“Between A Rock and a Hard Place”: The “Wicked Problem” Of Coproducing Chronic Oedema Care

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Abstract

Introduction

Coproduction is a term which refers to how customers and service-users contribute to the planning, design, delivery, and implementation of goods and services, with service providers. Contemporary coproduction literature reflects a paternalistic perception of service-users with lower socioeconomic status and their interactions and relationships with specialist and non-specialist health professionals.

Background

Within the contemporary coproduction literature there is a suggestion that that individuals living within a context of socioeconomic deprivation are less equipped to coproduce care. Whilst service-users living with LTCs may have the knowledge, skills to manage their LTC despite socioeconomic disadvantage, there is a lack of research exploring these experiences. This study explored how coproduction is operationalised, and the impact of socioeconomic position and social capital, within the context of ongoing care across hospital and home settings. Theories of coproduction were applied, to explore shared-decision making, the implementation of care “at home”, and the dynamics of power between service-providers and service-users living with long-term conditions (LTC).

Methods

A mixed methods study was undertaken using, in-depth, face-to-face interviews of service-users from two Lymphoedema Clinics (City and rural) within a regional service; overt non-participant observations within the clinics, to observe the dynamic between the service-users and specialist health

professionals. Service-users, partial postcodes and the addresses of General Practitioner" (GPs) were documented to identify the distribution of service-users attending the clinic 1, and to contextualise socioeconomic position of the study setting.

NHS ethical approval for the study was obtained through the Regional Ethics Committee, and permission was gained to access all study Sites within the NHS organisations.

Findings

The findings of this study indicate that socioeconomic status does not prevent service-users from coproducing their care, in terms of their skills and knowledge or the "operant resources" they uses to engage in shared-decision making. However, a lack of economic resources and social capital, or "operand resources", makes the coproduction of care more challenging for service-users; especially when treatment options are limited, and the implementation of care is within the "home". In addition, service-users often perceived that non-specialist health professionals lacked the skills, knowledge and expertise to meet their care needs.

Care was described by the participants as based upon a traditional, hierarchical and often biomedical model of care. This approach did not always align with the daily life of the participants, which involved balancing condition management against the desire to maintain normality, and achieve the goals that they identified as important

The mitigating factor for many of the participants was the social capital and network of support they developed with the SHPs and their significant others; this evolved as an "operand

resource”, in terms of trust and reciprocity and the tangible effect of co-implementing and co-delivering care.

Conclusion

This study addresses the research gaps related to exploration of coproduction for people with LTC, between hospital and home, and the need for more research to empirically evidence service-users’ experience. Social capital, trust, accountability, responsibility, and reciprocity are perceived as essential to operationalise the coproduction of care and actualise a more equitable partnership between service-users and service-providers.

Publications and conferences relevant to the thesis

Publications
Marufu, T.C., Setchell, B., Cutler, E., Dring, E., Wesley, T., Banks, A., Chatten, M., Dye, E., Cox, S., Boardman, R. and Reilly, L., 2021. Pressure injury and risk in the inpatient paediatric and neonatal populations: A single centre point-prevalence study. *Journal of Tissue Viability*, 30(2), pp.231-236.
Brand, S., Bramley, L., Dring, E. and Musgrove, A., 2020. Using patient and public involvement to identify priorities for research in long-term conditions management. *British Journal of Nursing*, 29(11), pp.612-617.
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Moffatt, C.J., Gaskin, R., Sykorova, M., Dring, E., Aubeeluck, A., Franks, P.J., Windrum, P., Mercier, G., Pinnington, L. and Quéré, I., 2019. Prevalence and risk factors for chronic edema in UK community nursing services. *Lymphatic research and biology*, *17*(2), pp.147-154.
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Publications in print
Gibson, L., Moffatt, C., Narahari, S., Kabiri, L., Ikhile, D., Nchafack, A., Dring, E., Kousthubha, S. N., Gorry, J., (2021) Global Knowledge Gaps in Equitable Delivery of Chronic Oedema Care: A Political Economy Case Study Analysis
Moffatt, C., Sykorova, M., Dring, E., Murray, S., Collard, E., Gordon, S., Quere, I., Norregaard, S., (2021) An international survey to explore outcome measures in Chronic Oedema and Lymphoedema (International Lymphoedema Framework (ILF) Chronic Oedema Outcome Project (ILF-COM)
Moffatt, C., Dring, E., Sykorova, M., Murray, S., Thomas, M., Keast, D., Collard, E., Karlsmark, T., Quere, I., Norregaard, S., (2021) An international study to explore the challenges faced by the medical device industry in the development and reimbursement of compression therapy (International Lymphoedema Framework (ILF) Chronic Oedema Outcome Project (ILF-COM)

Prizes	
2017	Graduate School Prize
2017	International Lymphoedema Framework Lymphoedema Impact and Prevalence: Outstanding Contribution to LIMPRINT

Conference presentations	
CHILL Event October 2017	
5th December 2018	Midlands Regional Doctoral Event in Birmingham - overview of preliminary findings
23rd May 2019	NUBS PhD Conference on the - Relational Exchange part of findings
4th June 2019	Clinical Nurse Research 2019 Symposium "Supporting Excellence in Patient Care" (Helsinki, Finland) presentation- "Relational Exchange" findings
13th June 2018	NUH (Nottingham University Hospitals NHS Trust) Engage, Enthuse Empower Research Conference -- overview of preliminary findings
Thursday 5th September 2019 -	Nottingham Trent University/NUH Skin Integrity Summer School - overview of all preliminary findings
Friday 9th October 2020	Presentation (Teams) to Vascular Trainees (NUH) overview of preliminary findings
Thursday 18th-Saturday 20th November 2021	Plenary lead at the International Lymphoedema Conference November 2021

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Abbreviations

Abbreviation	
CASP	Critical Appraisal Skills Programme
CDT	Complex decongestive therapy
CO	Chronic Oedema
CQC	Care Quality Commission
CRCO	cancer related chronic oedema
DLA	Disability Living Allowance
DoH	Department of Health
DWP	Department of Work and Pensions
GCP	Good Clinical Practice
GP	General Practitioner
HEE	Health Education England
HRA	Health Research Authority
ICD	Indices of Social Deprivation
ICF	Informed Consent Form
ICS	Integrated Care system
IRAS	Integrated Research Application System
KIBS	Knowledge-intensive business services
LADs	Local Authority Districts
LTC	Long-term condition
LYMQOL	Quality of life measure for limb lymphoedema
MLD	Manual lymphatic drainage
NCRCO	Non-cancer related chronic oedema
NIHR CRN	National Institute of Health Research Clinical

	Research Network
NMC	Nursing and Midwifery Council
NR	Narrative Review
NSHP	Non-specialist Health Professional (non-lymphoedema specialist)
PIP	Personal Independence Payment
PIS	Participant Information Sheet
REC	Regional Ethics Committee
RN	Registered Nurse
SDH	Social Determinants of Health
SLD	simple lymph drainage
SHP	Specialist Health Professional
TDC	Tissue Dielectric Constant
UK	United Kingdom
USA	United States of America

1 Focus of the PhD and Empirical study

1.1 Chapter overview

In this chapter I introduce myself, and the focus of the PhD and the empirical study, this includes the rationale for the discussion of coproduction, socioeconomic position and social capital within a healthcare context. I go onto to discuss the justification of chronic oedema, outlining the Primary Study objectives and purpose of the study, this is followed by an outline of the context of the thesis.

1.2 My PhD journey

My journey to this PhD began 30 years ago when I started my degree in Social Science (Sociology) in Bristol; my first experience of ‘doing’ research made me realise how adept I was at collecting and analysing data (mainly, talking to and with people). During my first year at university, I also worked in a care home, and decided that I wanted to pursue a career as a registered nurse. Knowing this meant another 3 years of study, I graduated from my degree with a 2:1, and demonstrated my drive, perseverance and motivation by securing a place at the University of Nottingham. I immediately started my Diploma in Nursing, and soon recognised the importance of translating theory into practice, and how I could use the research skills I had already acquired.

After qualifying, I commenced my 11-year career within Dermatology, and progressed from a junior staff nurse to the ward and outpatient’s department sister. It was in this role that my understanding and empathy towards caring for those with long-term skin conditions, enabled me to fully appreciate the impact of the social determinants of health. I am certain that my commitment to improving patient care and encouraging the learning of others, led me to a role as a Practice Development Matron (PDM). I have been in this role for 12 years, and it involves teaching and supporting the implementation of evidence-based practice.

In 2012/13, I was awarded an NIHR scholarship, and completed a Masters in Research Methods (2013), where I explored the barriers and enablers to the delivery of care, by nurses, to prevent pressure injury. Following completion of my MA and return to my PDM role, I had the opportunity to lead the implementation of the LIMPRINT study (2014/15). This was a seminal moment in my career, which encouraged me to apply for this PhD. I used the learning from my degree and my MA; my experiences caring for patients with chronic oedema within the dermatology services; and my commitment to ensuring the implementation of EBP, to establish and position myself as a nurse-researcher. This position encourages my interest in inquiry, and I have included within this thesis a section in Chapter 3.8 where I discuss my reflexivity throughout the research process.

I am committed and enthusiastic about improving patient care and promoting EBP and research as a fundamental aspect of safe, high-quality care. This is especially in terms of understanding of how the SDH, and context influences service-users’ interaction with health professionals, and especially regarding assumptions which may underpin the care delivered.

1.3 Introduction

1.3.1 The focus of the PhD

Business, management and improvement science coproduction literature predominantly focus upon the organisation and design of products and services, between service-users and healthcare providers, in multiple settings. Addressing this important issue of healthcare coproduction in domestic and healthcare sites, has several important implications for current business, services and improvement science research (Berwick, 2008, Dixon-Woods, McNicol and Martin, 2012, Realpe and Wallace, 2010). Coproduction is a term which is relatively new to healthcare, and historically is perceived in terms of the evolution of Patient and Public involvement (PPI), the "Expert Patient Programme"; the scoping, planning and design of new and existing services, or in terms of patient involvement in designing and planning research (Department of Health (DoH), 2001, Donaldson, 2003, Badcott, 2005, Brett, Staniszewska, Mockford et al., 2014b, Ocloo and Matthews, 2016, Brett, Staniszewska, Mockford et al., 2014a, Ocloo, Garfield, Franklin et al., 2021). In 1996, Ostrom described the first formal definition of coproduction as a

> *"process through which inputs from individuals who are not "in" the same organization are transformed into goods and services" (Ostrom, 1996, p.1073)*

The empirical study of this PhD explored the operationalisation of the coproduction of care and the interface of "hospital" (secondary care) and "home" (the domestic setting), for people living with a long-term condition (LTC), defined as:

> *"A long term condition (LTC) is a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies" (Department of Health, 2012, p.3)*

Chronic oedema was chosen as the LTC chosen as the clinical example, it is a complex condition defined as the presence of swelling to the limbs, which has been present longer than 3 months (Moffatt, Franks, Doherty et al., 2003, p.732).

This thesis explores coproduction of care in relation to service-users socioeconomic position (Stringhini, Sabia, Shipley et al., 2010), quality of life, and the decisions and motivation which influence the choices service-users make about their health. This is in terms of how care is coproduced between "hospital" and "home", how shared and individual decision making cannot be separated from the social determinants of health (SDH) (age, gender, poverty, wealth, education, race, religion, class) (Marmot, 2005, Marmot, Allen, Bell et al., 2012, Carey and Crammond, 2015, Crammond and Carey, 2016b, Cockerham, Hamby and Oates, 2017, Bourdieu, 1984), the structural inequalities of power. All of which influence whether an individual feels in control of their life, their self-perception and their psychosocial wellbeing (Hoggett, 2001).

Traditionally, services, in contrast to manufactured goods, were defined as "intangibles" (Dolfsma, 2011, p.920) where production and consumption occur at the same time, through the interaction of a service-provider and an service-user. Historically, coproduction has been applied to formalised healthcare initiatives. This includes "Patient and Public Involvement (PPI)" defined as the:

> *"active involvement of patients, service users, carers or family members in activities done with or by, rather than to" (Baines and Regan de Bere, 2018, p.327)*

in addition to the "Expert Patient Programme" (Department of Health (DoH), 2001, p.1), which focused upon sharing lay-expertise and individual empowerment, involving highly structured education for service-users living with LTCs, rather than coproducing care with health professionals.

This t contributes to the existing literature through the exploration of multiple definitions of the concept, and why these definitions, and how the operationalisation of coproduction can be considered a "wicked problem" (Rittel and Webber, 1973, p.155) or a "wicked issue" (Petticrew, Tugwell, Welch et al., 2009, p.453). Rittel and Webber (1973) described these as problems which are difficult to define, cannot be solved easily or easily concluded; are considered as "good or bad" not "true or false", and that the "wicked problem" is perceived as unique. A "wicked problem" is also often a symptom of a bigger societal problem, meaning social context is relevant, as there is no singular definition (Rittel and Webber, 1973, p. 155-169).

This concept has been previously used in healthcare, particularly related to mental health and stigma, health inequality, and planning services and care (Petticrew et al., 2009, Shaw and Rosen, 2013, Henderson and Gronholm, 2018, Cunningham, Ranmuthugala, Westbrook et al., 2019). However, this study was a novel exploration of service-users; and if, and how coproduction occurs in a domestic setting when service-users are responsible for the implementation of care within their home environment; and by considering the domestic home is a healthcare setting. This has not been fully considered within the coproduction literature.

