others in the room. Using the different visual and tactile materials can help get to different sides of people more

quickly and richly than just by using words. The more creative activities are also a good way of ensuring everyone in the group can participate equally.

Tip: Remember as facilitator or co-facilitator it is important that you participate and share your stories too as an equal member of the group

Activity 1   Being Human

Spread out a range of cards and images on a table or any flat surface in the room. Ask everyone in the group to get up, look at and move around the cards and then pick one or two that represent something important about Being Human to them.

Sit back down and invite each person (or 4 or 5 individuals in a larger group) to show the image(s) they have chosen and why that image appeals to them in relation to being human. This activity should highlight the rich diversity in what it means to be human the different ways we each engage in life.

Tip: Make sure you have a good range of cards including representations of different moods, humour, nature, urban life, different places, people, animals, people, art, culture, indoor and outdoor interests such as reading and sport, unusual sights as well as the everyday

Activity 2   A day in my lifeworld

Spread out on the table or a flat surface a selection of stones and/or buttons of different shapes, sizes and textures and a pile of wool and or ribbon in different colours and lengths. Leave some scissors in case people want to snip the wool and ribbon to different lengths. Ask participants to create an image that represents their experience of a day in their everyday life as

….a patient/ carer/ service provider. For example, for a healthcare assistant this may be a day in their life on the stroke unit; for a sister in the outpatient department it might be a day in her life of managing a service and delivering care; for a person with an acute medical condition it may be a day on the hospital ward; for a person with a long term condition it may be a day living with that condition in the community; for a relative it may be their everyday experience of caring for their relative at home. Remind people there are no rights or wrongs its just about whatever that experience feels like to them.

Allow participants quiet time and space to create their own image – usually about 5-10 minutes. Then encourage people to talk you through their image either in pairs and threesomes or to the whole group. You may want to model asking questions such as : 'And what does that big shiny stone there represent? What's this big clump of wool here? Be sure to accept all responses in an appreciative, non-judgemental way.

This activity can be a great way for patients and service users to get a little more insight into the life and pressures of working in health and social care systems as well as a different way for service providers to hear about the things that stand out for patients and relatives.

Look at some of the examples below or watch the DVD clip of Brian – A day on the ward, to get a feeling for how different people do this.

Brian describes how each interaction (a different stone) represents a high

point of a long day on the ward (the wool).

Jackie talked about loving her job (the heart stone). Coming onto the unit there are loads of issues to juggle and remember (the pile of

stones). A clear plan can quickly become entangled in the complex and busy life of the acute stroke unit (the mess of wool). And some times there are difficult and sad things that happen when patients are very sick (the black tangle).

Tip: Some people may feel a little uncomfortable or uncertain when engaging in the 'serious play' of this type of activity. Reassure people in the group that there is no right or wrong and that everyone does this differently. If people find it hard to get going just encourage them to see what materials their hands are drawn to and model reaching for materials and moving them around.

Activity 3   Journeys through care

Clinicians often talk about patient pathways as a way of attending to efficient ways of passing through a service and receiving good care. For patients the experiences of illness are often more complex and individual. This activity is a way to generate stories about illness and care that you may want to use later when you are talking about what makes care humanising or dehumanising. It is also a good way to highlight the moments and experiences that were really important, memorable and meaningful for patients and their relatives so it is another way of sharing deeper understanding about the experience of illness, suffering and wellbeing as people struggle to make sense of illness in the context of who they are and how they live their life.

Part 1 - Draw a twisting, winding road on a piece of flipchart. Starting with service users in the group ask them to indicate a point on the road, their experience of an illness or long term condition, that was significant or very memorable – either in a good or bad way. Ask them a few probing questions such as:

- What was it that made that moment particularly memorable?

- Why does it stand out?

- What was going through your head at that time?

- What were you feeling – physically and emotionally – at that time?

Ask service providers to add their thoughts on what they see as important moments in the experience of illness and care, also using the roadmap. The example in Figure 4.1 is from a group of people living with skin conditions.

Figure 4.1 Living with long term skin conditions
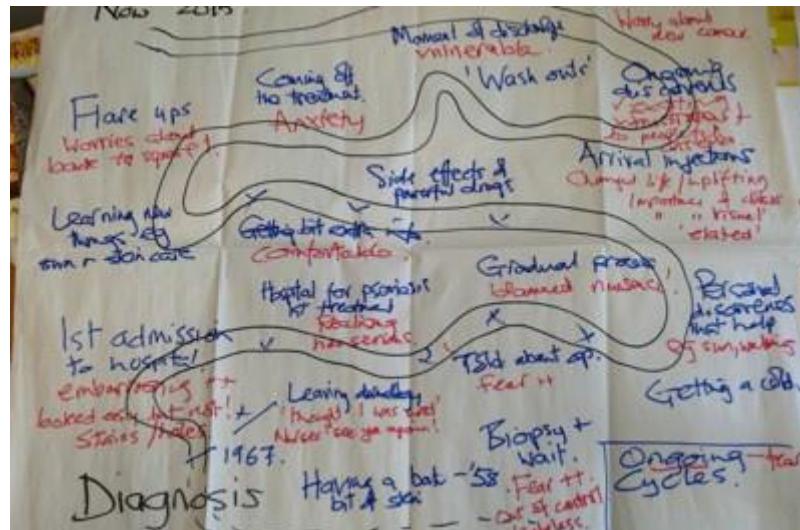
Part 2 – After everyone has shared some thoughts and experiences ask the group to look at a set of road signs (see Appendix x) and pick one or more that connects to the significant moments or events highlighted on the roadmap. For example, Figure 4.2 illustrates some of the comments that arose in one of our research groups discussing the experience of stroke.

Journeys through stroke and stroke care

Activity 4   Personal stories of suffering and wellbeing

If you don't have patients and service users in your group you may want to look at some freely accessible stories of being in hospital and/or care settings and / or living with a particular condition. See the list of resources containing patient stories in section 7, for example has a fabulous range of audio and video clips linked to different conditions.

Remember you can also draw on practitioner stories about being on the other side of the fence, either personally or in healthcare interactions where they are with children, older parents, relatives and friends.

In pairs you can spend 5 minutes each talking about a personal experience of healthcare. Describe any points in your interaction where you felt someone really connected with you as a human being.

- What was it that they did or said that made you feel met as a human?
- Was there anything or any parts of the experience where you felt unmet as a human, or treated just as a number or statistic?

Understanding the human dimensions and what makes care human

This next group of activities focuses more closely on the eight humanising dimensions that make up the framework for humanising care and practice. Don't feel you need to memorise or retain all of the dimensions all of the time. These activities are about understanding where the framework has come from, what each of the dimensions covers in relation to human experiences and how the framework is distinctive from other approaches to compassionate or person-centred care.

Activity 5   Background to humanising care

Watch the first clip in the toolkit DVD (Part 1 Introduction to Humanising Care). This segment and the overview presentation will help give you and your participants an introduction to humanising care, and the humanising framework.

In the film Professor Kathleen Galvin, co-author of the framework shares her thoughts about:

- Why the framework is necessary and relevant in today's health and social care landscape

- Where it came from – its theoretical and philosophical roots

- How it is similar to and also distinct from other approaches to improving care
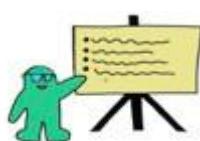
The powerpoint slides (see Presentation 1 and handout 4 Introduction to Humanising Care) present the same information as well as introducing, in overview the 8 dimensions of care. This presentation can be a useful way to introduce the idea of humanising care to colleagues, managers and commissioners.

Tip: Don't worry too much about the language of some of the humanising dimensions. In the following activities you will be asked to explore what these words and dimensions mean to you (and your audience) in your experiences as patients and providers. Think of the unfamiliarity of some of the language as a way to encourage curiosity, exploration and ways of grappling with the meaning for you and your participants.

Activity 6   Introducing the 8 dimensions

Watch clip 2 of the toolkit DVD (Part 1 - The 8 dimensions of humanisation). In this section Professor Les Todres, Emeritus Professor of Health Philosophy at Bournemouth University guides us through the meaning of each of the humanising dimensions. He asks us to use the framework and the different dimensions as a way to think about and better understand the stories of humanising care and practice that we will use in the following activity.
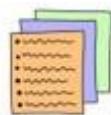
Watch the dimensions 1 or 2 at a time. Look at them on the humanising care framework (Handout 1a/1b/1c). Discuss with participants what you

and they understand by each dimension. Can you think of any examples from your everyday practice or experience of illness? Do any examples from the stories elicited in the first set of stories and experiences come to mind as illustrations?

If you are all linked to a particular condition eg stroke, skin care, mental health, do any of the dimensions immediately stand out as salient to experiences of care and living well with that condition?

Activity 7   Stories of humanising care

Having elicited stories of being treated in human and possible less human ways, and looked at each of the 8 dimensions, now its time for some activities that try to bring together experiences of receiving and delivering care with the different dimensions.

Remember that the dimensions are not exclusive or separate but are interlinked and interacting. Therefore some stories and experiences are likely to relate to more than one dimension.