Moreover, it is important to identify and critique the interplay between new innovations/products and services/ within the context of the environment/organisation in which they are planned and implemented, and the service-users who will access them. It is naïve to implement a new or complex intervention (Craig, Dieppe, Macintyre et al., 2013), or service from one setting to another and expect it to be successful, if the differences between service-users and the context in which they live have not been adequately considered. It is also unrealistic to expect the same contributions from service-users and to do so risks the development and implementation of healthcare services which are not responsive to the service-users' needs, and are therefore potentially unsustainable (Dixon-Woods and Martin, 2016)

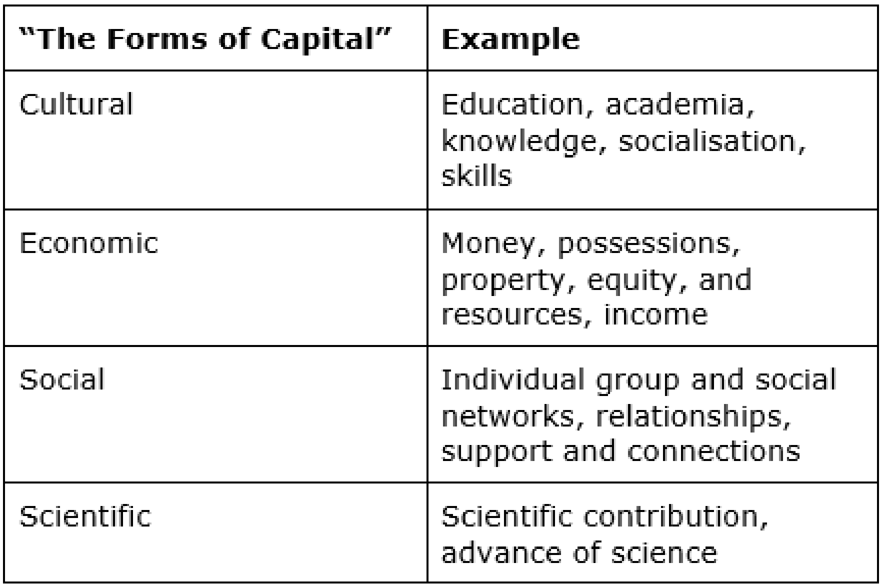
When exploring the concepts of coproduction it is imperative to consider the role of socioeconomic position and social capital in coproduction of care for people living with LTCs (chronic oedema); the extent to which service-users from different socioeconomic groups and/or expertise are involved with coproduction of products and services; the interaction between service-users (service-users) and professional service developers and the services and products at the point of delivery/consumption; and how service-users perceive, understand and control their contribution, dependent on their skills and knowledge (Needham, 2008).

1.3.2 Bourdieu and Social Capital

The aim of the PhD was to explore the operationalisation of coproduction within the "home", which takes into account of the socioeconomic context of the geographical location of a study, and how this is also relates to "social capital".

The concept of "social capital" first emerged through the seminal work of the French philosopher Bourdieu (1984), who identified differences between socioeconomic classes, including economic barriers, family traditions and socialisation, from a structural perspective. Bourdieu (1984), proposed that individuals use a range of resources (capital) when communicating and interacting with each other. The formation of structural class is dependent on the social distribution of three types of capital; economic, cultural and social (Bourdieu, 1986, p.82) (Table 1). Later in his work Bourdieu also discussed the concept of "scientific capital" (Bourdieu, 2004, p.55); whereby scientific specialities have greater status, prestige, symbolic capital and power, within science and the social sphere, because of their scientific contribution. This concept is further elaborated in Chapter 3, in the discussion of the philosophical perspective on the study.

The distribution and interaction of capital, determines the degree to which social relations of power, status and inequality (Abel and Frohlich, 2012) lead to the emergence of the greatest “symbolic capital” (Huppatz, 2015, p.374)



“The Forms of Capital”	Example
Cultural	Education, academia, knowledge, socialisation, skills
Economic	Money, possessions, property, equity, and resources, income
Social	Individual group and social networks, relationships, support and connections
Scientific	Scientific contribution, advance of science

Table 1: “The Forms of Capital” (Bourdieu, 1986, p.82) and ‘Science of science and reflexivity’ (Bourdieu, 2004, p.55)

This underlines the proposition that those living within a context of social deprivation (geographical location or socioeconomic status), may also lack the personal attributes, social position, or opportunity to engage in coproducing relationships (Bovaird, 2007, Bovaird and Loeffler, 2012, Bovaird, Van Ryzin, Loeffler et al., 2015, Nairn, Dring, Aubeeluck et al., 2019). Bourdieu suggested that how individuals’ perceive their capital is greatly influenced by their “habitus” (Webb, Schirato and Danaher, 2002, p. xii) or socialisation; their way of thinking and feeling, their cultural influences, their “collective” and “individual” class (Ferlander, 2007); the social networks and relationships trust and reciprocity which evolve through their interaction with others (Coleman, 1988, Lane, 2000, Jenkins, 2002, Putnam, 2004, Szreter and Woolcock, 2004, Ferlander, 2007, Grenfell, 2012, Cockerham, 2013a, Collyer, Willis, Franklin et al., 2015); and that individuals’ lives are socially constructed through their interactions and experience with others. Whilst other authors have also written prolifically about the concept of social capital as a:

> *"resource, individual or communal, accessed via various forms of social networks" (Ferlander, 2007, p.117)*

Which provides a:

> "supportive social atmosphere" (Song, 2013, p.9)

Bourdieu's "habitus" is the most useful way to discuss health inequalities which result from social inequality, in terms of the distribution of capital, hierarchy and the symbolism of healthcare professionals. In particular, how low socioeconomic status of individuals may negatively affect their implementation of care, and putatively lead to poorer health outcomes. Whilst a criticism of Bourdieu (1984) is that they did not write specifically about social capital in terms of health (Abel, 2008), it is considered a useful framework for exploring health inequality (Frohlich and Potvin, 2010, Pinxten and Lievens, 2014), specifically within the context of this PhD. Moreover, this thesis also reflects how Ferlander's (2007) interpretation of social capital within healthcare specifically, contributes to the understanding and relevance of Bourdieu's (1984) theorising of social capital.

Recognising the relevance impact of health, social capital, social networks and coproduction within neighbourhoods and communities, indicates that healthcare must be to be responsive to the needs of service-users (von Thiele Schwarz, 2016). This is in addition to how social capital develops within long-term coproducing relationships, in particular those service-users with LTCs, which are perceived as lacking “scientific capital” to promote relationships based upon trust (relational exchange), which has the capacity to positively affect future behaviours (Wu, Huang, Tsai et al., 2013). This perspective is relevant because of how coproduction activities are undertaken, and if any outputs fulfil the heterogeneous needs of diverse service-users. Furthermore, the concept of coproduction aligns to the NHS Outcomes Framework (NHS Digital, 2021), which advocates that the development and delivery of services should reflect the needs of service-users, enable choice, and creates opportunities for service-users to evaluate services.

The rationale for choosing Bourdieu’s (1984) version of social capital, is because it also aligns to a social constructivist perspective (Jovanović, 2021), which is significantly relevant to the conceptual lens of coproduction. Social Constructivism is underpinned by relativism and subjectivism (Guba and Lincoln, 1994, Lincoln, Lynham and Guba, 2011) and concerned with “what is happening here”. This in terms of the context, constructs and multiple ‘meaning-making’ (Lincoln et al., 2011, p.167), and the ontological (reality) and epistemological (subjective) dilemmas within the social world. It is also pertinent to the context of large welfare state agencies, such as the NHS, as coproduction involves interactions and relationships (long-term) between service-users and service-providers (Bovaird, 2007). This is within the context of service-users’ lives (their capitals and “habitus”), and the power dynamics (social constructivism and coproduction) which occur as these relationships develop with the service-providers.

The relevance of Bourdieu is the argument that there is no single determinant for service-users' health behaviour, it is the dynamic between the

> *"'objective' and 'subjective' social world"*
> *(Collyer et al., 2015, p.689)*

And the influence of habitus, the field and capitals (Collyer et al., 2015, p.689). Moreover, coproduction at the point of care is often perceived paternalistically; the "compliance" of service-users to treatment regimens (Ewert and Evers, 2014) or in terms of service-users' self-esteem and self-efficacy (Mayer and McKenzie, 2017), when implementing their own healthcare. Ocloo and Matthews (2016) suggest that shared decision making can improve outcomes for those in position of social inequality; therefore understanding behaviours, in relation to social inequalities (Stringhini et al., 2010) and the social construction of perceived choice (Collyer et al., 2015), is imperative to identify the drivers, which influence the decisions service-users make about their health.

There are also challenges related to decision-making (trust, goals, and autonomy) and the involvement of service-users with existing skills, knowledge and social networks (social capital); the factors which enable them to take a proactive role in coproduction. This may lead to a plan of care, and outcomes which both the service-provider and the service-user concur, whilst enabling them to be accountable (Stevenson and Scambler, 2005) and greater potential for the transformation of the service-users' experience of care through this interaction.

1.3.3 The relevance of Improvement and Implementation Science

This study contributes to the existing academic literature on Improvement Science, a systematic approach to improving healthcare and the delivery/implementation of services, based on sound, robust evidence, and a focus also upon quality and safety (Damschroder, Aron, Keith et al., 2009, Dixon-Woods et al., 2012, Bergman, Hellström, Lifvergren et al., 2015, Dixon-Woods and Martin, 2016). It integrates theory, rigorous research methods and data collection, methods of assessment, to produce data of a high quality, and evaluation which enables sustainable quality improvement within healthcare (Tansella and Thornicroft, 2009, Marshall, Pronovost and Dixon-Woods, 2013). Moreover, Implementation Science emphasises the importance of context and setting in the design, development, and implementation of health innovations and the service-users who will access them (Greenhalgh, Robert, Bate et al., 2008, Damschroder et al., 2009).

Whilst there is much discussion about the coordination of health (and social) service delivery by different organisations in the NHS (Greenhalgh et al., 2008, Greenhalgh, 2009, Greenhalgh, Humphrey, Hughes et al., 2009) aimed at improving health outcomes, a notable research gap exists concerning the coproduction of health that takes place in the home. The importance of the home, as a site for the coproduction of healthcare delivery, is perhaps most obvious with respect to LTCs. This is where the responsibility for the daily implementation of care is within the domestic setting. Therefore, the key contribution of this study is to extend the scope of the healthcare setting to include the home, and the operationalisation of the coproduction of care; the health activities of service-users, when not directly engaged with healthcare practitioners.

This study identifies a gap in the contemporary coproduction theory, which suggests the paternalistic perception of service-users, living within contexts of geographical and social deprivation. This includes the assumption that these service-users lack the “operant resources” (Vargo and Lusch, 2004, p.6); the tacit, or intangible, knowledge and skills required to coproduce care. Tacit knowledge develops when “socially embedded” (Collins, 2013, p.254) within a context, and is perceived as a social, rather than a scientific process (social constructivism). However, this study finds that whilst service-users often lack the “operand resources‟, the tangible economic, financial and physical resources (Vargo and Lusch, 2004, p.6), they describe having a range of “operant resources”, skills and knowledge to actively contribute to the coproduction of their care.

There are additional factors which motivate service-users to engage and coproduce care (identity, trust, and experience), and a lack of “operand resources” within the “home” (socioeconomic status and geographical position) may prevent the implantation of their care. This also includes whether service-users perceive continuity or trust in their relationships with care providers (social capital), especially GPs; which is particularly relevant in terms of complex LTCs and those living with multiple morbidities (Tarrant, Dixon-Woods, Colman et al., 2010, Tarrant, Colman and Stokes, 2008, Tarrant, Angell, Baker et al., 2014, Tarrant, Windridge, Baker et al., 2015). Therefore, it is also relevant to consider the relevance of healthcare terms such as “self-efficacy” (Bandura, 1977, p.191), "self-care" (Orem, 2003, p.8) and "self-management" theories (Lorig and Holman, 2003, p.1); and the involvement of significant others (family, friends and carers) in their care (Brewster, Aveling, Martin et al., 2015, Knowles, Combs, Kirk et al., 2016). There are several relevant definitions provided by other authors (Table 2), to explain these concepts, however confusion has arisen in practice, as these terms are used interchangeably.

Adherence	"The extent to which the patient's behaviour matches agreed recommendations from the prescriber" (Horne, Weinman, Barber et al., 2005, p.12) (no blame)
Non-adherence Intentional and unintentional	"Nonadherence is therefore best seen as variable behaviour with intentional and unintentional causes" (Horne et al., 2005, p.14). Intentional non-adherence: deliberately ignoring or altering the advice given, or decisions made with prescribers. Unintentional non-adherence: limits to capacity for understanding such as memory problems or impaired cognitive reasoning (Atkins and Fallowfield, 2006, Moffatt, Murray, Keeley et al., 2017a).
Compliance	"The extent to which a person's behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical advice (Haynes, 1979, p.1). This definition insinuates that the patient is not involved he process of decision making, that they are a passive recipient of instruction, or coerced" (Barofsky, 1978, p. 369)
Non-compliance (Intentional and unintentional)	This is described in exactly the same way as non-adherence (Chatterjee, 2006), in relation to patients not dispensing or taking medication (Chatterjee, 2006),
Concordance	This concept originated within the field of pharmacy and medication taking (Royal

	Pharmaceutical Society of Great Britain, 1997), and a focus is upon shared-decisions around care, (Stevenson and Scambler, 2005) Furthermore, "Concordance is sometimes used, incorrectly, as a synonym for adherence" (Horne et al., 2005, p.12). "Concordance describes an ideal, patient-centred process of supported decision-making that appears to be difficult to operationalize in practise" (Snowden, Martin, Mathers et al., 2014, p.47)
Non-concordance	When neither the patient nor the healthcare provider can reach an understanding together (Naidoo, 2013). Non-concordance is defined in exactly the same way as many definitions of non-adherence (Moffatt, Kommala, Dourdin et al., 2009)
Self-care	Orem's (2003) Self-Care Deficit Theory that if patients take responsibility and independence with aspects of their own care, there may be a more successful recovery from ill-health to well-being. The role of nurse is to facilitate independence (Orem, 2003)
Self-management	This is a concept first introduced by Lorig and Holman (2003), with a focus upon self-efficacy (Bandura, 1977), and the development of skills and knowledge to actively self-care (Orem, 2003). Greenhalgh (2009) describes that self-management is perceived as reducing healthcare costs, through a pyramid or hierarchy of care, which places self-management at the bottom, and ascending to the "Expert patient programme" (Department of Health (DoH), 2001), with specialist care at the top.
Self-efficacy	This is concept describes whether an individual perceives or believes they have the capacity to behave in a way which leads to the attainment of specific goals, aspirations or achievements, related to personal motivations, perception of self-control within their specific context (Bandura, 1977). Increased Self-efficacy facilitates behaviours which might lead to

	greater adherence to treatment (Moffatt et al., 2017a)

Table 2: An Explanation of healthcare terms

These definitions also imply how service-users are perceived by health professionals; whether they self-manage, adhere or comply with treatment. The concept of self-management (Lorig and Holman, 2003, Reeves, Blickem, Vassilev et al., 2014) is also well recognised through the "Expert Patient Programme" (Department of Health (DoH), 2001, Wilson, 2001, Wilson, Kendall and Brooks, 2007, Vadiee, 2012). Moreover, inherent in these definitions that service-users possess "health literacy"; that they can

> *"collect, process, and use health information" (Palumbo, Annarumma, Adinolfi et al., 2016, p.1183).*

Therefore, it is important to consider the extent to which service-users can make decisions based on this information, derive positive interactions with health professionals, and discern the health services available (Martin, Ruder, Escarce et al., 2009, Palumbo et al., 2016, Bowskill and Garner, 2012).

These definitions acknowledge the psychosocial position of service-users, particularly in terms of LTCs (Joachim and Acorn, 2000); where ill-health leads to a sudden change self-perception, body-image and identity, for example obesity or fatness (DeJong, 1980, Charmaz, 1983, Radley and Green, 1987, Radley, 1989, Goffman, 1990, Bircher, 2005, Jäger, Doller and Roth, 2006, Synofzik, Vosgerau and Newen, 2008, Vassilev, Rogers, Sanders et al., 2011, Backstrom, 2012, Vassilev, Rogers, Sanders et al., 2014, Fricker, 2019); and "biographical disruption" (Bury, 1982, p.167); with no hope of cure (Robertson, 2019).This potentially influences service-user behaviour (and coproduction of care) regarding prescribed medications, treatments, and recommended health and lifestyle changes (Hockey, Dilley, Robinson et al., 2014).

Therefore, this highlights the need for health professionals to acquire understanding and insight into lives of their service-users, in terms of why they may be perceived as “non-concordant”. Moreover, health professionals become “detectives”, as service-users describe and explain “their story”. The concept of health professionals being well positioned as detectives is not new to healthcare inquiry, and is often discussed within different contexts, for example physiotherapy, alcohol outreach, telephone consultation, communicable disease, and health visiting (Zerwekh, 1991, Kaminsky, Rosenqvist and Holmström, 2009, Whiteford, 2017, Ahlsen, Mengshoel, Bondevik et al., 2018, Rubin, 2020). However, it is a concept less recognised within healthcare for other LTCs, especially those with lesser “scientific capital”.

Service-users’ engagement with their care has implications for practice and health policy, (Hoggett, 2001, WHO, 1946, World Health Organization (WHO), 1984). The factors identified may explain differences in health lifestyles and preferences for those with diagnosis of a LTC, who are living within a context of socioeconomic deprivation (Morgan, Murray, Moffatt et al., 2012, Ridner, Bonner, Deng et al., 2012b, Mercier, Pastor, Clement et al., 2016a), and therefore chronic oedema is chosen as an example.

1.4 Why Chronic oedema?

Chronic oedema (Moffatt et al., 2003, p.732), is a complex, LTC, which occurs due to problems within the lymphatic system, and does not have one causal factor (Keast, Despatis, Allen et al., 2015, pp.329). Chronic oedema occurs as a result of a lymphatic system which is overwhelmed causing affected parts of the body to swell. The condition often presents, and is associated with deteriorating mobility, obesity, asymmetry of limbs, deformity and discolouration of the affected body part (Jäger et al., 2006). The term chronic oedema encompasses all types of lymphoedema, including primary lymphoedema (including a sub-group of genetic conditions), complex secondary lymphoedema, vascular anomalies, lymphovenous oedema, lipoedema; and includes those which have mixed aetiology and associated comorbidities, such as hidradenitis supparativa (an inflammatory skin condition), Crohn's disease and vascular anomalies (Keeley, 2017, Moffatt, Keeley, Franks et al., 2017c, Shikino and Ikusaka, 2018, Gordon, Varney, Keeley et al., 2020, Goss, Maclellan and Greene, 2019, Micieli and Alavi, 2018). The following terms are used interchangeably within the literature:

- Lymphoedema
- Lymphedema
- Chronic oedema
- Chronic edema
- Oedema
- Edema
- Swelling

Chronic oedema is complex because it can be difficult to diagnose at an early stage, due to the lack of acknowledgement of sub-clinical symptoms and unidentified genetic factors (Warren, Brorson, Borud et al., 2007). However, if allowed to continue without treatment, affected skin and tissues become hardened, due to chronic inflammation, which causes an increased risk of life threatening infection (Warren et al., 2007).

1.4.1 The public sphere: Chronic oedema as a "wicked problem"

Contemporary research suggests large variations in the knowledge and training of health professionals in chronic oedema; the resources within healthcare systems; service provision; and how those diagnosed with condition are "medically" managed. Furthermore, chronic oedema is perceived as heterogeneous problem, with no single medical specialty to "own" it (Moffatt et al., 2003, Williams, Franks and Moffatt, 2005, Rockson and Rivera, 2008, Fu, Ridner, Hu et al., 2013, Ridner, Deng, Fu et al., 2012a, Muldoon and Charles, 2013, Todd, 2013a, Benson, Gaskin, Moffatt et al., 2016b, Benson, Gaskin, Moffatt et al., 2016a). The prevalence of this condition is significantly underestimated, both in the United Kingdom (UK) and worldwide (Stout, Brantus and Moffatt, 2012, Cooper and Bagnall, 2016, Moffatt et al., 2017c, Quéré, Palmier, Nøerregaard et al., 2019).

This is relevant as early detection and access to appropriate treatment and services can prevent the progression of this burdening condition, decreasing treatment costs and improving service-users' quality of life (Franks and Jarrett, 1997, Hardy and Taylor, 1999, Shebel, 2002, Lewis and Morgan, 2008, Stanisić, Gabriel and Pawlaczyk, 2012, Walker and Thomson, 2012, Todd, 2013b, Quéré, Presles, Coupé et al., 2014, Hidding, Viehoff, Beurskens et al., 2016, Moffatt, Doherty, Franks et al., 2018). It is also recognised, by numerous authors, that lymphoedema has a significant and complex psychosocial impact on those living with condition (Joachim and Acorn, 2000, Williams, Moffatt and Franks, 2004, de Valois, Asprey and Young, 2016, Douglass, Graves and Gordon, 2016, Dudek, Białaszek and Ostaszewski, 2016, Stolldorf, Dietrich and Ridner, 2016, Tsuchiya and Takahashi, 2016, van de Pas, Biemans, Boonen et al., 2016, Greene and Meskell, 2017, Moffatt, Aubeeluck, Franks et al., 2017b).

Chronic oedema is also selected because it highlights several factors that are relevant for this PhD, as individuals with this condition are perceived to experience low social capital, lower socioeconomic status, social isolation (Papadopoulou, Tsiouri, Salta-Stankova et al., 2012, Nairn et al., 2019, Piller, 2013). Furthermore, current literature does not sufficiently explore the social context (Quéré et al., 2019, Nairn et al., 2019) or the availability of "affective resources" (Whiteford, 2017, p.185), or "social prescriptions" (Drinkwater, Wildman and Moffatt, 2019) for service-users living with chronic oedema; lifestyle choices or activities which enable a sense of belonging and potentially improve their quality of life, even if they do not improve their clinical outcomes (Wei, Wu, Chen et al., 2019, Wanchai and Armer, 2020, Sneddon and Lewis, 2007).

This applies to chronic oedema due to the perceived paucity of service-user, professional and public knowledge and awareness, recognition, and education (Franks, Moffatt, Murray et al., 2013, Stout, Weiss, Feldman et al., 2013, Keast et al., 2015). Nairn et al. (2019) suggest that chronic oedema is a condition with little "scientific capital" (Bourdieu, 2004, p.55) because of the newness of the definition (Moffatt et al., 2003, Nairn et al., 2019) and combined with the other factors identified, this means it can also be considered a “wicked Problem” (Rittel and Webber, 1973, p.155). Therefore, it is relevant to consider the interplay of physical, psychosocial and structural factors (Morgan et al., 2012, McGowan, Williams, Davidson et al., 2013) to explore the relationship between service-users’ implementation of care at “home”, shared-decisions with service-providers (coproduction) and the influence of socioeconomic status and perceived health inequalities (Mercier et al., 2016a, Mercier, Pastor, Clement et al., 2016b, Mercier, Pastor, Moffatt et al., 2019b, Taylor, 2021).

1.4.2 Burden of Treatment

The burden of treatment is an important factor, and this is where the PhD proposes to contribute to the literature. The current lack of standardised UK health policy related to chronic oedema (Department of Health (DOH), 2005, Lymphoedema Framework, 2006, National Institute for Clinical Excellence (NICE), 2017) means that even with specialist health professional guidance, the exact treatment an individual receives depends upon access within their geographical area; whether services and treatments, including surgical intervention, are commissioned by the NHS; or the “School” of treatment to which a particular clinician is aligned (Casley - Smith, Boris, Weindorf et al., 1998, Földi, Földi and Clodius, 1989, Kasseroller, 1998, Leduc, Leduc, Bourgeois et al., 1998, Rockson, Miller, Senie et al., 1998).

Chronic oedema is a treatable although incurable, condition, and the most common intervention is referred to as complex decongestive Therapy (CDT). The principles of CDT include manual lymphatic drainage (MLD) or simple lymph drainage (a form of self-massage) (SLD); compression bandaging and/or garments; exercise and rigorous skin care to prevent and/or recognise infection; maintaining mobility; and focussing on psychological wellbeing (Elwell, 2016, For-Szabo and Ralph, 2017, Sezgin Ozcan, Dalyan, Unsal Delialioglu et al., 2018). Treatment may also include surgical options (Tang, Ramakrishnan and Shayan, 2021); pneumatic compression pumps (Phillips and Gordon, 2019) and Kinesio taping treatment, which is a method used to support soft tissue and joints (Williams, 2019, González Blanco and Soto González, 2020).

Most service-users will move from an intensive period of CDT, to a phase of maintenance which they undertake themselves, and this is recognised as requiring significant commitment to therapy (Franks and Jarrett, 1997). Furthermore, this treatment also fulfils the definition of a "complex intervention" as there are multiple factors to consider, specific aspects of the intervention which cannot be exactly replicated, and unpredictable clinical outcomes. (Campbell, Fitzpatrick, Haines et al., 2000, Campbell, Murray, Darbyshire et al., 2007, Craig, Dieppe, Macintyre et al., 2008, Craig et al., 2013, p.587, Cathain, Croot, Duncan et al., 2019).

However, there are no standardised models and reliable clinical outcomes for chronic oedema (Morgan et al., 2012, Keeley, Franks, Quéré et al., 2019, Moffatt, Sykorova, Dring et al., 2021b, Moffatt, Dring, Sykorova et al., 2021a), including patient reported outcomes (Gabe-Walters and Thomas, 2021). The main clinical outcome is validated limb volume measurement (Williams and Whitaker, 2015) using either a tape measure or a perometer. The perometer is an instrument which creates a 3-dimensional measurement of the total limb volume, and is a validated method of measurement (Sharkey, King, Kuo et al., 2018). However, there is debate as to whether perometry is considered the “gold standard” and whether it should be used interchangeably with a tape measure (Batista, Baiocchi, Campanholi et al., 2018, Sharkey et al., 2018, Reza, Nørregaard, Moffatt et al., 2020). Whilst perometry is considered reliable and reproducible, it is not exact. It cannot determine whether the measurement is evidence of a change in lymphatic fluid, or due to other physiological factor as it measures total volume. It is also important to recognise that perometer measurements are perceived as unreliable in detecting subclinical chronic oedema, when there are no obvious skin changes (White, Lu, Kao et al., 2020).

Devices which measure tissue dielectric constant (TDC), are increasingly used to detect a more accurate amount of fluid in a specific area of the body (Jensen, Birkballe, Nørregaard et al., 2012, p.317). The accuracy of fluid measurement is complicated (Moffatt et al., 2021a), and dependent upon a number of confounds, such as consistency in user skill, measurement bias, weight loss or gain, and the time of day measurement is taken; moreover, this is a physiological outcome and the focus upon limb volume does not necessarily reflect to what matters to individuals, when evidence suggests that they do not maintain the decrease in volume, and the improvement gained during intensive treatment (Reza et al., 2020, Bjork and Hettrick, 2019).

This is a significant problem, as the International Lymphoedema Framework (ILF) (2012) asserts that effective treatment outcomes are only achieved if those with chronic oedema engage in self-management; are adequately educated about their condition, and receive the medical and psychological assistance they need (ILF, 2006, Everett, Lawrance and Phillips, 2021, National Wound Care Strategy Programme (NWCSP), 2020). However, the recommendations assert that those with chronic oedema need appropriate and consistent help and support to achieve this (Lay-Flurrie, 2011). This is challenging when the emphasis is upon committing to a lifetime of treatment regimens, without a hope of cure (Franks and Jarrett, 1997, Kerchner, Fleischer and Yosipovitch, 2008).

Furthermore, there is limited exploration within the current literature, regarding social capital, the structural and economic position of the service-user and how this affects the implementation of their care at home (Mercier et al., 2016b, Pastor, Mercier and Quéré, 2018, Mercier, Pastor, Clément et al., 2019a). This is particularly for those service-users with non-cancer related chronic oedema (NCRCO), as evidence identifies the considerable personal and healthcare costs associated with living with this condition (Morgan, Franks and Moffatt, 2005, Keast et al., 2015, Humphreys, Thomas and Morgan, 2017, Nairn et al., 2019). The onus is upon the service-user to ensure their care at home is “successful” in terms of control of reducing swelling, absence of infection and any improvement in their life quality.

1.4.3 Chronic oedema and socioeconomic status

The relevance of sociodemographic position and quality of life is even greater for those individuals with lower leg chronic oedema, and those who also live with leg wounds (Franks, 2006, Franks and Moffatt, 2006, Franks, Moffatt, Doherty et al., 2006, Moffatt, Franks, Doherty et al., 2006, Lam, Wallace, Burbidge et al., 2006). Wigg and Lee (2014) suggest that care and treatment must align with service-user's lifestyles and therefore it is imperative to discover what those diagnosed with chronic oedema, perceive are barriers in terms to implementing care at "home". Factors which influence their interaction within their own social groups and with others, such as care services are likely to be diverse and this social process remains hidden in any of the existing literature. This PhD and the empirical study facilitated the exploration of socioeconomic circumstances and access to care, in terms of health behaviours, as a social product and not a personal attribute (Crammond and Carey, 2016a, b).