Start by listening to several of the stories of humanising care in part 2 of the video. Appendix 1 gives you an idea of the content and general themes of each short story. After the clip, stop the video and talk in small groups about what dimensions seem to be coming into play. You will need to have the framework in front of you. It may be more manageable to have 2 sets of 4 dimensions as presented in Handout 1c and to work in smaller groups. Each small group can focus on just 4 of the dimensions as a more gradual way to familiarise themselves with the different dimensions.

As the groups get more familiar with the 8 dimensions the group can listen and watch the story of humanising care and then discuss the best fit with one or more dimensions.

Figure 4.3   The 8 dimensions of humanising care in 2 groups (Handout 1c)

Dimensions of humanisation - possibilities for humanising healthcare

Forms of humanisation	Forms of dehumanisation
Treatment for you as a whole person- mind and body, thoughts and feelings and connection to the world through your body. Being alive to the world (Embodiment)	The whole focus is on medical symptoms and the way your illness/condition affects your body. Geared towards fixing a body part. (Reductionist view of the body)
Understanding what's happening; making sense of your condition, your treatment(s) and recovery. Treatment and care that helps you make sense of your illness/condition (Sense-making)	Lost; hard to make sense of the events in your care; not understanding what's happening and why. (Loss of meaning)
Comfortable, relaxed, at ease. Feeling that things are familiar , feeling 'at home' and at peace in the environment and surroundings and culture. (Sense of Place)	Displaced; feeling uncomfortable and alien. Feeling out of place, or in an alien context that doesn't fit with you (Dislocation)
Having a say and a sense of control in your own healthcare; free to make choices; asked for your opinion in making decisions about your care. (Agency)	Passive recipient of healthcare; no say in decisions; feeling 'done to'; others decide and you have no control over what happens. (Passivity)

Dimensions of humanisation - possibilities for humanising healthcare

Forms of humanisation	Forms of dehumanisation
Takes account of your feelings, interested in your mood, how things are for you on the inside (eg feeling uncertain or scared) (Insiderness)	As if you as a person are invisible; feeling labelled, just an object without thoughts or feelings (Objectification)
Treated as an individual, a person with your own particular likes, dislikes, fears and priorities. (Uniqueness)	Categorised into a group, not treated as an individual; everyone is assumed to be the same. Treated with a 'one size fits all' care plan (Homogenisation)
Treatment and care helps you find continuity; connecting your past, with who you are now and your future hopes. More than just a snapshot in time. (Personal Journey)	There is no continuity or connection of care and planning to who you are as an individual. Care is short term. May feel 'stuck', not moving forward. (Loss of Personal Journey)
Feeling connected to other people who share your experiences and interests; a sense of belonging, community and connection to other (Togetherness)	Isolated and alone with your experience. No one to share what you are feeling and experiencing. (Isolation)

Activity 8   Mapping stories of care to the 8 dimensions

This is another way to match experiences and stories to the different dimensions but draws on the stories generated in your own groups and settings rather than those on the DVD.

In the toolkit you will find 8 coloured cards. Each card contains a description of the humanising end of the dimension and a brief, user friendly description of its meaning. These are reproduced in handout 1 d in case you need to produce more coloured cards.

Produce some short vignettes of the stories that have come up in your discussions of illness and care experiences. Aim for a good range of vignettes including service user and service provider stories and illustrations of positive as well as less positive experiences. Have each vignette on a separate piece of paper so that you produce a pile of 10-15 stories. The vignettes should be recognisable to the original story teller, perhaps using some of their own words. You can find some examples of vignettes from the stroke unit in appendix 2.

Ask a group member to read out the vignette. Then ask others in the group to point to the dimension or dimensions it fits with. Ask someone to write the dimension(s) you decide on the back of the vignette as this may be useful to revisit later.

At the end of the activity you should end up with different vignettes grouped around different dimensions – as illustrated below.

Tip: Try to keep the writing up of the vignettes short but authentic. Don't confuse the story with too many different ideas at once – if necessary make it into more than one vignette.

Promoting and noticing humanising care in your setting

These activities have a focus on small-scale initiatives that you can undertake in your own setting. They aim to support practitioners and care staff to go about their everyday work with heightened awareness about what makes care humanising and through noticing and gently drawing attention to small examples of the human aspects of care, ensure it has a more visible and alive presence.

Activity 9   Evaluating humanising care in your setting

In your humanising care group focus on your own particular care environment and setting. Think about the people who use and interact with your service, the procedures and treatments that happen there, the routines and rituals that take place, the environments and buildings and departments that your staff and patients/ visitors use.

Look at the 8 dimensions of humanising care (use the coloured cards or the coloured framework). Take each of the 8 dimensions in turn or break into small groups with each group focusing on up to 4 dimensions. Discuss how well you think your unit does in delivering humanised care on this particular dimension. If you are giving yourself a very high self-evaluation, what are your reasons and examples. If you are rating your service(s) less highly on a particular dimension, what is it that detracts from fully humanising care, give examples and illustrations.

At the end of the activity can you identify your unit/ setting's relative strengths and weaknesses in relation to each of the human dimensions of care?

Activity 10   Appreciating what works well

In your group of service users and service providers generate a list of all the human aspects of care that participants have noticed and really value. You can do this in a group or give everyone 3 or 4 post its to generate a wall of post its. Think about people, spaces, attitudes, behaviours, activities, routines etc.

Do these really valued aspects, attitudes and behaviours group into different headings. Have a go at moving the post it notes around a bit to see if there are any common themes. In our research groups some common themes were:

- Friendly, consistent relationships

- Atmosphere and culture

- Places and spaces

- Knowing what's going on

- Reassurance and kindness

- Taking your mind off your illness / condition

- Support for relatives and friends too

Select one or two areas.

√   What would it take to get even more of the good stuff?

√   Can you think of ways to raise awareness on your unit / care setting of how these
    small acts of humanising care are valued?

√   How can you make sure they are modelled routinely by more staff?

√   How can you make sure they are highlighted in induction programmes for new
    staff?

Activity 11   Acknowledging and noticing humanising care as individuals– the humanising care tree

Watch Lucy (Part 3 of the DVD) talk about and demonstrate the humanising care tree. This was a light touch way that the team of humanising champions in a stroke unit decided to bring ideas and illustrations of the human aspects of care to everyone's attention. The tree has the 8 dimensions of care as its roots and a little box of write on/wipe off leaves to collect examples of humanising care they witness in their day-to-day work on the ward. The tree is also a way to encourage anyone on the ward to initiate conversations about humanising care or raise issues about occasions where care has failed to meet people as fully human.

Discuss different ways your team can notice, talk about and make visible moments of humanising care.

Tip: Try to think about ways your initiative will stay alive and remain interesting to and interactive with other staff, patients and visitors. For example at Christmas some of the leaves on the humanising tree changed shape to become Christmas baubles.

Activity 12   Humanising care team initiatives in busy clinical settings

Watch part 3 of the toolkit DVD. Practitioners from our 2 research sites talk about some of their humanising care initiatives. For example, Lucy talks about the humanising care tree on the stroke unit and how the humanising champions work to highlight and capture moments of great humanising care that they see on the ward or in the community work. Karen talks about a similar initiative in the Skin Care unit at Hull. Yvonne tells how the huddle helps staff to value and share specialist knowledge that keeps the human side of care at the forefront of a busy outpatient Dermatology unit. Abby talks about the very small things that staff can remember to do which make a big impact on patient experience. See Appendix 1 for a description of what the different stories on the Humanising Care DVD illustrate.

Discuss different ways your team can try small but significant ways to focus on or raise the profile of humanising care in your unit.

√   What could you realistically do to humanise interactions and conversations with patients, relatives and peers?

√   How could you find a regular team time to highlight or share top humanising moments of the week?
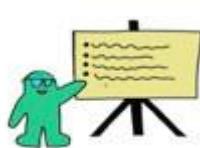
You may also want to run this activity as part of a presentation and/or workshop. See presentation 2 for some pre prepared slides focusing on initiatives to develop and nurture humanising care in your setting.

This section has provided suggestions for activities and resources to help you and your local team to share experiences, thoughts and ideas about the human aspects of care and practice. The next section looks at different ways you can think about embedding raised awareness of humanising care and keeping the idea of humanising care alive and evolving in your setting.

Section 5: Keeping going: Sustaining and embedding humanising care in practice

The humanising care activities and initiatives you have addressed in previous sections have hopefully lit some small candles of humanising activity in your setting. In this section we encourage you to think about ways to keep these humanising care flames alive rather than be snuffed out by the everyday pressures and stresses of workplace activity. This section encourages you to think about ways to embed humanising care and practice and gently but stealthily spread the word.

Support for humanising care and cultures

Here are some questions to ask yourself:

- What is the level of support for the humanising care sessions – from your peers, your professional discipline, your care team, your managers, executive and non-executive directors, commissioners?

- Do you have a small budget or access to any funds that might resource follow up sessions and activities?

- What are the opportunities to re run humanising care workshops?