Furthermore, a limited literature search of the involvement of service-users in the design of chronic oedema services in the last 10 years identified only one paper, which discussed recommendations for service-redesign, however this publication was over 10 years old, and did not include service-users (Bulley, 2007). Only one study was found which considered the socioeconomic or geographical position of the service-user (Moffatt et al., 2003). However, the ILF has a history of ensuring service-user involvement and consensus with the development of their best practice guidelines (Morgan, Doherty, Moffatt et al., 2004, Lymphoedema Framework, 2006, Morgan and Moffatt, 2006, Franks and Morgan, 2007). Therefore, the timing of the PhD was critical as there is uncertainty as to how different social settings affect clinical outcomes. Douglass et al. (2016) suggests:

> *"high quality studies that investigate reversal of early stage disease and analysis of individual components of self-care by age, gender, stage and location of lymphedema are essential to*

> *determining optimal, financially sustainable, management" (Douglass et al., 2016, p.17).*

This is even greater given the current unprecedented pressure upon the NHS (Steen and Brandsen, 2020) and the emphasis upon service-users undertaking their own healthcare within the home.

1.4.4 Aims of the study

This PhD contributes to new understanding regarding the coproduction of care, which meets the needs of service-users and influences existing, and future health policy. The specific contribution will be in relation to coproduction of healthcare in terms of geographical position and space, between "hospital" (secondary care) and "home" (domestic setting), and the assumptions underpinning the dichotomous relationship between service-users and service-providers. This includes the factors which influence if, and how service-users access services; how care is implemented at home; the relevance of social capital and socioeconomic position; and the coproduction of care in terms of definitions of health and wellbeing, such as:

> *"The extent to which an individual or group is able to realize aspirations and satisfy needs and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living; it is a positive concept, emphasizing social and personal resources, as well as physical capacities" (World Health Organnization (WHO), 1984, p.4)*

The aim of the study was to explore this through the experience of service-users, with a poorly recognised and inconsistently diagnosed LTC. The existing literature portrays a group of service-users, for whom there is absent or worsening care provision, who live within a context of social deprivation, have lower socioeconomic status, income, and reduced opportunities to find, or remain in paid employment (Morgan, Murray, Moffatt et al., 2011, Ridner et al., 2012b, Mercier et al., 2016a, Mercier et al., 2016b, Nairn et al., 2019). Moreover, most economic evaluation studies of chronic oedema measure service costs rather than financial cost to service-users (Tan, Thomson, Wann et al., 2015).

An exploration was necessary to reveal the differences in how service-users make decisions about implementing care and treatment, and how they individually manage their chronic oedema. This includes if, and how service-users access appropriate and timely healthcare to manage, prevent, or reduce the risk of comorbidities and complications associated with chronic oedema, such as obesity (Mehrara and Greene, 2014, Ching, Anderson and Kumarasinghe, 2015, O'Malley, Ahern, Dunlevy et al., 2015, Moffatt et al., 2017c, Conolly and Davies, 2018, Hooper, Anderson, Birch et al., 2018); life threatening infections, cellulitis and sepsis (Cox, 2006, Al-Niaimi and Cox, 2009, Morgan et al., 2012, Zhang, Moore and Bousfield, 2016, Thomas, Brindle, Chalmers et al., 2017, Musumeci, Scilletta, Sorci et al., 2019, Burian, Karlsmark, Franks et al., 2021, National Institute for Health and Care Excellence, 2021); and disability and death (Moffatt et al., 2003, Keast et al., 2015). Moreover, the impact of chronic oedema, and associated complications are not fully understood or recognised within UK health policy literature;

and there is little understanding of service-users' needs, and how these service needs differ with respect to socioeconomic groups (Moffatt, Franks, Doherty et al., 2004).

There remains inadequate insight into the impact of chronic oedema upon service-users, in terms of their health outcomes, social functioning and associated wound healing; particularly if the condition is not diagnosed and treated at an early stage (Moffatt et al., 2003, Williams et al., 2004, Morgan et al., 2004, Williams et al., 2005, Moffatt et al., 2017c, Burian et al., 2021). Therefore, this inquiry was of even greater importance, when compared to existing research and service-provision for conditions such as cancer, dementia, inflammatory bowel disease chronic pain, diabetes, depression, rheumatoid disease and chronic obstructive pulmonary disease (Newbronner, Chamberlain, Borthwick et al., 2013, Elwyn, Nelson, Hager et al., 2019, Brand, Bramley, Dring et al., 2020), which demonstrate greater scientific capital (Bourdieu, 2004) than new and emerging conditions.

A possible consequence, for conditions with less scientific capital and public awareness, is delayed presentation, diagnosis, and appropriate treatment for service-users (Morgan et al., 2012, Moffatt et al., 2017c, Nairn et al., 2019). Evidence-based healthcare suggests that treatment decisions should take into account service-users' priorities and worries (Bath-Hextall, 2010), in addition to assessing and evaluating the access and availability of resources within the local area (Brölmann, Ubbink, Nelson et al., 2012). There is also limited data regarding what motivates service-users to share-decisions with health professionals, regarding their treatment options and the implementation of care; without this insight challenges around implementing evidence-based treatment will continue (Rockson and Rivera, 2008). Enabling the implementation of interventions, which are effective, and responsive to the needs of service-users (Tarrant et al., 2014) is multifaceted, is imperative if it has the potential to lead to positive patient outcomes (Damschroder et al., 2009).

1.5 Primary Study objectives and purpose

This empirical study explored how coproduction is operationalised in this context of ongoing care across "hospital" and "home" settings for an LTC, and how socioeconomic position and social capital impact on coproduction in this context.

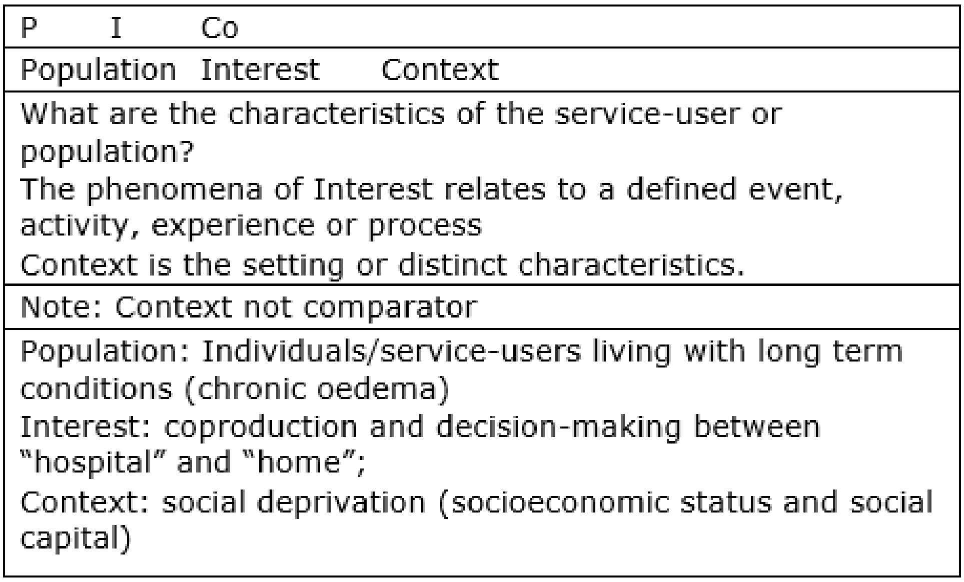
The specific contribution is in relation to coproduction of healthcare, and the assumptions around the dichotomous relationship between service-users and service-providers. This includes if and how service-users' access services, or if and how service-users can ever be "discharged" from care (Moffatt, Aubeeluck, Stasi et al., 2019a). Therefore, it is relevant to consider coproduction in relation to shared- decision making regarding treatment options; and what happens if the services available are not responsive to the needs of the service-user, particularly in relation to social capital and socioeconomic position.

While there is much discussion about the coordination of health (and social) service delivery by different organisations within the NHS (Greenhalgh et al., 2008, Greenhalgh et al., 2009), a significant research gap exists concerning the coproduction of health that takes place across multiple sites, and in particular the home.

Moreover, the home is a healthcare setting which has not been fully considered within the prior coproduction literature. It is evident that this is an existing gap, especially in terms of the coproduction of services, and what happens to service-users when they attempt to implement care at “home”; the concept of coproduction is problematized, in terms of what this means in practice within the UK, and the lived experience of service-users.

1.5.1 The research questions

The PICo tool (Methley, Campbell, Chew-Graham et al., 2014) (Table 3) was used to develop the primary research question.



P	I	Co
Population	Interest	Context
What are the characteristics of the service-user or population? The phenomena of Interest relates to a defined event, activity, experience or process Context is the setting or distinct characteristics.		
Note: Context not comparator		
Population: Individuals/service-users living with long term conditions (chronic oedema) Interest: coproduction and decision-making between “hospital” and “home”; Context: social deprivation (socioeconomic status and social capital)		

Table 3: PICo table for framing research questions

Primary study question:

How is coproduction operationalised within this context of ongoing care, across hospital and home settings, for individuals living with a long-term condition (chronic oedema);

and how is care coproduced, at the point of implementation within the "hospital" and "home"?

This includes:

- If and how socioeconomic position and social capital influences coproduction between service-users and service-providers in this context
- Do the social determinants of health and socioeconomic factors influence the decision-making strategies and coproduction of care, for service-users living with chronic oedema?
- An exploration of the socioeconomic context and geographical location of the setting, in terms of the distribution of service-users.
- Recommendations to policy makers in relation to access to chronic oedema care.

1.5.2 Context of the thesis

This PhD, funded by the Health Foundation, is positioned within Improvement Science (Dixon-Woods et al., 2012, Marshall et al., 2013, Brewster et al., 2015, Dixon-Woods and Martin, 2016) , and explores the pertinent issues which affect service-users, access to care, such as socioeconomic position. Both Improvement Science and Implementation Science emphasise that shared and individual decision-making cannot be separated from structural inequalities of power, and service-user engagement with the health system has implications for practice and health policy (Dixon-Woods et al., 2012). A recognition that service-user motivations are not necessarily associated with the known or perceived benefits to their health and may be due to sociodemographic factors.

Therefore, an urgent review is necessary to explore the existing differences in how service-users make decisions about accessing care and treatment, in a context of social deprivation. Chronic oedema as a "new" complex, long-term, incurable condition (Moffatt et al., 2003) is relevant as a clinical example, of the interplay of the coproduction of care between "hospital" to "home".

1.5.3 Structure of the thesis

Chapter 1: Study Background Information and Rationale

This introduces the purpose, aims and objectives of the thesis and empirical study. It outlines the context of the study and the rationale for using chronic oedema as the example for this study.

Chapter 2: Literature Review

This chapter presents the literature search strategy and a narrative literature review of the literature on coproduction, explaining how this is relevant to the PhD and empirical study.

Chapter 3: Philosophical Perspective, Methodology and Methods

This chapter outlines the philosophical perspective, methodology and methods of data collection, study design, analysis of the data, ethical approval, Good Clinical Practice and my reflexive position, as a nurse-researcher

Chapter 4: Observational findings

This chapter discusses access to the study setting, the observational findings, analysis and interpretation. This chapter also includes the discussion of the socioeconomic context, findings and conclusion, postcodes and GP Surgery data collection.

Chapter 5: Findings of the In-depth, Face-to-Face interviews

This chapter describes the participants, an overview of demographic findings, and outline and discussion of the main findings of the Face-to-Face interviews.

Chapter 6: Developing Expertise

This chapter describes how people with chronic oedema develop expertise in their condition and self-management at home, and discuss the role of “operant resources”

Chapter 7: Interface with Healthcare Professionals:

In this chapter, the way the service-users navigate the healthcare system and develop “relational exchange” with the specialist (chronic oedema) and non-specialist healthcare (General Practitioners/secondary care consultants) professionals involved with their care is described, this includes how the coproduction of care is operationalised.

Chapter 8: “Operand resources”: socioeconomic impact

In this chapter the socioeconomic factors associated with living with chronic oedema are discussed, in terms of their financial situation, social networks (social capital) and “operand resources”, and how these affect the coproduction of care.

Chapter 9: Final Discussion of the thesis

This is the final discussion of the thesis; this includes overview of main findings in terms of revisiting the definitions of coproduction, and the discussion in terms of scientific capital, structural capital, social capital, and economic capital; how this relates to power, status and capital and coproduction; and the conclusion of the thesis

Chapter 10: Strengths, Limitations and Recommendations for Clinical practice and service re-design, and suggestions for further research

Here the Strengths, Limitations and Recommendations for Clinical practice and service re-design, and suggestions for further research and the dissemination strategy.

2 Literature Review

2.1 Chapter overview

This chapter begins with an outline of the aims, and objectives of the literature review research questions specifically for the review, and the justification for a Narrative Review (NR). This includes a summary of the methodological framework, which includes the search strategy, data extraction and analysis of included papers, which is demonstrated pictorially in the literature map. This identifies how the literature interconnects and how the coproduction literature is distributed throughout the search.

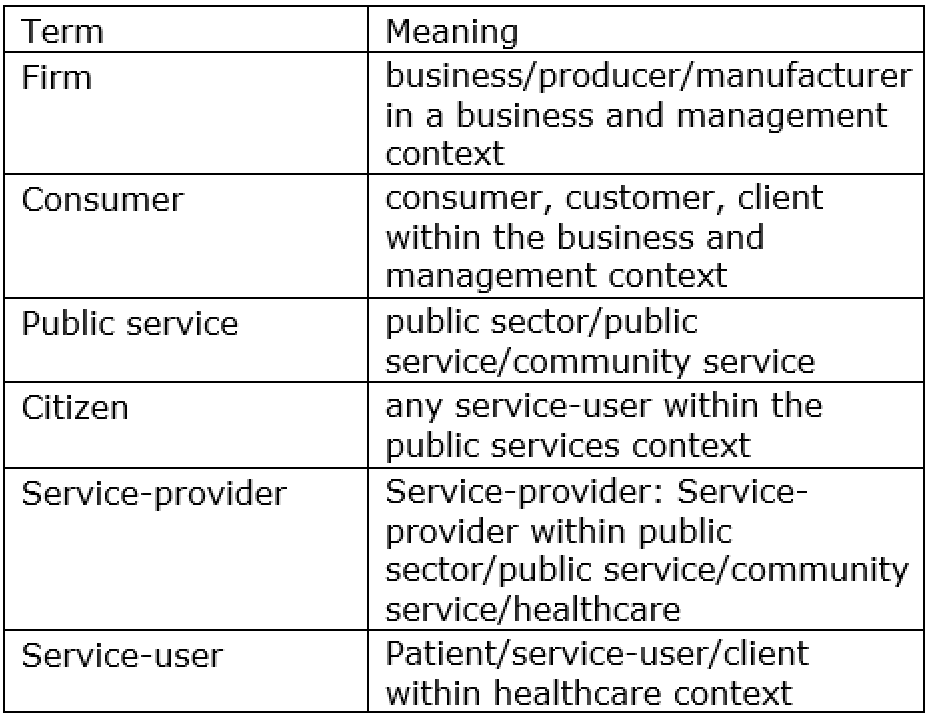
The NR explores the emergence of coproduction as a concept, with relevant definitions; then a discussion of the origins of coproduction and the paradigm shift within the business and management literature. I go onto discuss relevant studies exploring coproduction within the public sector and the coproduction within Healthcare. The chapter ends with a section where I discuss my analysis of the coproduction literature, including limitations and my conclusions. The final section discusses the relevance of the NR to the empirical study.