- How can your setting embed attention to humanising care in the more routine aspects of your setting – eg induction and training processes; appraisal and CPD; patient and staff satisfaction surveys; in-service training

Activities that focus on sustaining humanising care in practice

Activity 1 – Spreading the word – humanising cultures and leadership

Think about the opportunities to introduce more humanising care in your work setting. For example, you may want to think about:

√ Meetings where you discuss patient goals

√ First interviews with patients

√ Interactions with patients and relatives to discuss progress

√ Routines that happen on the ward such as mealtimes, visiting times, ward rounds

√ Settings where you review practice

√ Ways you think about and respond to complaints and/or patient feedback

√ Places where staff and patients interact

Take one of these examples – with the 8 dimension cards in front of you think about all the aspects of that setting/ activity/ process that …

- Are valued by staff/patients/relatives/ visitors as humanising?

- Are there any aspects that are less humanising?

Focus on one activity and one positive example of humanising care. What would one small way to get more of this humanising aspect of care look like?

Some examples of Humanising Leadership

Following a session on what makes care and leadership in care humanising, we asked staff at a charity providing acute and long-term care to think about ways they could introduce a heightened focus on humanised care. Here are some of their thoughts:

ü Introduce the set of humanising cards for 5 minutes at the end of operations meetings. Check whether the way staff have behaved together in the meeting has been consistent with the 8 humanising dimensions. Check whether a driving interest in the human experience of care is at the forefront of all agreed actions (Director of Operations)

√ Introduce more humanising language in to the business plan and commissioning documents (Director of Commissioning)

√ Review communications about the service with careful attention to language – avoid language that homogenises or strips away uniqueness (Communications and Fundraising)

√ Reflect on how to be with, rather than 'tell off' or dehumanise colleagues. Consider how interactions between board members and staff support the staff who support the frontline workers (Board member)

Activity 2   Finding a space for reflection: humanisation and Continuous Professional Development

In our research study participants in both sites highlighted the importance of finding quiet, reflective space, away from the hurly burly of life on the unit, to reflect on what humanising care means to patients and staff. For some staff this was an important way of reconnecting with why they pursued a career in caring. Others talked about how using the creative activities with a focus on humanising care, with their peers and service users, enabled them to feel motivated and re-energised in their work role.

Watch the film clip of Abby (Part 3- Pause and Reflect) talking about what she found useful from some of the creative activities.

Can you think of any ways to introduce creative reflections on humanising care into your own or your team's CPD activity?

Activity 3   Embedding humanising practices in culture

Most care settings are overwhelmed with initiatives and inspections promoting better quality care and improved patient experience. It's important that a spotlight on humanising care doesn't feel like yet another new initiative. Much of our learning from the research study demonstrated that humanising care isn't something brand new but more a way of remembering what's important about being a human and meeting others as human beings in care settings. It may be helpful to think about the way humanising care interacts with other initiatives and interests directed at improved care and patient experience. A key point to remember though is how to keep care and attention on the human aspects of caring rather than tick box procedures that care more about systems and processes.

Watch the film clip of Catherine (Part 3 – Sustaining Change) talking about why she feels humanising care is important to improving patient experience for those who are particularly vulnerable within modern economies of health and social care.

Discuss how humanising care fits with current initiatives in your setting.

√ How do you think humanised care might differ from these initiatives?

√ How could these initiatives eg person-centred care, the 6 Cs, responses to CQC reports have a more humanised and humanising focus?

Celebrating the human aspects of care and practice

Another way of attending to sustainability of humanised care initiatives is to think about ways your setting can recognise and validate those individuals who are talented and exceptional at modelling humanising care and the initiatives that work well at bringing humanisation to the fore. In our research sites staff members who attended the humanising care workshops took on roles as Humanising Champions in their settings. In the Dermatology Unit the humanising champions and researchers gave a presentation to local commissioners to highlight the importance of truly humanising skin care to people living with long term skin conditions.

In the stroke unit service managers recognised the important role of these staff members and facilitated them to take on new roles coaching peers as next generation humanising champions and supporting training initiatives across the hospital trust. The trust also recognised the achievement of the stroke unit as a Humanising Care model through presentations to the Trust Board, articles in hospital newsletters, and support to present at international conferences.

 Watch the film clip of Jackie (Part 3 – The impact for staff) talking about the confidence she has gained both from becoming more aware of her own humanising care skills and from playing a more prominent role in championing great humanising practice ion the stroke unit.

 Think about ways you can shout about the success of your humanising care initiative. How can you advocate for humanising care across your team, unit, directorate?

Developing a support network for Humanising Champions

As other humanising care projects develop we hope to be able to establish a community of people engaged in humanising care work. We encourage all those with an interest in humanising care to stay in touch with us by sharing your stories, ideas and experience. See section 7, for further details about ways to stay in touch and our plans for a network of humanising care champions.

This section has focused on ways you and your team can think about sustaining and embedding humanising care initiatives. The next section will give an overview of ways of thinking about evaluating your initiatives and their impact.

The humanising care tree at the stroke unit, Royal Bournemouth Hospital

Section 6: Making a difference: tracking change in humanising care

This section offers some suggestions about ways to evaluate changes that may result from your humanising care initiatives. It describes briefly the humanising assessment tool, which we have developed and piloted as part of this research study. It also offers some more informal ways of gathering feedback and data about any changes that may result from being involved in and carrying out humanising care activities in your care setting. Finally this section asks you to stay in touch and help us to create a network of humanising champions to share successes and learning about developing humanising care in your setting.

The Humanising Assessment Tool

As part of this study we wanted to pilot a quantitative measure for healthcare professionals to measure humanised care. We were aware of the challenge of producing a quantitative measure for a relatively new and little explored phenomenon. So the tool is currently undergoing face validity testing.

The Humanising Assessment Tool (HAT) aims to assess perceptions of humanised care behaviours as they relate to each of the 8 humanising questions. Developed from learning in the research project and 2 pilot sites the pilot version of the HAT consists of 98 items in a questionnaire format, spread across the 8 dimensions and including a series of dummy items. The stem question for each item is 'My work environment enables me to ….'. participants are asked to reflect on their setting and practice and answer as honestly as possible on a 5 point likert scale, using the labels:1 : Always, 2: Most of the time, 3: Some of the time, 4: Rarely and 5: Never. Items.

Items have undergone a first phase of face validity testing in the UK and Sweden You can view the pilot version of the HAT in the full project report.

As the HAT evolves we hope to make it available to humanising champions so that they can use it in their settings both as a way of measuring change in humanising practice and as a way to help us further develop a vocabulary to talk about humanising care and the specific dimensions.

Capturing change informally

We also encourage humanising champions to capture and document change in more informal ways that link to your specific interventions and initiatives.

Many of the initiatives in our pilot sites aimed to bring about subtle shifts in perception and heightened awareness of or visibility of humanising care as a feature of the care culture. Here are some ideas that may demonstrate change in awareness:

Increased evidence of conversations about humanising care in the care setting

√ Visible signs that staff and visitors are noticing aspects of humanising care eg comments on the humanising care tree or information board

√ Regular training and induction of new humanising champions and a growth in numbers of champions in specific wards, units and settings

√ Humanising care has a more visible presence within the meetings, routines, and quality initiatives that regularly take place in your care setting, eg Humanising Care as an item on staff meeting agendas, in service training, or within staff supervision and CPD activities

Another way of capturing the impact of your initiative is by collecting stories that illustrate how staff members have started to do something just a little differently as a result of participating in your humanising care workshops and coaching. Although humanising care can support service and culture change, it is also very much about individuals 'being' the change, becoming a little more aware of the human aspects of care and consistently modelling humanising behaviour for those around them.

At the end of sessions focussing on humanising care you can ask participants to comment on their own perceptions of change – in awareness, in behaviours, in the

ways they think and talk about the human aspects of care. For example, at the end of our action research groups we asked participants if they had noticed any changes in their everyday ways of being and working. Some of their paraphrased comments included the following:

√ Smiling when I say hello to patients in the morning, even though I'm not really a morning person

√ I take more time gently explaining what people might expect when they go home, even when they have a very mild stroke

√ I'm more aware of some of the big emotions feel when they first go home and how new and scary it cam all seem after you've had a stroke

√ I feel more confident about talking to patients and sharing a little bit of myself so that we build a relationship

√ I try to have more conversations with patients about everyday things, rather than always asking about their illness

√ I'm more aware of the fear some patients experience while they are waiting for results – if I can I give them a ring

√ I think more about humanising care in operational meetings – we try to ask how will this decision impact on keeping the service focused on the human aspects of care and practice

Developing the toolkit and a network of Humanising Champions

We are very keen to gather your comments and feedback on the tools and ideas in this toolkit. We hope to feed these into further iterations of the toolkits and future projects to support humanising care in health and social care settings. We encourage you to share your stories with us by email, through images and video (with participants consent) in Skype calls, or face to face conversations.

As other humanising care projects develop we also hope to be able to establish a community of people engaged in humanising care work and a network of humanising care champions. The aim of the network will be both to offer mutual

support and to share ideas relating to humanising initiatives and their impact on individuals, services and culture.

We encourage all those with an interest in humanising care to stay in touch with us by sharing your stories, ideas and experience.