Reference to Appendices 1-5

2.2 Aims and objectives of the review

The aim of this literature review was to examine and critique the emergence of the concept of coproduction within the business and management literature, the public services literature, and to establish the relevance of coproduction theory to healthcare. This was to explore the relevance of socioeconomic position and social capital, as related to the study research question.

The theory of coproduction is relevant, as a framework to establish the relevance to healthcare and rise of service-user involvement in their healthcare. For the purposes of the review, it was necessary to be clear and consistent, therefore the following terms were used throughout this review (Table 4).



Term	Meaning
Firm	business/producer/manufacturer in a business and management context
Consumer	consumer, customer, client within the business and management context
Public service	public sector/public service/community service
Citizen	any service-user within the public services context
Service-provider	Service-provider: Service-provider within public sector/public service/community service/healthcare
Service-user	Patient/service-user/client within healthcare context

Table 4: Service-user: patients and service-users, specifically within the healthcare context.

The specific purpose of the literature review was to answer the following questions (Ferrari, 2015)

- How did theory of coproduction emerge?
- What are the strengths and limitations of definitions?
- What are the assumptions and gap within the literature?
- How will the NR contribute to existing coproduction theories, and what new perspective can it offer?

Aims

The overarching aim of the NR was to provide a historical overview of coproduction, from business and management, public services; and how it is relevant to healthcare, in terms of the interaction between service-users and healthcare professionals, at the point of care. This included the revelation of

> *"problems, weaknesses, contradictions, or controversies" (Baumeister and Leary, 1997, p.312)*

2.2.1 Objectives of the narrative review

The objectives of the NR:

- To present the most relevant overarching theories of coproduction and evaluate current theorisation
- To explore their relevance of coproduction in terms of answering the primary research question.
- To explore of structural and socioeconomic position and social capital, in relation to coproduction
- To explore of concepts within healthcare, which align to the theories of coproduction, in relation to shared decision making between service-providers and service-users.
- To explore the challenges of a succinct definition of coproduction
- To discuss the limitations of the coproduction literature,
- To explore where these theories can be applied in practice (healthcare) and suggestions for further research.

2.3 Justification for a narrative review

All literature reviews involve searching the available publications in order to describe, analyse, interpret, synthesise, and argue a theoretical field of knowledge (Baumeister and Leary, 1997, MacLure, 2005). However, when undertaking a literature review it is imperative to also define the type of review (Horsley, 2019), and to justify why this approach has been chosen. Given the overarching research question and the aims and objectives, a NR (Baumeister and Leary, 1997, Cooper, 1998, Green, Johnson and Adams, 2006, Bae, 2014, Ferrari, 2015, Gregory and Denniss, 2018, Horsley, 2019) was perceived to be the most appropriate approach. NRs enable a greater opportunity for interpretation and reflection, and to summarise a breadth of relevant literature and studies which take into account the context and perspective of the research (Greenhalgh, Thorne and Malterud, 2018). A NR was also more appropriate for an in-depth exploration of coproduction theory, in order to:

> *"provide a map of research in the relevant field" (Hammersley, 2001, p.544).n*

And:

> *"scholarly summary along with interpretation and critique" (Greenhalgh et al., 2018, p.2)*

This includes the synthesis and appraisal of published papers, techniques for reducing bias, and the identification of new areas of study for wide and diverse subjects. NRs are common to reviews of medical literature, which include different study designs and the hierarchy of evidence (Baumeister and Leary, 1997, Evans, 2003, Ferrari, 2015).

NRs are also a way to address wider questions and enable a historical account of emerging topics which are nebulous and/or diverse (Baumeister and Leary, 1997, Ferrari, 2015, Siddaway, Wood and Hedges, 2019). This is especially when a theory or subject is addressed by a number of scholars, within different disciplines, and from differing perspectives; and a NR approach enables the exploration and refinement of a wide subject (Baumeister and Leary, 1997, Greenhalgh, Robert, Macfarlane et al., 2004, Wong, Greenhalgh, Westhorp et al., 2013, Snyder, 2019, Horsley, 2019). Moreover, any conclusions will contribute to areas of further research, through the subjective discussion of the literature (Cooper, 1998, Hammersley, 2001).

NRs are invaluable when exploring a wide and diverse field of knowledge, especially if the contemporary body of evidence does not offer a satisfactory theory, definition or solution, and when the findings lead to several conclusions (Baumeister and Leary, 1997, Cronin, Ryan and Coughlan, 2008). This narrative approach was justified, to present the most pertinent theories of coproduction; fulfilling the aims, objectives, and research questions, and which the empirical study intended to answer. It offered a way to interpret the broader principles of coproduction, led by the relevant studies

The main criticism of NRs is that they can be biased due to the subjectivity of included papers. However, criticisms of NR searches, and reviews in general, are that they are that non-replicable and/or lack rigour, as there is no agreed way of undertaking a NR(Baumeister and Leary, 1997, Ferrari, 2015). However, many argue that this is a benefit, and NRs are unparalleled due to wide searches, leading to copious amounts of data (Ferrari, 2015, Collins and Fauser, 2005, Baumeister and Leary, 1997). Therefore, a methodological approach may mitigate this bias (Ferrari, 2015), to ensure that:

> *"The goal is to ensure that the methods of all reviews should be explicit, transparent, clearly stated and reproducible by interested readers."*
> *(Collins and Fauser, 2005, p.104)*

It is also important to highlight that a traditional systematic review approach (Munn, Peters, Stern et al., 2018) was not undertaken because this risked difficulties in identifying papers and excluding relevant literature, on the basis of a narrow search strategy (Greenhalgh et al., 2018, Henderson, Craig, Willis et al., 2010). Any limitations of a systematic review were overcome, by undertaking a NR which:

- ensured that findings relate to each other and the breadth of research
- explained the methods and analysis of the literature search
- provided a comprehensive robust critique which explores the gaps, limitations, contribution, and any exceptions
- and made recommendations for future research (Baumeister and Leary, 1997, Cronin et al., 2008).

In conclusion, whilst the strength of NRs is the potential for the inclusion of a breadth of studies and evidence, it is good practice to demonstrate a methodological approach to literature searching. Although there is no strict guidance on how to interpret findings, it is possible to ensure a comprehensive search strategy, which aims to deliver a representation of the publish papers, which meets the aims and objectives of the review (Collins and Fauser, 2005).

2.4 Methods

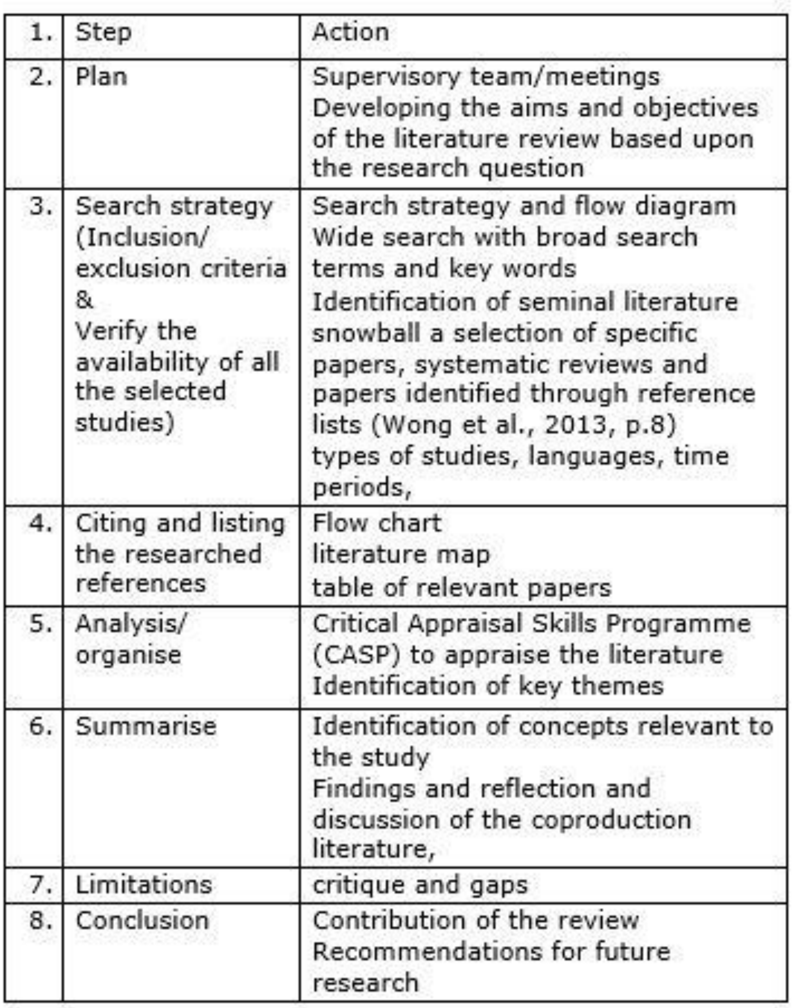
2.4.1 Methodological Framework

Whilst a methods section is not compulsory in a NR, it is good practice to describe the steps undertaken for the literature search (Greenhalgh, Wong, Westhorp et al., 2011, Ferrari, 2015, Greenhalgh et al., 2018). Justifications for using the principles of a NR were that it enabled the management of a significant number of papers, and the subsequent analysis of copious amounts of data. I prepared for the review, following the steps outlined in Table 5 "Stages of the narrative review" (Wong et al., 2013, Ferrari, 2015, Creswell and Creswell, 2018). This ensured that the NR was undertaken using a structured and robust process, to search and to identify the most relevant literature. The first steps in this process were to identify the aims and objectives and develop the search strategy.

NR methods can be perceived as flawed, and therefore it was important to explain the theoretical framework of the NR, and how the conclusions contributed to existing theory (Baumeister and Leary, 1997). The following steps were undertaken, for searching and reporting the literature:

- Searching strategy: databases, keywords
- Inclusion/exclusion criteria: types of studies, languages, time periods, others
- Verify the availability of all the selected studies
- Citing and listing the researched references (Ferrari, 2015, p.232)

and some of the phases suggested by Wong et al. (2013) were added to identify integrate, organise and summarise any identify any significant limitations, (Creswell and Creswell, 2018) and then used an exploration of this literature to frame the subsequent study. These steps are presented in Table 5,



1.	Step	Action
2.	Plan	Supervisory team/meetings Developing the aims and objectives of the literature review based upon the research question
3.	Search strategy (Inclusion/ exclusion criteria & Verify the availability of all the selected studies)	Search strategy and flow diagram Wide search with broad search terms and key words Identification of seminal literature snowball a selection of specific papers, systematic reviews and papers identified through reference lists (Wong et al., 2013, p.8) types of studies, languages, time periods,
4.	Citing and listing the researched references	Flow chart literature map table of relevant papers
5.	Analysis/ organise	Critical Appraisal Skills Programme (CASP) to appraise the literature Identification of key themes
6.	Summarise	Identification of concepts relevant to the study Findings and reflection and discussion of the coproduction literature,
7.	Limitations	critique and gaps
8.	Conclusion	Contribution of the review Recommendations for future research

Table 5: Stages of the narrative review (Wong et al., 2013, Ferrari, 2015, Creswell and Creswell, 2018)

2.4.2 The Search Strategy

The literature search started by using key words, and then used those key words to search all major databases such as CINAHL, EBSCOhost: Regional Business News, Business Source Premier, SPORTDiscus, The Nation Archive, eBook Collection (EBSCOhost), MEDLINE, CINAHL Plus with Full Text, Child Development & Adolescent Studies, European Views of the Americas: 1493 to 1750; and those found through

NUSearch, which is an online library discovery tool of books, journals, databases (University of Nottingham, 2021) (see Appendix 3 For examples of searches). Google Scholar was used to locate full papers which were not available within these data bases. Papers were also searched which were cited in other papers, and which had not been picked up on any of the other databases.

- Co-Production
- Coproduction
- Cocreation
- Co-Creation

Further searches were undertaken which included combinations of the following terms

- Social Capital
- Health*
- Shared-decision
- Social Deprivation
- Health Inequality

A further search was undertaken for papers about chronic oedema and lymphoedema, which included European and American spelling

- Lymphoedema
- Lymphedema
- Chronic Oedema
- Chronic Edema
- Oedema
- Edema
- Swelling

All types of study qualitative, quantitative, systematic review, published and unpublished papers in English from 1950-2021. This included editorials and narratives if appropriate. All the above terms were used to ensure full exploration of databases, repeated searching led to several papers appearing recurrently and no terms were excluded. This iterative process continued until it did not generate any new studies. I systematically screened the literature, and all abstracts were read to ensure appropriateness, and excluded any which were not related to the research question. The search strategy is outlined in Appendices 1 and 2.

2.4.3 Data Extraction and analysis of included papers

The 152 papers, identified as relevant, were systematically screened, and can be found in the appendices 1-5. This was in terms of initially reading the abstract, discarding those which were not relevant. I used the Critical Appraisals Skills Checklists (CASP) (Nadelson and Nadelson, 2014, Clinical Appraisal Skills Programme (CASP), 2020, Long, French and Brooks, 2020), Systematic Review Checklist and CASP Qualitative Studies Checklist, to ensure a standardised approach to appraising the literature. I used the PRISMA (Moher, Liberati, Tetzlaff et al., 2009) flow diagram to demonstrate the steps taken to discern the eligible studies:

- Records identified through database searching 1997-2021 (n = 475),
- Additional records (n=31), identified through other sources (including papers pre-1997) (n=506)
- Records after duplicates removed (n = 380)
- Records excluded (n= 77)
- Full-text articles assessed for eligibility (n = 307)

- Studies included (n=152).