The points of contact at the current time are:
Carole Pound cpound@bournemouth.ac.uk
Kathleen Galvin K.Galvin@brighton.ac.uk

We also invite anyone with an interest in Humanisation and care to join the Humanisation Special Interest Group which is hosted by the Centre for Qualitative Research at Bournemouth University. If you wish to be added to the contact list please email Caroline Ellis-Hill: cehill@bournemouth.ac.uk

Section 7 Reading and Resources

This section lists some of the reading, practical tools and resources that you may find helpful in developing your understanding of humanising care and running practical sessions for others. As we stated in section 1 we encourage you to develop your own examples and resources that will support you to explore humanising care for yourself and alongside others. Please let us know if you discover other tools and resources that you think we should share with other humanising champions.

Reading about humanising care and practice – articles and books

Cowdell, Fiona , Galvin, Kathleen (2016) Practice Question. *Nursing Older People*. (ISSN 14720795) v. 28. no. 2.   20160301. p. 14-15
This article presents some practical illustrations in answer to the question;'How can I care for older people in a more human way.'

Dahlberg, K., Todres, L. & Galvin, K. (2009) Lifeworld led healthcare is more than patient-led care: The need for an existential theory of well-being. *Medicine, Healthcare and Philosophy*, 12, 265-271.
This article illustrates key concepts of the lifeworld and the way lifeworld led practice differs from patient or person- centred practice.

Galvin K & Todres L. (2013) *Caring and Wellbeing*. London: Routledge. This book is a series of previously published peer reviewed articles about humanisation theory and its application to practice. The text provides a comprehensive background to humanising care and lifeworld approaches to caring within the challenging context of modern health and social care provision.

Hannah, M (2014) Humanising Healthcare. International Futures Foundation.
Although this book is not specifically grounded in the theory of humanisation it examines why current healthcare delivery struggles to retain a strong focus on the human beings at the centre of the system. Magaret Hannah, a public health

consultant shares insights and hope for more humanised cultures of health and social care.

Hemingway, A, Scammel J & V Heaslip (2012) Humanising nursing care: a theoretical model. Nursing Times 02.10.12 / Vol 108 No 40 / www.nursingtimes.net

Scammel,J ,Hemingway ,A and Heaslip,V (2012) Humanising values at the heart of nursing education. Nursing Times 09.10.12 / Vol 108 No 41 / www.nursingtimes.net

Scammell, J and Tait, D (2014) Using humanising values to support care. Nursing Times 09.04.14 / Vol 110 No 15 / www.nursingtimes.net

These three papers offer a short introduction to the humanising care framework and ways the framework is relevant to nursing education and care.

Pound, C and Greenwood, N (2016) The human dimensions of post stroke homecare: Experiences of older carers from diverse ethnic groups. *Disability & Rehabilitation online.*

This paper provides examples of what older carers (relatives of people who have had strokes from Black and Minority Ethnic communities) perceive to be important components of humanising homecare.

Todres L, Galvin K, Holloway I. (2009) The humanisation of healthcare. *International Journal of Qualitative Studies in Health & Wellbeing*, 4, 68-77.

This article introduces the humanisation framework and gives more detail on the background to and illustrations of the 8 dimensions of humanising care.

Websites with an interest in humanising topics and practice

The Daily Good website is a volunteer run website that delivers good news stories to you by email. Many of the stories have a focus on kindness, compassion, empathy, creativity and other themes that overlap with aspects of humanising care and practice. You can subscribe for free at:

DailyGood.org <dg-news@servicespace.org>

Professor Belinda Dewar has developed a web resource for practitioners wanting to develop more compassionate conversations in care settings. Belinda's website and academic articles also talk in more depth about appreciative inquiry as a method of working together to encourage more humanising experiences. A range of practice development tools and resources relating to caring conversations are available via MyHome Life Scotland

http://myhomelife.uws.ac.uk/scotland/resources/

Books and resources on group facilitation

Elwyn, G, Greenhalgh, T& Mavfarlane,F (2001) Groups: a guide to small group work in healthcare, management, education and research. Oxford: Radcliffe Medical Press.

Tuckman, BW (1965) Developmental sequence in small groups. Psychological Bulletin, 63, 384-399.
Tuckman's classic work describing the stages of groups coming together and learning to function effectively as a small group to achieve theie group aims.

There are also some freely available online tools, for example Prendiville (2008) Available from:

http://www.combatpoverty.ie/publications/DevelopingFacilitationSkills_2008.pdf

A Ketso Kit is a commercially available resource designed to help you facilitate inclusive group work and offer creative ideas for engaging people in your projects http://www.ketso.com

Collecting your own materials and resources

Most of the materials we use in sessions are things that we have gathered from everyday life.

Cards to illustrate what it means to be human. You can collect a set of cards from retailers or by collecting cards that people send you, images that are available in

places of art and culture or downloadable from the internet. You may also want to use images developed from your own photographs. The key thing is to ensure you have variety, covering different people, animals, relationships, places, cultures, moods etc

Evoke cards – a set of images conveying different landscapes, moods and activities. Available from: http://www.evokecards.com

A set of freely available cards has been produced by NES. These can be downloaded from: http://nes.scot.nhs.uk/education-and-training/by-discipline/nursing-and-midwifery/resources/publications/valuing-feedback-envision-cards.aspx

Wool, ribbon and stones and other material can generally be collected from left over party decorations, trips to the beach, relatives and friends who enjoy handicrafts, or local craft stores.

Stories of care

There are a range of freely available online resources in which people talk of their experiences of illness and care. Support groups will often have a section for patient or survivor stories where you can find video and audio material of people telling their stories.

Other good resources include:

Healthtalkonline – a resource of video and audio recordings of people talking about their experiences of different conditions and the care they received
http://www.healthtalk.org/peoples-experiences

Patient voices – a resource of digital stories which use audio, video, music and still images to tell short stories about the experiences of people living with different conditions and people who work in healthcare .
http://www.patientvoices.org.uk/stories.htm

Appendices/Handouts

These appendices contain many of the materials referred to in the toolkit. They are downloadable in word, powerpoint and/or PDF form and may be freely photocopied for use in your humanising care sessions. Please acknowledge that they are part of the Humanising Care Tooolkit and let us know about any changes and adaptations you want to make to suit your setting.

Handout 1	1a - The 8 dimensions of humanising care	
	Version 1b – 8 dimensions on a page	
	Version 1c – 4 dimensions on a page	
	Version 1d – 8 dimensions - 1 dimension to a card	
Handout 2	Example of information and recruitment materials	
Handout 3	Sample of ground rules	
Handout 4	Powerpoint slides – Introduction to Humanising Care (from Presentation 1)	
Handout 5	Powerpoint slides –Developing and sustaining humanising care initiatives (from Presentation 2)	
Appendix 1	Contents of the DVD – the 21 clips and descriptions of what they illustrate	
Appendix 2	Examples of vignettes from the stroke service	

Handout 1a

The human dimensions of care (after Todres et al, 2009)

Forms of humanisation	Forms of dehumanisation
Insiderness Care takes account of your feelings and how things are for you on the inside; attends to feeling uncertain or scared	**Objectification** Care that labels you and treats you as a person as invisible; treated as an object, without thoughts or feelings
Agency Having a say and a sense of control; free to make choices and decisions; asked for your opinion and treated as knowledgeable about your experience	**Passivity** Passive recipient of care; no say in decisions; others decide for you; little or no control over what happens
Uniqueness Treated as an individual with your own particular likes, dislikes, preferences and priorities	**Homogenisation** Categorised into a group; not treated as an individual but with a 'one size fits all' approach
Togetherness Feeling connected to other people who share your experiences and interests; a sense of belonging and community	**Isolation** Isolated and alone with your experience; no one to share what you are feeling and experiencing
Sense Making Understanding what's happening; care that helps you make sense of your condition, treatments and recovery	**Loss of meaning** Hard to make sense of your care, what's happening and why; feeling lost and bewildered
Personal Journey Care and treatment that helps you find continuity; connecting your past with who you are now and future hopes and aspirations	**Loss of Personal Journey** A lack of continuity with who you are as an individual; care that is short term or feels disconnected from you and your life
Sense of Place Feeling familiar and 'at home'; Environments, surroundings, architecture, culture that help you feel relaxed and at ease	**Dislocation** Feeling uncomfortable and alien; displaced; feeling out of place or in an alien context that doesn't fit with or feel familiar to you
Embodiment Care and treatment for you as a person and in your bodily connections with the world; attending to mind, body, mood, relationships. Being alive to the world and what your body is telling you	**Reductionist Body** The whole focus is on medical diagnostics and symptoms and the impact of your condition on your physical body. Geared towards fixing a body part

Handout 1b

Dimensions of humanisation - possibilities for humanising healthcare

Forms of humanisation ←	→ Forms of dehumanisation
Treatment for your mind, body and who you are in the social world. Linking mind & body & connection to the world *(Embodiment)*	The whole focus on medical symptoms and the way stroke affects your body. Geared towards fixing a body part *(Reductionist view of the body)*
Understanding what's happening; making sense of stroke and your treatment and recovery. Care that helps you make sense of stroke *(Sense-making)*	Lost; hard to make sense of the events in your care; not understanding what's happening and why *(Loss of meaning)*
Comfortable, relaxed, at ease. Feeling that things are familiar, feeling 'at home' and at peace in the environment, surroundings and culture *(Sense of Place)*	Displaced; feeling uncomfortable and alien. Feeling out of place, or in an alien context that doesn't fit with you *(Dislocation)*
Having a say and a sense of control in your healthcare; free to make choices; asked for your opinion in making decisions *(Agency)*	Passive recipient of healthcare; no say in decisions; feeling done to; others decide and you have no control over what happens *(Passivity)*
Takes account of your feelings, interested in your mood, how things are for you on the inside (eg feeling uncertain or scared) *(Insiderness)*	As if you as a person are invisible; labeled, just an object without thoughts or feelings *(Objectification)*
Treated as an individual, a person with your own particular likes, dislikes, fears and priorities *(Uniqueness)*	Categorised into a group, like other stroke patients, not treated as an individual;. Treated with a 'one size fits all' care plan *(Homogenisation)*
Finding continuity; connecting your past, with who you are now and future hopes. More than a snapshot in time *(Personal Journey)*	Events and experiences are unfamiliar. No continuity or connection of care and planning to who you are as a person *(Loss of Personal Journey)*
Feeling connected to other people who share your experiences and interests; a sense of belonging *(Togetherness)*	Isolated and alone with your experience. No one to share what you are feeling and experiencing *(Isolation)*

Handout 1c

Dimensions of humanisation - possibilities for humanising healthcare

Forms of humanisation	Forms of dehumanisation
Treatment for you as a whole person- mind and body, thoughts and feelings and connection to the world through your body. Being alive to the world. (Embodiment)	The whole focus is on medical symptoms and the way your illness/condition affects your body. Geared towards fixing a body part. (Reductionist view of the body)
Understanding what's happening; making sense of your condition, your treatment(s) and recovery. Treatment and care that helps you make sense of your illness/condition (Sense-making)	Lost; hard to make sense of the events in your care; not understanding what's happening and why. (Loss of meaning)
Comfortable, relaxed, at ease. Feeling that things are familiar, feeling 'at home' and at peace in the environment and surroundings and culture. (Sense of Place)	Displaced; feeling uncomfortable and alien. Feeling out of place, or in an alien context that doesn't fit with you (Dislocation)
Having a say and a sense of control in your own healthcare; free to make choices; asked for your opinion in making decisions about your care. (Agency)	Passive recipient of healthcare; no say in decisions; feeling 'done to'; others decide and you have no control over what happens. (Passivity)

Dimensions of humanisation - possibilities for humanising healthcare

Forms of humanisation	Forms of dehumanisation
Takes account of your feelings, interested in your mood, how things are for you on the inside (eg feeling uncertain or scared) (Insiderness)	As if you as a person are invisible; feeling labelled, just an object without thoughts or feelings (Objectification)
Treated as an individual, a person with your own particular likes, dislikes, fears and priorities. (Uniqueness)	Categorised into a group, not treated as an individual; everyone is assumed to be the same. Treated with a 'one size fits all' care plan (Homogenisation)
Treatment and care helps you find continuity; connecting your past, with who you are now and your future hopes. More than just a snapshot in time. (Personal Journey)	There is no continuity or connection of care and planning to who you are as an individual. Care is short term. May feel 'stuck', not moving forward. (Loss of Personal Journey)
Feeling connected to other people who share your experiences and interests; a sense of belonging, community and connection to other (Togetherness)	Isolated and alone with your experience. No one to share what you are feeling and experiencing. (Isolation)

Handout 2

Insert your logos here

Burdett Trust for Nursing

BU Bournemouth University

The Royal Bournemouth and Christchurch Hospitals NHS

The Humanising Care Project

General Information Summary and
Invitation to a Question and Answer session

Humanising Care Toolkit Handout 2

The Humanising Care Project:
How older adults' experiences of care can guide practice and enhance dignity.

What is the purpose of the Humanising Care Project/group?
This study aims to investigate what human aspects of care mean to older people accessing healthcare services. We want to explore:
- what makes **older people feel human** ?
- what **really matters** to them in terms of the **human aspects of care** they receive ?
- how can **practitioners** enhance **human aspects of care and practice**?

The study/group is particularly interested in the experiences of:

- People who receive treatment from the [insert name of your unit]

- People who work on the [insert name of your unit]

What do we plan to do?
Firstly, we will recruit:
- 4-5 service users [amend to suit your project]
- 3-4 clinicians [amend to suit your project]

Along with researchers these participants will form an **Action Research Group**.
This group will have a series of about **x meetings** at [insert name of your unit]

The Action Research group will **discuss** how **patients** can be at the **centre of health care** and how **practitioners** can best support **humanised care** for older people. The group will talk about their own **experiences**. Members will discuss **what makes people feel human** (or not) on [insert name of your unit]. The Action Research group will help **develop a plan** to support some small **changes to services** and to **enhance human aspects of care and practice**. [amend to suit your plan]
For example, these might include:

- *Ways people can feel more in control*
- *Changes to the healthcare environment*
- *Having conversations that make people feel like staff really understand their individual needs*

Humanising Care Toolkit Handout 2

The Humanising Care Project

Please come to a **question and answer session** to find out more about the project. And decide if you want to be involved.

- This session will be on   [date]
- Time   [time]
- Venue   [insert venue]

We do hope you can come

If you need **more information** or help with **transport arrangements** please contact: [name]
[email address]
[telephone contact]   [insert your photo]

Handout 3

Ground Rules

üListen – allow each person time to

   talk

üOne person at a time

üEveryone is different - respect different

   points of view

üNo rights or wrongs

üAvoid jargon – ask if you don't understand

üConfidentiality – keep what we share in the

   room in the room

üStart and finish on time

üLet [facilitator] know if you can't make it

Other - anything else you think we should

add?

Handout 4

The Humanising Care Toolkit Presentation 1
Introducing the human aspects of care

Humanising Care Toolkit
Presentation 1

Exploring the human aspects of care: Introducing the humanising dimensions

Burdett Trust
for Nursing

BU
Bournemouth
University

University of Hull

The Royal Bournemouth and
Christchurch Hospitals NHS

Hull and East Yorkshire Hospitals NHS

About the session

- Conversa;ons and explora;on about:
- Being human – you in your life
- Being met as a human …as a pa;ent, rela;ve, visitor, staff member in your seBng
- Background to the human aspects of care and prac;ce
- Introduc;on to the 8 humanising dimensions
- Your experience – exploring what the dimensions might mean for you

---

Remembering the human aspects

- Pick a card

- What does being human mean and feel like to you?

Buzz words in policy and prac;ce

PERSON CENTRED CARE
Compassion
Dignity
Values-based care
6 CS

Why Humanising Care?

Compassion ?

Person-centred care

Values-based care

Dignity ?

What's dis;nc;ve about humanising care ?

- Strong theore;cal and philosophical underpinnings – European philosophy, lived experience
- Over 15 years of research at Bournemouth University about what it means to be human
- Well ar;culated dimensions –these offer direc;ons for prac;ce
- Beyond 'pa;ent care' - humanisa;on rela;ng to each other and the environment in human ways
- Methodology- reinforces higher sense of wellbeing for ALL concerned

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For further information about the
Humanising Care Toolkit
cpound@bournemouth.ac.uk

The Humanising Care Toolkit Presentation 1
Introducing the human aspects of care

Dimensions of humanisa-on - possibili-es for humanising healthcare (Todres et al,2009)	
Forms of humanisa-on	**Forms of dehumanisa-on**
Togetherness	*Isola.on*
Sense-making	*Loss of meaning*
Sense of Place	*Disloca.on*
Agency	*Passivity*
Insiderness	*Objec.fica.on*
Uniqueness	*Homogenisa.on*
Personal Journey	*Loss of Personal Journey*
Embodiment	*Reduc.onist body*
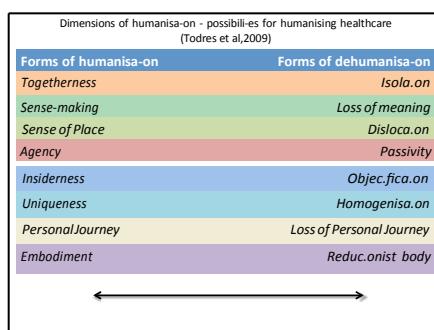
Humanising Care – Whats different

- Not just a list of dos and don'ts
- Not about techniques
- About being not just doing tasks
- Emphasises rela-onships – pa-ent experience, rela-ve experience, staff experience
- Well ar-culated dimensions – not too generic
- Help capture depth and breadth of lived experience

## Background to Humanising Care

1. You and your lifeworld

- Think of a day in **your everyday experience** of working or receiving care in this seRng
- Use the **materials** to create **an image** of that experience – what it looks like, what it feels like
- Talk through your image in pairs/threes

What does it mean to be treated as a human being here?

- Think about the card exercice
- Think about your images

- Generate some words and phrases on post it notes that summarise 'what it means to be treated as a human in this seRng'

Sense-making

Togetherness

Personal Journey

Sense of Place

Agency

Uniqueness

Embodiment

Insiderness

The human dimensions of stroke care

For further information about the
Humanising Care Toolkit
cpound@bournemouth.ac.uk

The Humanising Care Toolkit Presentation 1
Introducing the human aspects of care

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2. Humanising dimensions – meanings for you

Keeping your images in front of you …

- Pick a humanising **dimension** that **interests** you or you would like to **explore more**
- Talk about this dimension in rela?on to your image and your experience (as a pa?ent/ rela?ve/ prac??oner)?
- What sort of **issues and examples** come up?