These papers are relevant in terms of the following:

- Exploring the definitions and concepts around coproduction involvement of service-users in co-producing their healthcare, from business and management, public administration, and healthcare
- The exploration of socioeconomic position, SDH and social capital, in relation to coproduction
- Social capital and health
- Coproduction in relation to shared-decision making between professionals and service-users.
- Exploring the contradictions and limitations of the coproduction literature, including any of the relevant chronic oedema literature
- Relevant theory, including PPI

All of the selected papers were inputted into an excel spreadsheet and analysed and categorised into emerging themes (Braun and Clarke, 2006, 2012)(Appendix 5):

- Coproduction/Business
- Coproduction/Health,
- Coproduction,
- Health, Health/Shared-decisions,
- Health/LTCs,
- Social Determinants of Health,
- Social Capital,
- Social Capital/Health,
- Coproduction/ Cocreation,
- Coproduction/Innovation,
- Coproduction/ Marketing,
- Coproduction/Public Administration,

- Coproduction/Policy,
- Coproduction/Social Capital,
- Coproduction/Value,
- Coproduction/Public Services,
- Coproduction/Social Determinants of Health
- Coproduction/Health/Chronic Illness, Coproduction/Health/Innovation and Coproduction/Expert Patient.

This was demonstrated in the Literature map (Greenhalgh et al., 2004) (Figure 1) and included a table of selected papers most relevant he the study (Appendix 5).

2.4.4 Literature map

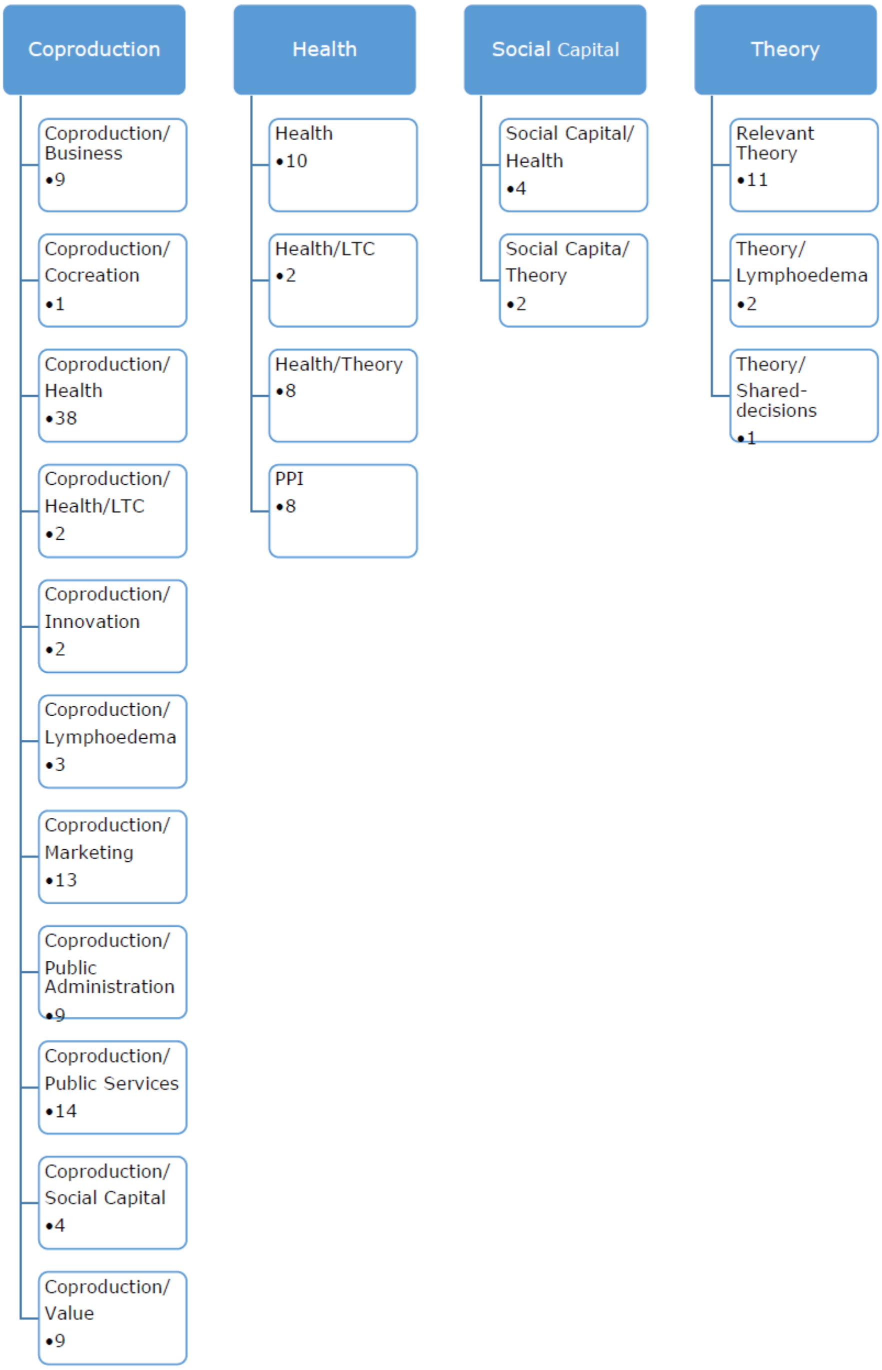


Figure 1: Literature Map of identified papers

2.5 Results

2.5.1 The emergence of coproduction as a concept: relevant definitions

The intention of this NR was to explore the origins and chronology of theories of coproduction, from business and management; and how these emerged this in terms of the relevance of coproduction within public services, and the theories and perspectives which are specifically relevant to healthcare.

When Ostrom (1996) identified that the participation of those involved with using a service, whether public or private is imperative, they suggested that coproduction reflects a dynamic and transformative relationship between customers and firms those involved, regarding their contributions to the development and delivery of a product or service. Moreover, this relationship can lead to a better design, maintenance and sustainability of services when these contributions of the complement each other. Even more important is to recognise the factors which might risk the failure of a co-producing relationship (distribution of roles, deception etc.). The literature on coproduction may be difficult for service-users to navigate without a succinct definition, and several definitions were identified as relevant to this NR (Table 6):

Authors	Year	Definition	Key factors
Lovelock and Young	1979	“If customers assume a more active role in the service production and delivery process, they effectively remove some of the labour tasks from the service organization.	Active role, benefits, exchange of resources

		There may be benefits for both consumers and service organizations”. (P.177)	
Brudney and England	1983	“Coproduction is considered the critical mix of activities that service agents and citizens contribute to the provision of public services” (p.59)	Involvement, quality
Morgan and Hunt	1994	“Successful relationship marketing requires relationship commitment and trust” (p.20) and “activities directed toward establishing, developing, and maintaining successful relational exchange” (p.34)	Trust, relational exchange, reciprocity,
Ostrom	1996	“Coproduction is a process through which inputs from individuals who are not “in” the same organization are transformed into goods and services” and “Coproduction implies that citizens can play an active role in producing public goods and services of consequence to them” (Ostrom, 1996, p.1073)	Active role
Bettencourt et al.	2002	“Client co-production refers to the range of client collaborative behaviors that contribute to more optimal knowledge-based project	Relationships, sharing, knowledge, goals

		solutions, effective working relationships with the KIBS firm, and increased likelihood of goal achievement" (p. 102)	
Vargo and Lusch	2004	The customer becomes primarily an operant resource (coproducer) rather than an operand resource ("target") and can be involved in the entire value and service chain in acting on "operand resources". (p.11)	Resources (operant and operand)
Lusch and Vargo	2006	"The customer is always a co-creator of value" (p.284).	Value, cocreation
Bovaird	2007	"We define user and community coproduction as the provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions" (Bovaird, 2007, p.847)	Long-term relationships, exchange of resources
Boyle and Harris	2009	"Co-production is central to the process of growing the core economy. It goes well beyond the idea of "citizen engagement" or "service user	Equal partnership, knowledge and skills

		involvement" to foster the principle of equal partnership" (p.12)	
Freire	2010	"co-production asks people's help, using their capacities to deliver public services in an equal and reciprocal relationship between professionals and the *core economy* (family, neighbourhood and community), shifting the balance of power, responsibility and resources from professionals to individuals" (p.3)	Reciprocity, responsibility, power
Piller, Ihl and Vossen,	2010	"Customer co-creation is a multi-faceted phenomenon" and an "active, creative, and social process, based on collaboration between producers (retailers) and customers (users)" (p.10).	
Jacob and Rettinger	2011	"Customer co-production is seen as a component of co-creation of value. It is distinct from co-creation of value even though it is nested within this concept". (p.1)	Value, cocreation, sharing, information
Mccoll-Kennedy	2012	"Coproduction is participation in relatively direct service provision activities, such as self-service, service design, and new service development."	Participation,

		(p.377)	
Ewert and Evers	2014	"co-production as a notion that refers to exchange relationships that include several dimensions of interaction (for example., dialog, practical matters, and cooperation" (p.427)	Reciprocity, relationships
Palumbo	2015	Coproduction of care – usually dealt with in terms of user empowerment, involvement, and/or engagement	Empowerment
Voorberg et al.	2015	"Co-production is being considered as the involvement of citizens in the (co-)implementation of public services" (p. 1347)	Implementation, exchange of resources
Mccoll-Kennedy	2017	"Coproduce is defined as health care customers assisting with redesigning the treatment programs and reconfiguring the composition of the health care customer's medical team" (p.57)	Redesign
Oertzen et al	2018	"In services, co-creation manifests itself in different forms depending on the phases of the service process (co-ideation, co-valuation, co-design, co-test, co-launch, co-production	Phase, cocreation, context

		and co-consumption) and is influenced by a contextual, multi-actor network". (p.657)	
Batalden	2018	"Coproduction of health describes the interdependent work of users and professionals who are creating, designing, producing, delivering, assessing, and evaluating the relationships and actions that contribute to the health of Individuals and populations." (p.2)	creating, designing, producing, delivering, assessing, evaluating, relationships
Palmer et al	2019	"Participatory methods increasingly used in healthcare improvement coalesce around the concept of coproduction, and related practices of cocreation, codesign and coinnovation." (p.247)	Codesign, participation, quality improvement
Marston et al	2020	"The coproduction of health, whereby health professionals work together with communities to plan, research, deliver, and evaluate the best possible health promotion and health-care services" (p.1676)	plan, research, deliver, evaluate

Table 6 Definitions of coproduction which are useful and relevant to this study

Historically, the first interpretation of coproduction was the shift in customer roles. Lovelock and Young (1979), explored the role of customers in increasing firms’ productivity; customers’ adopt roles which employees previously provided, for example self-service supermarkets. This also changed the focus from a goods-dominant environment to one which is service-dominant; placing customer choice and their experience of consumption first, as opposed to a focus on the actual goods/products being manufactured.

This shift was perceived as a “new paradigm in marketing” (Chien and Chen, 2010, p.185) whereby the development of the “value-chain” (Porter, 1985, p.33) observed a progression from craftsmanship, mass production, mass consumerism to a focus upon products, and market orientation (Piller, Ihl and Vossen, 2010), to the satisfaction of customers as the focus. Furthermore, a plethora of literature attempts to provide a succinct definition and clarify the differences between coproduction and cocreation, as these concepts are frequently discussed together and used interchangeably (Needham, 2008, Hardyman, Daunt and Kitchener, 2015, Voorberg, Bekkers and Tummers, 2015).

2.5.2 The Paradigm shift: Business, Management and Marketing literature

Historically, within the business, management and marketing literature, many original papers did not mention coproduction (or cocreation), and focused upon the productivity of services (Lovelock and Young, 1979). The emphasis was upon a greater understanding of the consumers’ behaviour, to increase productivity and profits within firms. This also posed a challenge given the heterogeneity of customers’ behaviours, socioeconomic position and cultural backgrounds. Lovelock and Young (1979) outline 7 steps to take into consideration to avoid “insensitivity” to customers, and nurture customers’ relationship with the firms. These steps were aimed at developing trust, through building relationships; understanding customer habits and behaviour; understanding the determinants of behaviour and what influences customer choice; pre-testing services; creating opportunities to teach consumers; promote the benefits of the services; and evaluating this process to learn. Whilst this process enables the opportunity for customers to participate with the firm, it is notably within a paternalistic relationship, with the firm continuing to maintain a hierarchical position over the customer.

Despite this power dynamic, the shift indicated the importance of the involvement and experience of customers as key to successful businesses, both manufacturing and service-providers (firms). This recognised the customer as inherently part of the production process, through a more active, participatory role, rather than resistant to change (Brudney and England, 1983). This also considered the symbolic and emotional experience of buying products or using services (Holbrook and Hirschman, 1982), recognising how cognition and emotion affect consumers behaviour. Fournier (1991) explored the experiential view of consumption, in terms of emotions, context, symbolism and non-utilitarian value; emphasising the value which consumption creates, rather than the product/service alone. This demonstrated the changing perspective acknowledging customers' prerogative to determine value; in terms of what a firm can offer, whether through a tangible product or the experience of using a service. Moreover, this motivates customers to participate, and creates lasting relationships between customer and producer (Morgan and Hunt, 1994)

Morgan and Hunt (1994), built upon the idea of value when they explored the development of successful relationships between firms and customers, and suggested that these depend upon mutual trust and commitment. They refer to “relational exchange” (Morgan and Hunt, 1994, p.22) in terms of the description by Dwyer, Schurr and Oh (1987), which suggests that the coproducing process is ongoing and long-lasting. Morgan and Hunt describe 4 types of relational exchanges, (supplier partnerships; lateral partnerships; buyer partnerships and internal partnerships) (Morgan and Hunt, 1994, p.21)

However, their focus was ultimately upon trust and relationship commitment, rather than increasing firm’s productivity or customer participation. The emphasis is placed upon any endeavour which creates, cultivates and sustains successful relational exchanges. Trust and commitment are paramount because, they facilitate the preservation of relationship investment with “exchange partners” (Morgan and Hunt, 1994, p.23) (customers). The long-term benefits of staying with existing customers, suggest that they will not act opportunistically. Therefore, the development of such relationships is seen to promote efficiency, productivity and cooperation, leading to more satisfaction for the customer, and greater success within the firm. Relationship commitment is important because nurturing a valued relationship is considered an intrinsic part of developing this partnership.

Most contemporary definitions of coproduction reject the outdated and historical view of customers as passive (Brudney and England, 1983), with little involvement in the design and delivery of the services they use. This shift is also seen to reflect the concept of coproduction as a way of cocreating value. Ramirez (1999) adds that value also occurs in the exchange, not only consumption, and therefore reiterates the relevance of a relationship between the customer and firm. Furthermore, this is an opportunity to accumulate customer knowledge, and therefore customers are perceived as a source of intelligence and competence (Prahalad and Ramaswamy, 2000).