(Discuss in small groups)

The 8 Dimensions of Humanising Care

Humanising care and cultures – Why bother?

- BeKer pa?ent experience
- Understanding complaints and challenges
- BeKer staff experience - mo?vated / energised/ resilient staff – increased staff sa?sfac?on & wellbeing
- Staff at all levels who demonstrate and embody humanising excellence are recognised and validated

- The nega?ve impacts of de-humanising experiences and ways of working e.g. poorer pa?ent, rela?ve and staff wellbeing

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References and further reading

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- Todres L et al (2009) The humaniza?on of healthcare: a value framework for qualita?ve research. *Interna.onal Journal of Qualita.ve Studies on Health and Well-being*; 4: 2, 68-77.

Follow up thoughts, ques?ons, reflec?ons
cpound@bournemouth.ac.uk [add

own email]

For further information about the Humanising Care Toolkit
cpound@bournemouth.ac.uk

Handout 5

Humanising Care Toolkit Presentation 2
Developing and Sustaining Humanising
Care

Slide 1

Humanising Care : Developing and sustaining the human aspects of care

Humanising Care Project team

Burdett Trust for Nursing

BU Bournemouth University

The Royal Bournemouth and Christchurch Hospitals NHS

Hull and East Yorkshire Hospitals NHS Trust

UNIVERSITY of Hull

Slide 2

The Humanising Care Project — What really ma=ers to older people in rela>on to humanly sensi>ve care?

Stroke Unit Bournemouth

Burdett Trust for Nursing

Dermatology Unit Hull

The Royal Bournemouth and Christchurch Hospitals NHS

BU Bournemouth University

Hull and East Yorkshire Hospitals NHS Trust

UNIVERSITY of Hull

Slide 3

The Humanising Care Project

Service providers

Service users

Researchers

Stroke Service

Dermatology Outpatient Service

What really matters to service users and providers?
What do they really value about the service?

Slide 4

Sense-making

Togetherness

Personal Journey

Sense of Place

Agency

Uniqueness

Embodiment

Insiderness

Stories of humanising stroke care

Slide 5

Examples from Hull

- *if you come in and everybody's friendly and the nurse comes up and says, "Oh this way, please," you know, "Have a seat, I won't be a minute," and you relax...'*
- *Its comfor@ng knowing that you're seeing the same specialist nurse, you're not going over and over the story...You're life story of psoriasis*
- *they're very friendly, they seem to understand dermatology and especially psoriasis, can be embarrassing, and they put you at ease*
- *Stepping out of their profession to humanity.*

Slide 6

Thinking about your service

- What do you (staff members/service users/ visitors) **really value** about the **human aspects** of your service?

- Think about some **key areas**: rela>onships, environments and atmosphere of a place, knowing what's going on, feeling really met as a human being, …

- **Priori4se 3 valued things** from your list – **how could you get more** of these human aspects of care?

Further information about the
Humanising Care Toolkit:
cpound@bournemouth.ac.uk

Humanising Care Toolkit Presentation 2
Developing and Sustaining Humanising
Care

Examples from other seQngs:

OSen not big changes but about **raising awareness** more widely about the importance of human aspects of care (see DVD Abby Li=le things make a difference)

Championing and valuing humanising car (see DVD Lucy – the humanising tree)

Reflec>ng on ways **staff can be more suppor4ve** of other team members (see DVD care teams in Hull)

Humanising care ini>a>ves in Hull & Bournemouth

'Togetherness >me' eg staff shadowing, morning huddles

Humanising Champions & tree

Embedding humanising care in HCA training and HCA induc>on programmes

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Family commented 'what a lovely caring ward the stroke ward is'

Student nurse said individual goodbyes at the end of her placement(Personal Journey/ Togetherness)

Uniqueness – remembering the importance of hair wash & style in busy ward rou>nes

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Humanising care and cultures – opportuni>es and poten>al

- Be=er pa>ent and family experience
- Posi>ve approach to understanding and responding to complaints
- Mo>vated / energised/ resilient staff – increased staff sa>sfac>on & wellbeing
- Opportunity for staff development – e.g. staff at all levels who demonstrate and embody humanising excellence are recognised and rewarded
- Star>ng with the self, greater sense of shared responsibility
- A focus on *being* human not *doing* the checklists of care

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Further information about the
Humanising Care Toolkit:
cpound@bournemouth.ac.uk

Handout 5: Content of the Humanising Care Toolkit DVD

Section	Title / story	Description
Part 1 Introducing humanising care	1. Introduction to humanising care (Professor Kathleen Galvin)	Kate describes why attention to humanising care is important in today's health and social care. She introduces the theoretical and philosophical underpinnings of humanising care.
	2. The 8 dimensions of humanisation (Emeritus Professor Les Todres)	Professor Todres asks us to consider what it takes to met as a human in complex healthcare contexts. He sums up the meaning of each of the 8 dimensions of care and asks us to keep these in mind as we listen to service user and provider stories in the next section.
Part 2 Stories of humanising care	3. Introduction to people who have experienced a stroke	Brian, Peter, Wynn, Sylvia and Leila, the service users who took part in the project in Dorset, introduce themselves.
	4. Peter – The breakfast club	Peter describes his confusion when he didn't get his breakfast and also some of the benefits of being in a group. Key themes: Sense Making / loss of sense making; Togetherness
	5. Brian – Hard to swallow	Brian talks about finding his own solution for keeping his feeding tube in place. He describes his joy at feeling his swallow reflex returning and how he celebrated this with his nurse. Key themes: Agency; Embodiment ; Togetherness
	6. Leila – A person not an illness	Leila describes the importance of conversations about who you are not what you've got. Key themes: Personal Journey; Uniqueness
	7. Sylvia – Going home	Sylvia talks about the fear and uncertainty on returning home after a stroke, and how helpful the Early Supported Discharge team were with their gentle guidance and reassurance Key themes: Insiderness ; Sense-Making; Personal Journey
	8. Wynn – Feeling special	Wynn also valued the Early Supportive Discharge team. She feels they cared about her, communicated about her and were almost like friends. Key themes: Uniqueness; Sense Making; Togetherness
	9. Sylvia – The power of tea	Sylvia describes how a nurse's brusque response for a cup of tea after a long, stressful day on the ward affected her. Key themes: Isolation; Homogenisation; Passivity
	10. Brian – A day on the ward	Brian creates an image from wool and stones to represent a day on the ward. He highlights the importance of relationships and making sense in an alien environment. Key themes: Sense of Place; Sense Making
	11. Sylvia, Leila, Wynn – Human contact and connection	Sylvia, Leila and Wynn talk about what and who makes care more human for them. Key themes: Uniqueness; Personal Journey

	12. Jackie – Building humanising relationships	Jackie, a healthcare assistant working on the stroke unit, gives an example of building reciprocal relationships with patients and taking account of who we are as service providers. Key themes: Embodiment; Sense of Place
	13. Lucy - Remembering the impact	Lucy, a physiotherapist, describes the impact for her of listening to patients' stories. She was surprised at how vividly they remembered experiences on the ward and it highlighted for her how alien, unfamiliar and frightening these events can be for service users Key themes: Insiderness; Sense Making; Sense of Place
	14. Abby – Having a say	Abby, a speech and language therapist, describes the importance of noticing and not taking for granted great humanising care by others, for example taking a little more time to find out an individual's preferences when they have communication difficulties: Key themes: Uniqueness; Agency
	15. Abby – Little things make a difference	Abby highlights one of the key themes of the project, that little acts of humanising care like smiling or providing gentle explanations, can make a big difference to how both patients and service providers feel about care experiences Key themes: Sense of Place; Sense Making
Part 3 Impact & sustainability; Embedding humanising care and culture	16. The humanising care tree	Lucy describe how the staff on the Stroke Unit are keeping humanising alive by championing and recording little acts of humanising care
	17. The impact for staff	Jackie reflects on what she gained from being involved in the project and the importance of recognising and valuing those who are great at modelling the human aspects of care
	18. Pause and reflect	Abby reflects on the importance of finding time out and a quiet reflective space to have conversations about the human aspects of care
	19. Transferable benefits: Humanising care and care teams in Hull	Karen and Yvonne, specialist nurses in the Dermatology Outpatient unit in Hull talk about the meaning of humanising care in their setting. They discuss 2 service improvement initiatives: The Humanising Care board and the huddle
	20. Sustaining change	Catherine, a stroke research nurse talks about the relevance of humanising care to quality of care and improved patient experience, particularly for more vulnerable patient groups. She talks about embedding humanising care within hospital culture and leadership.
	21. Championing the dimensions in policy and practice	Les offers some final comments about using the humanising framework to support change in practice. He talks about the need for those within practice, management, training and policy making to use and champion the dimensions and vocabulary of humanising care.

Appendix 2 Examples of vignettes from a stroke service

Service User Experiences

Going home and feeling scared
The difficult feelings when you are all alone after coming home from hospital. Feeilng scared about what might happen next, what's the best way to recover, will I have another stroke

Reassurance from the Early Supported Discharge team visits
Feeling more confident to do things. Being told what to expect next. Lots of reassurance that you will be walking, talking, swallowing in x amount of time.