Bettencourt, Ostrom, and Brown et al. (2002) advanced these ideas further in their work on knowledge-intensive businesses (KIBs), by suggesting that the service they provide satisfies the unique needs of their customers. They suggest that the specific skills and knowledge of customers, and their "knowledge transfer" (Bettencourt et al., 2002, p.101) optimises the opportunities for a valuable experience for both. This generates opportunities for customers and firms to accumulate knowledge, innovate and disseminate together. However, they also recognised that not all clients can coproduce, and therefore the firm seeks out the customers most likely to remain focused on their mutual goal.

Bettencourt et al., (2002) also suggest is that it is essential for customers to take a leading role in coproduction interactions. They outline 7 customer responsibilities essential to successful coproduction; communication and openness; shared-problem solving; tolerance; accommodation; advocacy; involvement in project governance and personal dedication (Bettencourt et al., 2002, p.103). This offers a dichotomous perspective to the customer/firm relationship proposed by Lovelock and Young (1979). Whilst some of Lovelock and Young (1979) 7 steps align to Bettencourt et al's 7 responsibilities, Bettencourt et al., (2002) suggest that customers need to acknowledge and respect that they are equally accountable; the relationship relies upon a degree of commitment, and equality between the customer and the firm. Moreover, Lovelock and Young (1979) and Bettencourt et al., (2002) infer there is a hierarchical relationship, which favours the firm.

Gibbert, Leibold and Probst (2002) further the idea that customers need to possess the knowledge and skills to fulfil the assumptions of coproduction. They outline 5 styles of "customer knowledge management" (Gibbert et al., 2002, p.464). First is "prosumerism", where the customer is also the producer; "team based-co-learning", are interactions which add value; "mutual innovation", whereby customers and firms work closely together, using customer knowledge to integrate innovation activities; "communities of practice, which involves putting firms together with expert customers; and "joint intellectual property" whereby the long-term relationships are nurtured as part of a shared innovation and cocreation process (Gibbert et al., 2002, p.465). The function of these styles to access invaluable knowledge about customers' preferences. This is of value because it offers important insights, which firms capitalise upon. However, this is dependent upon how well customers can coproduce, given the diversity of their socioeconomic context/backgrounds, and the degree to which they see the value in these long-term relationships.

The heterogeneity of customers characteristics and contexts, is relevant, in terms of the assumption that customers are always knowledgeable and skilled, or competent enough to be involved with the process of innovation (Prahalad and Ramaswamy, 2000). Prahalad and Ramaswamy (2004b) also advocate that coproduction interactions and activities should be risk-assessed, to enable customers to accept responsibility for their involvement and contribution. They concluded that there is a constant need to understand what drives and motivates customers to participate, their social and psychological attitudes and behaviours, knowledge and skills. Therefore, the only way to cocreate value is for firms to engage with their customers and service-users and focus on the quality of those interactions (Prahalad and Ramaswamy, 2000, 2004b, a).

A significant contribution to the discussion of customers as a source of information and knowledge, derives from the service-dominant literature, and specifically the work of Vargo and Lusch (2004). The customer is perceived as a co-producer of a service, in terms of their units of "relational exchange" or their "operant resources"; the "tacit" or intangible, skills and knowledge (Vargo and Lusch, 2004, p.5). These represent the economic denominator, and the unit of exchange within the coproducing relationship; and the "operand resources", or the outputs, tangibles, raw materials, goods and products, including financial profits (Constantin & Lusch (1994) cited in Vargo and Lusch, 2004, p.2). These units of exchange are relevant during the planning, designing and producing stage, and determine the cocreation of value, at the point of consumption. They perceived this as a new paradigm, the "new dominant logic" (Vargo and Lusch, 2004, p.2) and value, for the customer, is no longer determined by the acquisition of goods and products. Value is inherent in the process and the transfer of skills and knowledge. The customer is perceived as an active coproducer, through their developing relationship with the firm, specifically in terms of the application of their "operant resources", for the firm's benefit.

The perspective by Vargo and Lusch (2004) also assumes that individual customers are actively and consciously engaged with the process of coproduction (Prahalad and Ramaswamy, 2004b, a). This infers there is shared learning and communication between firms and customers, and that both are equal "problem solvers" with open lines of communication. Korkman (2006) also suggests this creates value embedded in customers' practices, enhanced through positive interventions within the context of interaction. Fundamental to Lusch and Vargo's (2006) theory is that this value is only created at the point of consumption, not through design or manufacturing, therefore:

> *"the customer is always a co-creator of value"*
> *(Lusch and Vargo, 2006, p.284)*

Furthermore, Payne, Storbacka and Frow Payne, Storbacka and Frow (2008) suggest this experience defines value to the customer. They place importance on what the customer learns from this process, and how this can lead to changes in attitudes and preferences; if a customer can learn from good experience, they will remain a loyal customer. They describe 3 types of learning: remembering (attention), internalization (emotion) and proportioning (reflection) (Payne et al., 2008, p.88) and it is the latter which is relevant to how the customer reflects upon on their experience, and how the anticipation of value relates to their lives. Therefore, firms find opportunities to create value, by understanding the customers' preferences.

Payne et al. (2008) also suggest that the opportunities for learning are through innovation and technological breakthroughs, transformations in business dominant logic, for example, self-service/self-build furniture and individualisation of services, which reflect customers' preferences and everyday life. This suggests that insight is needed into customers' preferences through listening, customising and cocreating value with customer, through coproduction activity. The service-dominant logic becomes the “operant resource” and process of interaction and transaction, is referred to as a “critical encounter” (Payne et al., 2008, p.90); those instances which have a profound effect on the cocreation of value, whether positive or negative. This may also contribute to managing customer expectations because outputs from the coproduction process may not be immediate, or lead to a satisfactory coproduction experience. Furthermore, emphasis is placed upon the appropriate division of activities; this reflects Bettencourt et al’s (2002) focus upon customers’ responsibility and accountability, which emerges as a pivotal to coproduction theory.

Etgar (2008) also presents a coproduction framework with an emphasis upon an “explicit consumer strategy” (Etgar, 2008, p.105) which emphasises understanding customers’ preferences and behaviour. There are 5 stages within the framework; the development of antecedent conditions; development of motivations which prompt consumers to engage in coproduction; calculation of the coproduction cost benefits, activation when consumers become engaged in the actual performance of the co-producing activities; and generation of outputs and evaluation of the results of the process (Etgar, 2008, p.99).

Moreover, Piller et al. (2010)’s work focuses upon customer satisfaction and “customer-centric” initiatives (Piller et al., 2010, p.6). They suggest that cocreation and customer participation is a complex social process, based on 3 elements; customer autonomy; the firm-customer collaboration; and the stage of innovation. The emphasis upon customers’ experience suggests that it is not only relevant to understand their preferences and behaviour; it is also essential to understand the cultural context in which coproduction takes place, and therefore the behaviour of both the customers and the firms. Moreover, understanding customers' "cultural value orientation" through service-user participation and interactions with the firm (Chan, Yim and Lam, 2010, p.52) leads to economic and psychological benefits. This infers that better outcomes, and fewer performance risks, can be achieved by increasing the levels of customisation and control, and shifting power to the service-users, individually and collectively. This includes developing strategic, long-term relationships with service-users, where shared-decision making should cocreate value, and reduce uncertainties (Chien and Chen, 2010). This enables the firm to gain greater insight into customers' social and cultural background, to cocreate opportunities for a more positive coproducing relationship.

2.5.2.1 Structural position and conflict

However, this also raises important questions about the structural position of customers, and their "operant" and "operand resources" to engage within a coproducing relationship and be responsible and accountable. Lehrer, Ordanini, DeFillippi et al. (2012) highlight the importance of "operant resources" and the relationship between the customer and the firm. In their study, using semi-structured interviews with (KIBS) (Lehrer et al., 2012, p.499), they focused upon firm organisation, knowledge coproduction processes with customers, and how knowledge and competences were strategically developed by the firm. They suggest that the "intermediate stage" (Lehrer et al., 2012, p.501) of coproduction, is a time of heightened innovation and creation, and both the KIBS and the customer can benefit from separation. This is due to a risk that customers will interfere, and make "unwarranted assumptions" (Lehrer et al., 2012, p.504) which delay processes. However, whilst the "operant resource" of the customers is required, the authors infer that customer may not always possess those required to coproduce at specific points, which risks undermining value in their relationship. They concluded that coproduction interactions are not always transparent or consistent; often only interactions at the beginning and the end stage (service delivery) demonstrate genuine coproducing activity.

This challenges the assumption that coproduction activities always cocreate value, and suggests that coproducing relationships are a source of create conflict. Lehrer et al. (2012) also support the idea that "value-cocreation" may enable an exchange of knowledge and learning, with a potential for lasting relationships, however it may also lead to conflict is a revamping of coproduction. Furthermore, whilst cocreation and value are perceived as intrinsic aspects of collaborative processes, it is naïve to assume that this is always a positive process or without "adverse effects" (Lehrer et al., 2012, p.500). The cocreation of value cannot be assumed; coproduction interactions fluctuate, dependent on the motivation and skills of the customer, the stage of coproduction, and the duration of the co-producing relationship. Ultimately, any benefits and value are perceived to occur at the point of delivery and consumption.

Ngo and O'cass (2013) define coproduction in a similar way to Lehrer et al. (2012); that customer participation is dependent upon the extent that they wish to engage. Their survey of service firms within Australia, explored the innovating capabilities of firms to improve their quality and service, when engaging in customer participation. They concluded that the involvement of customers enhanced the quality of a firm's service; supporting the idea that the active participation of customers, with firms can lead to better outcomes. The authors investigated which activities with customers lead to increased productivity, and they considered how firms interact with customers, to construct their own consumption, and co-create value. This is referred to, by firms, as "what you can do with us", in response to customers' "unique and changing" needs (Ngo and O'cass, 2013, p.1136). Furthermore, the authors also inferred that customers bring risks to the relationship because of the unpredictability of cocreation, a similar finding to Lehrer et al. (2012) and Piller et al.(2010). The authors concluded that a participatory relationship does not always drive firm performance and does not necessarily affect the productivity of the firm.

2.5.2.2 Trust and Loyalty

The findings from the literature review and empirical study (a survey of a self-service coffee shop in Taiwan) by, Wu, Huang, Tsai et al.(2013) suggested that the benefits of coproduction are not always related to increased productivity and reduced costs, more in terms of relationship quality and loyalty. They refer to coproduction as a behavioural construct, through the physical and mental contribution customers bring to the design, production and delivery of a service. The authors reported that trust contributes to loyalty, as it is perceived to affect future behaviours; service quality is described as the driver for relationship quality, because of the potential relational interaction; and communication quality occurs through relationship quality because of the potential for a long-term relationship (Wu et al., 2013, p.1074). They concluded that trust, loyalty, service quality and the "relational exchange" lead to value coproduction which occurs at the point of consumption or delivery.

Nahi's (2016) systematic review explored customers from "base of the pyramid" (Nahi, 2016, p.416); low income communities where there may be inequitable power relationships. These customers were perceived to be more at risk of coercion or exploitation, due to their lack of socioeconomic resources ("operand resources"). However, Nahi (2016) also perceives that cocreation enables opportunities to empower those in a lower social position. It has both business and societal value, through the inclusion of the "operant resources" of socially deprived communities. Nahi (2016) suggests that cocreating value, through coproduction, can contribute to addressing the structural drivers of poverty and social position.

This concern with the structural drivers of coproduction is pertinent and relevant to the empirical study. This is especially in terms of how coproduction can lead to "value co-creation" (Hardyman et al., 2015 pp.91), beyond the focus of a goods-dominant logic, to a service-dominant logic. This is where the business and management literature shifts and overlaps with the public sector literature, with a growing concern for the context in which customers reside and/or their socioeconomic position.

2.5.3 Coproduction within the public sector

The idea of social position and social context is specifically relevant when exploring the emergence of coproduction theory within public services, and much of this literature is concerned with collective coproduction and “citizens”, as rather than the individual, or “customer”. When examining the definitions of coproduction it is imperative to explore the drive and commitment of citizens (Bovaird, 2007) to a coproducing relationship; recognising where they are situated in society, and the social networks and capital available to them (social, economic, cultural) (Bourdieu, 1984). The value of coproduction, as opposed to cocreation, relates to the potential longevity of relationships, trust and loyalty (Bovaird, 2007) and how coproduction activity creates value.

Within public services literature an emphasis is placed upon equality within a coproducing relationship, based upon the social construction of relationships, and inequitable power relations between service-providers and citizens. This inequity highlights issues about trust, decision-making shared goals, autonomy, and the “operant resources” customers/service-users possess for coproducing (Ostrom, Bitner, Brown et al., 2010, Hibbert, Winklhofer and Temerak, 2012, Jacob and Rettinger, 2011, Fledderus, Brandsen and Honingh, 2014).

Bovaird and Loeffler (2012) suggest a useful framework which identifies the specific phases of coproduction, rather than an overarching term of coproduction; “co-planning”, “co-design” “co-prioritisation”, “co-financing”, “co-management”, “co-delivery” and “co-assessment” (Bovaird and Loeffler, 2012, p.1124). The authors also discuss how quality of life can be improved by using certain services, and how this value can also benefit their families, friends and carers, now and in the future. They discuss the concept of social responsibility, which is dependent on the consciousness of all citizens, for example community or environmental issues. They suggest that this positively influences individual motivation for coproducing.

Importantly, they emphasise that a coproducing relationship should be equal and mutually beneficial (Bovaird and Loeffler, 2012, Bovaird et al., 2015, Loeffler and Bovaird, 2016). Whilst the authors perceive reciprocal relationships as fundamental, with a focus on improved outcomes, lower expenditure and the exchange of each other's "operant resources", however they do not perceive long-term relationships as imperative.

A relevant systematic review by Voorberg et al. (2015) explored the nebulous definitions of coproduction and cocreation, as terms and concepts relating to opportunities for citizen participation in innovation. They suggest "co-creation" is a more appropriate term for citizen engagement in the planning, design and delivery of service innovation, as a "co-initiator" or "co-designer"; whereas "co-production" applies at the point of delivery, implementation and consumption as the "co-implementer" (Voorberg et al., 2015, p.1347). The authors articulate well the complexity and difficulties with both concepts. Consistent with Bovaird and Loeffler (2012), Voorberg et al. (2015) also acknowledge that both terms are interchangeable, however they their importance relates to a specific stage of the coproduction process.