Night time on the ward
Bleeps going off, different staff, sometimes staff who are not so familiar or friendly.
As a patient feeeilng worried about asking for help when the ward is short staffed

On the ward at weekends
Feels like a 'dark tunnel' and time drags slowly. Not much happening. No therapy, no visits from doctors. A different routine but less to break the monotony.

Importance of kindness and compassion
Feeling really grateful when a staff member is kind and comforting. A kind word, a gentle touch, feeling someone cares about you.

The importance of smiling staff
Interactions with staff can be the highlight of a boring morning or afternoon. The importance of a smile. Makes you feel better or feel like they really care.

The reactions of family members (cotton wool)
When you go home family members want to wrap you up in cotton wool. Treat you differently than before your stroke. So being at home can feel an unfamiliar environment

Tiredness
Feeling tired a lot – and not being sure of how to deal with feeling tired.
Should I do more or should I do less ?

Worries about the future
What will happen next?
How will my recovery be, and what's most important
When will I be able to ….
Will it happen again?

Feeling lucky
Feeling lucky compared to others.
Feeling grateful that it was only a mild stroke and not many long lasting effects
Feeling grateful for professional staff

Ending therapy and support
Feelings when therapy or support visits (eg Home stroke team) stop
Feelings when therapist says 'theres nothing more we can do to help'

Visitors
Seeing a friendly and familiar face at visiting time.
Breaking the boredom

Chatting to others
Lunch group as a way to meet others
Positive experience of chatting to others in the same boat

Strawberry Yogurt story
Jacky's story of remembering what flavour yogurt a patient really liked. Going to a little bit of trouble to get something special for them

Headless chickens stories
The organised chaos of the unit. The impact of always having lots to do and lots of people to see. Always in a rush.

Working with families
Struggling to meet the needs/wishes/expectations of patients and of family members – may be different
Hard to know if the family members are always putting the best interests of the patients at heart or prioritising their own needs and interests, eg not wanting someone to go to a different unit because its further for them (the relatives) to travel

When people can't talk
Knowing what to do when people have impaired communication.
How to know what they want or think. Harder to involve them in decisions and discussions. Can end up having all decisions made for them.

The speed of discharge
A feeling that sometimes we 'write people off too soon'

Being part of the team
Good team working – feeling a part of a good team.
Being valued for your role in the team
Knowing the team is doing a good job- a sense of pride.

Difficult discharges
Sometimes it's hard to get the support in place that people need.
People who don't improve and have to leave the Stroke Unit and go to another ward without specialist rehab.

Consistency and getting to know people
Hard to really get to know patients if you're part-time
Not knowing what happens to people when they go home

Expectations of decision making
Being expected to make decisions as a patient when being in hospital is all very new and disorientating

Ways to get to know people a little more
Seeing patients in their own homes as very helpful to hear about who they are.
Other experiences of getting to know patients as people
Eg Storytelling group, breakfast club

Make the experiences more vivid and recognisable by adding a short quote or a few verbatim phrases from the person who shared the experience with you/ your group

Appendix 7

Humanising questionnaire items grouped by humanising dimension

1) Sense making/loss of meaning (n=11)

1) Update patients on treatments regularly

2) Understand the everyday consequences of treatments or care plans, which have to be carried out by the patients themselves

3) Keep patients informed at regular intervals when they are awaiting results

4) Assure patients that they can always call for advice

5) Acknowledge, with each patient, the fear that can come with health conditions

6) Use non clinical language when talking with patients

7) Help patients feel comfortable enough to ask questions

8) Build trusting relationships with patients and their significant others.

9) Repeat information about what is happening to patients regularly

10) Offer sensitive explanations on what is happening (now and in the future

11) Create a sense of calmness (when possible)

2) Personal Journey/loss of personal Journey (n=13)

1) Focus on what is of concern to the patient (even if outside or unrelated to treatment)

2) Ask patients how they are finding their journey through care

3) Find ways to help patients stay in touch with important things from their everyday life

4) Help patients to stay close to their own everyday routines

5) Ask patients how it is going for them

6) Take space to listen to the patients worries, even if they can not be resolved

7) Offer support to patients moving through a system they are unfamiliar with

8) Appreciate that how a patient sees the severity of their illness or condition may differ from my own

9) Regularly check that treatment is going okay from the patient's point of view

10) Recognise the importance of a regular review of care with the patient

11) Make sure patients are treated by a named or consistent member of staff.

12) Be prepared to change direction if treatment is not working for the patient

13) Consider how patient's future aspirations may be affected by their current treatment.

3) Homogenisation/Uniqueness (n=7)

1) Consider how generic treatment pathways fit with the individual patient

2) Remember small details about patient's personal stories

3) Consider the different responses patients can have to the same illness or condition

4) Ask the patient how they assess their own health

5) Seek out how care could be adapted to suit the individual patient's situation

6) Remember small details about patient's personal care preferences

7) Use patients preferred name

4) Togetherness/Isolation (n = 14)

1) Care about the wellbeing of my colleagues

2) Take steps to put patients at ease

3) Be able to support colleagues

4) As far as possible facilitate contact with important people in the patient's life

5) Consider the patient feelings about being isolated

6) Show patients you are pleased to see them when they arrive for treatment

7) Encourage patients to support each other, wherever possible and when wanted

8) Make sure patients know your name and role

9) Notice patients at particular risk of isolation

10) Introduce patients to others who share their condition, when wanted

11) Provide patients with information on peer support

12) Ensure families and friends feel welcome

13) Feel supported by colleagues

14) Have a sense of a human connection with the patient

5) Insiderness/Objectification (n = 8)

1) Try to see the person behind the illness or condition

2) Show that you want to know 'what it's like' from the patient's perspective

3) Provide care that is not only technical/task focused

4) Be aware of the anxiety patients can experience when waiting for results

5) Show that you want to know about patients fear about their situations

6) Notice what affects your patient's mood

7) Give patients time to talk about their emotional response to their illness/condition

8) Frequently ask patients how they are

6) Embodiment/ Reductionist view of the body (12)

1) Be aware of the personal meaning any bodily (physical) changes for the patient

2) Consider the emotional aspects of the patient's treatment or condition

3) Check that patients are comfortable

4) Think of the patient as a person and more than just a body

5) Discuss each patient as a person (not just health condition or case) when sharing information with other health professionals

6) Have the time to reflect on my own feelings

7) Be aware of the physical impact of bad news for the patient

8) Be aware of the physical impact on me, of giving bad news

9) Notice what makes the patient feel tired

10) Notice what makes the patient feel relaxed

11) Notice what makes the patient feel energised

12) Help patients understand the changes that may be happening to them

7) Dislocation/Sense of place (n = 15)

1) Create a welcoming environment

2) Consider how the care setting we operate in can be initially unfamiliar to patients

3) Where possible, to help patients to have some meaningful possessions close at hand

4) Focus on making the patient feel at home

5) Where safety concerns allow, adapt the environment to make it as homely/personal as possible

6) Notice barriers that can get in the way of patients feeling welcome

7) Notice barriers that can get in the way of families feeling welcome

8) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes patients feel comfortable

9) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes families or significant others feel comfortable

10) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes staff feel comfortable

11) Consider how the environment (e.g. noise, images, smells, friendliness) could make patients uncomfortable

12) Consider how the environment (e.g. noise, images, smells, friendliness) could make patient's significant others feel uncomfortable

13) Show patients where they can find peaceful spaces

14) Encourage other staff to introduce themselves by name and role

15) Provide information about how the service works (meal times etc.)

8) Agency/Passivity (n = 16)

1) Ask patients about their expectations of care and treatment

2) Notice how staff behaviours could create embarrassment, shame or vulnerability, during treatment

3) Give patients the skills to manage their own conditions

4) Ensure that the patient has a means of communication with a named health service provider on discharge

5) Support patients to have a say in their care or treatment

6) Take an interest in what patients tell me about how they like things done

7) Seek out flexibility in the system to respond to patients priorities

8) Explain to patients where there is no flexibility in the system and why

9) Give patients the confidence to manage their own conditions

10) Try to find out information that the patient wants on their behalf

11) Try to involve significant others as the patient wants

12) Where possible offer patients choices about what happens to them next

13) Notice what can support patients to take a role in care and treatment decision making

14) Encourage patients to ask what is happening and why

15) Understand what prevents staff asking for help/information

16) Understand what prevents patients asking for help/information

Dummy items (n = 13)

1) Check all equipment is accessible before seeing patients

2) Update your training regularly

3) Actively seek promotion

4) Gain experience treating a variety of cases

5) Attend staff development events

6) Keep updated on the latest policies in your field

7) Read a professional journal frequently

8) Be able to set clear goals

9) Be aware of hospital dignity/health and safety/ cleanliness (i.e. any type of policy) policy

10) Show patients and family members the hospital complaints policy

11) Be organised when booking annual leave

12) Encourage patients to complete patient satisfaction forms

13) Show visitors how to use soap dispensers

Appendix 8

This questionnaire is assessing care and what things your current work environment enables you to do to focus on the human aspects of care.

Please read over the following questions and consider each item in terms of, <u>on average</u>, how often your <u>current</u> work environment enables the following behaviours. Please then circle your answer on the scaled response between 1 – 5, e.g. with 1 being 'always' and 5 being 'never'.

My work environment enables me to ….	Always, Most of the time, Some of the time, Rarely, Never 1　　　2　　　3　　　4　　　5
1) Attend staff development events	1　　　2　　　3　　　4　　　5
2) Ask the patient how they assess their own health	1　　　2　　　3　　　4　　　5
3) Remember small details about patient's personal stories	1　　　2　　　3　　　4　　　5
4) Ask patients about their expectations of care and treatment	1　　　2　　　3　　　4　　　5
5) Make sure patients know your name and role	1　　　2　　　3　　　4　　　5
6) Give patients the confidence to manage their own conditions	1　　　2　　　3　　　4　　　5
7) Use non clinical language when talking with patients	1　　　2　　　3　　　4　　　5
8) Where safety concerns allow, adapt the environment to make it as homely/personal as possible	1　　　2　　　3　　　4　　　5
9) Use patients preferred name	1　　　2　　　3　　　4　　　5
10) Ask patients how it is going for them	1　　　2　　　3　　　4　　　5
11) Where possible offer patients choices about what happens to them next	1　　　2　　　3　　　4　　　5
12) Show patients you are pleased to see them when they arrive for treatment	1　　　2　　　3　　　4　　　5
13) Consider how the environment (e.g. noise, images, smells, friendliness) could make patients uncomfortable	1　　　2　　　3　　　4　　　5
14) Help patients to stay close to their own everyday routines	1　　　2　　　3　　　4　　　5
15) Ensure that the patient has a means of communication with a named health service provider on discharge	1　　　2　　　3　　　4　　　5
16) Try to involve significant others as the patient wants	1　　　2　　　3　　　4　　　5
17) Assure patients that they can always call for advice	1　　　2　　　3　　　4　　　5
18) Try to find out information that the patient wants on their behalf	1　　　2　　　3　　　4　　　5

My work environment enables me to ….	1	2	3	4	5
19) Be prepared to change direction if treatment is not working for the patient	1	2	3	4	5
20) Notice what can support patients to take a role in care and treatment decision making	1	2	3	4	5
21) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes patients feel comfortable	1	2	3	4	5
22) Keep patients informed at regular intervals when they are awaiting results	1	2	3	4	5
23) Provide information about how the service works (meal times etc.)	1	2	3	4	5
24) Remember small details about patient's personal care preferences	1	2	3	4	5
25) Notice barriers that can get in the way of patients feeling welcome	1	2	3	4	5
26) Consider how patient's future aspirations may be affected by their current treatment.	1	2	3	4	5
27) Show patients and family members the hospital complaints policy	1	2	3	4	5
28) Encourage patients to support each other, wherever possible and when wanted	1	2	3	4	5
29) Actively seek promotion	1	2	3	4	5
30) Give patients the skills to manage their own conditions	1	2	3	4	5
31) Ensure families and friends feel welcome	1	2	3	4	5
32) Understand the everyday consequences of treatments or care plans, which have to be carried out by the patients themselves	1	2	3	4	5
33) Update patients on treatments regularly	1	2	3	4	5
34) Consider how generic treatment pathways fit with the individual patient	1	2	3	4	5
35) Introduce patients to others who share their condition, when wanted	1	2	3	4	5
36) Notice what affects your patient's mood	1	2	3	4	5
37) Encourage other staff to introduce themselves by name and role	1	2	3	4	5
38) Help patients understand the changes that may be happening to them	1	2	3	4	5
39) Seek out how care could be adapted to suit the individual patient's situation	1	2	3	4	5
40) Encourage patients to complete patient satisfaction forms	1	2	3	4	5
41) Consider how the care setting we operate in can be initially unfamiliar to patients	1	2	3	4	5
42) Create a welcoming environment	1	2	3	4	5

My work environment enables me to ….	1	2	3	4	5
43) Notice barriers that can get in the way of families feeling welcome	1	2	3	4	5
44) Seek out flexibility in the system to respond to patients priorities	1	2	3	4	5
45) Offer support to patients moving through a system they are unfamiliar with	1	2	3	4	5
46) Recognise the importance of a regular review of care with the patient	1	2	3	4	5
47) Be able to set clear goals	1	2	3	4	5
48) Be able to support colleagues	1	2	3	4	5
49) Read a professional journal frequently	1	2	3	4	5
50) Show visitors how to use soap dispensers	1	2	3	4	5
51) Have the time to reflect on my own feelings	1	2	3	4	5
52) Consider how the environment (e.g. noise, images, smells, friendliness) could make patient's significant others feel uncomfortable	1	2	3	4	5
53) Show that you want to know about patients fear about their situation	1	2	3	4	5
54) Find ways to help patients stay in touch with important things from their everyday life	1	2	3	4	5
55) Consider the patients feelings about being isolated	1	2	3	4	5
56) Have a sense of a human connection with the patient	1	2	3	4	5
57) Ask patients how they are finding their journey through care	1	2	3	4	5
58) Be aware of the physical impact on me, of giving bad news	1	2	3	4	5
59) Show patients where they can find peaceful spaces	1	2	3	4	5
60) Explain to patients where there is no flexibility in the system and why	1	2	3	4	5
61) Take steps to put patients at ease	1	2	3	4	5
62) Focus on making the patient feel at home	1	2	3	4	5
63) Feel supported by colleagues	1	2	3	4	5
64) Help patients feel comfortable enough to ask questions	1	2	3	4	5
65) Check all equipment is accessible before seeing patients	1	2	3	4	5
66) Notice patients at particular risk of isolation	1	2	3	4	5
67) Support patients to have a say in their care or treatment	1	2	3	4	5

My work environment enables me to ….	1	2	3	4	5
68) Notice what makes the patient feel energised	1	2	3	4	5
69) Make sure patients are treated by a named or consistent member of staff'.	1	2	3	4	5
70) Take an interest in what patients tell me about how they like things done	1	2	3	4	5
71) Be aware of the anxiety patients can experience when waiting for results	1	2	3	4	5
72) Regularly check that treatment is going okay from the patient's point of view	1	2	3	4	5
73) Frequently ask patients how they are	1	2	3	4	5
74) Consider the different responses patients can have to the same illness or condition	1	2	3	4	5
75) Provide care that is not only technical/task focused	1	2	3	4	5
76) Appreciate that how a patient sees the severity of their illness or condition may differ from my own	1	2	3	4	5
77) Gain experience treating a variety of cases	1	2	3	4	5
78) As far as possible facilitate contact with important people in the patient's life	1	2	3	4	5
79) Create a sense of calmness (when possible)	1	2	3	4	5
80) Try to see the person behind the illness or condition	1	2	3	4	5
81) Be aware of the personal meaning any bodily (physical) changes for the patient	1	2	3	4	5
82) Give patients time to talk about their emotional response to their illness/condition	1	2	3	4	5
83) Provide patients with information on peer support	1	2	3	4	5
84) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes staff feel comfortable	1	2	3	4	5
85) Keep updated on the latest policies in your field	1	2	3	4	5
86) Understand what prevents patients asking for help/information	1	2	3	4	5
87) Be aware of the physical impact of bad news for the patient	1	2	3	4	5
88) Acknowledge, with each patient, the fear that can come with health conditions	1	2	3	4	5
89) Offer sensitive explanations on what is happening (now and in the future)	1	2	3	4	5
90) Focus on what is of concern to the patient (even if outside or unrelated to treatment)	1	2	3	4	5
91) Notice what makes the patient feel tired	1	2	3	4	5

My work environment enables me to ….	1	2	3	4	5
92) Show that you want to know 'what it's like' from the patient's perspective	1	2	3	4	5
93) Consider the emotional aspects of the patient's treatment or condition	1	2	3	4	5
94) Understand what prevents staff asking for help/information	1	2	3	4	5
95) Discuss each patient as a person (not just health condition or case) when sharing information with other health professionals	1	2	3	4	5
96) Notice how staff behaviours could create embarrassment, shame or vulnerability, during treatment	1	2	3	4	5
97) Update your training regularly	1	2	3	4	5
98) Be organised when booking annual leave	1	2	3	4	5
99) Consider how the surroundings (e.g. noise, images, smells, friendliness) makes families or significant others feel comfortable	1	2	3	4	5
100) Where possible, to help patients to have some meaningful possessions close at hand	1	2	3	4	5
101) Repeat information about what is happening to patients regularly	1	2	3	4	5
102) Care about the wellbeing of my colleagues	1	2	3	4	5
103) Build trusting relationships with patients and their significant others	1	2	3	4	5
104) Check that patients are comfortable	1	2	3	4	5
105) Encourage patients to ask what is happening and why	1	2	3	4	5
106) Think of the patient as a person and more than just a body	1	2	3	4	5
107) Make space to listen to the patients worries, even if they can not be resolved	1	2	3	4	5
108) Notice what makes the patient feel relaxed	1	2	3	4	5
109) Be aware of hospital dignity/health and safety/ cleanliness (i.e. any type of policy) policy	1	2	3	4	5

Thank you for your time completing this questionnaire