Voorberg et al. (2015) also reiterate that the coproduction process should be open and transparent between the relevant stakeholders; building relationships which address the specific needs of individuals and society, with insight into what motivates citizens to coproduce (Voorberg, Jilke, Tummers et al., 2018). Bovaird and Loeffler (2012) also consider the barriers which prevent coproduction opportunities, using examples of case studies within the UK. They cite funders and commissioners; difficulties in generating sound evidence to demonstrate the value of coproducing; enabling the development of professional skills amongst non-experts; risk aversion due to the inherent risks perceived with the unpredictable behaviours of service-users; and issues related to power dynamics, due to the status and control of professionals. These together necessitate a culture change, before the real value of coproduction is realised

Voorberg et al.(2015) also suggest that the role of the citizen should be more fully explored, to appreciate the value of citizen involvement; the role diversity of stakeholders; and particularly the political and cultural context. The structural context of coproducing relationships is a recurring theme within much of the public sector literature. This in relevant for citizens who are more vulnerable and who may be at risk of exploitation, yet expected to be accountable for their participation (Bettencourt et al., 2002, Cova and Dalli, 2009); therefore greater effort should be made to involve these citizens in coproducing activities (Vanleene, Voets and Verschuere, 2017). Moreover, this reiterates that citizens, who may not contribute to a coproduction relationship because of a lack of "operant" and "operand resources", are at risk of underrepresentation. In a time when public expectations are constantly increasing, coproduction activities are under greater scrutiny in terms of what they can deliver. Moreover, whilst cost savings can be made in the coproduction process, the process is not without cost (Bovaird and Loeffler, 2012), and therefore services must be designed robust measurable outcomes, to ensure their success and sustainability.

The pursuit of value creation and relationship building is perceived as a key motive within the public sector. Therefore, there are also emotional and psychological risks which citizens may mediate, to maintain value. This returns to the concept that within coproduction relationships citizens should also adopt or accept certain responsibilities (Bettencourt et al., 2002). Whilst socio-cultural circumstances may be the impetus behind citizens' ability or desire to coproduce, only the citizens determine that value or benefit of the experience. This is relevant, given the paucity of papers which do not consider fully the implications of coproduction in populations where there may be an inequality in terms of operant and "operand resources". It cannot be presumed that all service-users are have the skills and knowledge outlined by Bettencourt et al. (2002) and Gibbert et al. (2002).

Etgar (2008) proposes that those most likely to coproduce have a higher socioeconomic position in society; are better educated; can adequately mitigate for any risks; and have more advanced communication skills. This is in addition to other SDHs, such as age, gender, immigration status, social capital and geographical context, social settings, cultural beliefs, ethnicity and religion consciousness and traditions (Alford, 2002, Etgar, 2008, Jacob and Rettinger, 2011, Nahi, 2016, Thijssen and Van Dooren, 2016, Lwembe, Green, Chigwende et al., 2017) which influence why, and how they coproduce. Moreover, social position, social networks, and social capital (Bourdieu, 1984) are perceived as the drivers for participation in coproducing relationships and activities. Therefore, social capital, and characteristics of service-users involved in the coproduction process is critical (Bovaird and Loeffler, 2012) and is a prerequisite for sustaining relationships (Voorberg et al., 2015).

Therefore, from a structural position the distinction between individual, group and collective coproduction is relevant, especially where citizens offer their services voluntarily

(Brudney and England, 1983, p.59, 63). This may influence the extent to which a citizen feels empowered or proactive towards coproducing (Durose, Needham, Mangan et al., 2017). Again, as with Bettencourt et al. (2002), there is a focus upon service-users' social responsibility and consciousness of users (community, environmental etc.) rather than as an individual. This is particularly in terms of how coproducing and how cocreated value may benefit their extended social networks. This reflects the importance of understanding the typology of coproducers; the social identity of those involved, and opportunity to involve those citizens perceived as marginalised (Renedo and Marston, 2011, Marston, Renedo and Miles, 2020).

These factors may also strengthen the potential for coproducing relationships to increase social contacts, social esteem and status (social capital) (Ostrom, 1996) through developing new skills, which influences service-users capacity to coproduce (Alvarez, Kawachi and Romani, 2017). Nabatchi, Steen and Sicilia (2017) suggest that it is necessary to define who, when and what is involved in coproduction activities and interactions. They acknowledge the complexity of defining coproduction, and suggest detailed definitions may be more useful, to reflect whether they apply to individuals and/or groups.

The study of a community development project in a socioeconomically-deprived area of Belgium by Vanleene, Voets and Verschuere (2017) also suggested that reasons for coproducing must also be acknowledged as personal and circumstantial, and therefore it is imperative to understand what motivates citizens. This is especially in terms of the ease, and perceived importance of the coproducing activity, and the extent to which it is a “normative purpose” (Vanleene et al., 2017, p.115), or part of their existing belief system. The authors refer to previous studies which also suggest the relevance of individual hopes and self-esteem (Alford, 2002, Van Eijk and Steen, 2014, Vanleene et al., 2017).

Much of the public sector literature focus is upon the structural position and context of coproduction, and the demographic and socioeconomic factors, including “rewards”, which influence whether a citizen or citizens engage (Voorberg et al., 2018). The authors discussed how individual and community coproduction may benefit future relationships and behaviours (Bovaird and Loeffler, 2012), and promote the value of social networks, relationships, trust and reciprocity. However, they do not fully answer important questions about what citizens gain in return, or how inequitable power relationships are addressed (Meijer, 2016). Additionally, coproduction should not be construed disingenuously, as an outcome, more a way to achieve outcomes (Tuurnas, 2016). This evident in the examples which are drawn from healthcare, found frequently in both business and management, and the public services literature (see Appendix 5). Therefore, this leads appropriately to an exploration, and consideration of the coproduction theories explored and applied to a healthcare context, and how these emerge as the most contemporary literature in this NR.

2.5.4 Coproduction within Healthcare

Coproduction within healthcare, emerged from the United States of America’s (USA) social care system, the Civil Rights Movement (Realpe and Wallace, 2010), and social and political rights movement, during the first half of the 20th century

(Beresford, 2019). Within the UK, the perceived exclusion of service-users from policy decision-making, in particular the rights and voice of the disabled and mental health service-users (Beresford, 2019), led to coproduction through the emergence of PPI. PPI arose during internal markets' and NHS reform in the 1980's (Freire and Sangiorgi, 2010), following the abolition of the 1970's Community Health Councils (CHCs). Subsequent health reform and modernisation of the NHS in the 1990's and early 2000's, led to service-user involvement through Patient Advice and Liaison services (PALS) (Hogg, 2007, p.130) which advocates with service-users regarding complaints and concerns about the management of healthcare organisations and services. The CHCs, which advocated for the concerns locally, were replaced by Commission for Patient and Public Involvement in Health (CPPIH), which was subsequently replaced by local involvement networks in 2006, (LINks), (Hogg, 2007). The purpose was to redress recognised power imbalances, giving service-users a platform to raise concerns, or influence care service provision.

The shift of rhetoric through these reforms and internal markets within the NHS, led to the rise of understanding service-users as consumers of healthcare. These initiatives, emerged in response to grave failings in the NHS (Ocloo et al., 2021), outlined in a number of government documents (DoH, 1999, DoH, 2008, DoH, 2010, NHS England Public Participation Team, 2017, Realpe and Wallace, 2010). Furthermore, health policy reflected a drive for PPI and recommendations which emphasise shared-decision in terms of:

> *"no decision about me, without me"*
> *(Department of Health, 2010, p.13)*

Coproduction within healthcare is often framed in terms of consultation and providing feedback on the development, planning and evaluation of generic healthcare services, rather than partnerships or long-term therapeutic relationships with health service-providers (Summers and Tudor, 2000, Vinall-Collier, Madill and Firth, 2016). This agenda also includes scrutiny of terms such as “compliance” and “adherence” (Table 2), as value judgements about whether service-users are considered to be “good” or “bad” patients, dependent upon their perceived health behaviour and engagement with self-care (Sointu, 2017). This included the emergence of terms such as “patient-centred care”, “concordance”, “self-management”, “self-efficacy”, “service-provider”, “service-user”, and “shared-decision making” (Batalden, Batalden, Margolis et al., 2016, van Houtum, Rijken and Groenewegen, 2015, von Thiele Schwarz, 2016, Elwyn et al., 2019, Royal Pharmaceutical Society of Great Britain, 1997). However, the definitions of these terms and concepts are challenging, as many continue to be used inconsistently and interchangeably and are frequently misunderstood by service-users (Snowden et al., 2014); these included “intentional” and “non-intentional” service-user compliance; “intentional adherence” and “non-adherence”. Whereas definitions of “concordance” (Snowden et al., 2014, p.47) suggest that service-users are more actively involved, and at the centre of shared-decisions with their health professionals (Snowden et al., 2014, Shay and Lafata, 2014).

However, these definitions either assume, or neglect the motivations of service-users, and these definitions reflected the shift away from all care delivered by service-providers to an emphasis upon “self-care” (Orem, 2003, Vadiee, 2012).

The emergence of the “Expert Patient programme” (DoH, 2001, p.1), appeared to challenge the perceived coercive power dynamic between service-provider and service-user. This is especially relevant in terms of the power dynamic, whereby healthcare providers are considered experts because of their scientific prowess, and “specialist expertise” (Collins, 2014, p.58). Collins’s “relational theory of expertise” (2014, p.49), is a useful theoretical contribution when the expertise of “specialist” of healthcare providers (Timmons and Nairn, 2015) is under scrutiny. Collins (2014) writes about this specifically in relation to those who live with chronic illness, and become “experience-based experts” (Collins, 2014, p.64), The development of tacit knowledge enables service-users to become a “contributory expert” (Collins, 2014, p.64). This definition not only aligns to the historical perspective of the “Expert Patient Programme” (Department of Health (DoH), 2001, p.1), it is also extremely relevant to the concept of coproduction, and the exchange of “operant resources” and tacit knowledge between the service-user and the health professional.

However, tension occurs if a medical condition is perceived as having minimal “scientific capital”, and without available, sufficient, acceptable, or proven treatments, and this uncertainty may lead service-users to question existing power relationships. Service-users may “empower” themselves, and reclaim their “default expertise” (Collins, 2014, p.15), which is the tacit knowledge which service-users employ when they perceive the fallibility of the healthcare professionals “specialist expertise” (Collins, 2014, p.58). When “default expertise” is not validated by health professionals, it causes “testimonial injustice” (Fricker, 2019, p.61), where the credibility of the information and experience that the service-users provide is discredited or undermined. This leads to “expectancy violations” (Burgoon, 1993, p.30), when the service-provider or health professional does not respond in a way, which aligns to the service-user’s or society’s expectations of their professional role.

Furthermore, even if the relational exchange between a service-provider and service-user is seen as positive, this cannot not assumed as evidence of an equitable relationship between service-user and service-provider; their structural position and interpretation of knowledge and expertise may lead conflict. Palumbo and Manna (2018) suggest that such conflict and tension can lead to:

> *“value co-destruction” (Palumbo and Manna, 2018, p.370)*

particularly if the service-users are perceived to have little health literacy, or if the service-providers resist the challenge to a bio-medical model of care; that is care which is focused upon illness and cure, without considering psychosocial factors (Tresolini, 1994).

Whilst this may be a pessimistic perspective, Palumbo and Manna (2018) support the appeal by Brach, Dreyer and Schillinger (2014) and Adinolfi, Starace and Palumbo (2016) for “organizational health literacy” (Brach et al., 2014, p.274). This is defined as how service-users access the knowledge and information, which enables them to navigate care systems easily and to actively coproduce their care. Moreover, further criticisms of service-user involvement within healthcare are that it is tokenistic and disingenuous, with scepticism about the representativeness of service-users involved (Ocloo and

Matthews, 2016), particularly regarding the design and service-improvement. Jacob and Rettinger (2011) also suggests that improvement is essential in settings where coproduction rarely occurs, or when there is a perceived lack of a trusting relationship.

Several authors continue to question the sincerity of coproduction initiatives (Ocloo and Matthews, 2016, Palumbo, 2015, Palumbo, 2016, Palumbo et al., 2016, Palumbo and Manna, 2018, Williams, Robert, Martin et al., 2020). These range from the criticism that the bio-medical model of care remains pre-eminent within healthcare, to concerns regarding the genuine inclusivity of PPI forums, and whether service-users are actually empowered through their participation and involvement (Cooke, Langley, Wolstenholme et al., 2017). There is a suggestion that those with greater health literacy and those who possess the personal characteristics of those most likely to access and benefit from coproductive relationships (Thijssen and Van Dooren, 2016, Etgar, 2008, Alford, 2002). This leads to concerns as to whether all service-users have are capable of developing the required level of awareness of their health, health literacy or self-efficacy to enable a coproducing relationship (Palumbo, 2015, Zarcadoolas, Pleasant and Greer, 2005).

Palumbo, Annarumma, Manna et al. (2019) suggest that health literacy, is a pre-requisite for the cocreation of value in a coproducing relationship, and health policy makers need to consider this in relation to enabling equitable access to care. This suggests that there are specific barriers to the coproduction of care, however of these may be due to service-users active reluctance or disinclination to engage, as opposed to lacking the “operant resources” (Palumbo, 2015, Palumbo, 2016, Palumbo et al., 2019). This is possibly because much of the coproduction literature is perceived to favour those individuals who are viewed as capable and possess the skills and knowledge to engage. The onus of responsibility is upon the service-user (Bettencourt et al., 2002), regardless of whether they are able to fulfil this role. Despite this discouraging perspective, there have been advances in service-user involvement in all aspects of healthcare, for example the "UK Standards for Public Involvement", the National Institute of Health Research (National Institute for Health Research (NIHR), 2019), a UK government programme to support public participation in health research.

Service-user engagement with the health system has implications for practice, research and health policy, particularly the recognition that service-user motivations are not necessarily associated with the known or perceived benefits to their health, and may be due to sociodemographic factors (Chatterjee, 2006). This is in terms of how the SDHs, might explain the difference in health lifestyles, preferences and the implementation of care at home. It is imperative to explore existing healthcare provision in terms of access to healthcare services, and how service-users' economic and financial position (income and employment) may affect their decision-making strategies. This is especially given that the NHS Safer Patient Strategy (NHS England & NHS Improvement, 2019) criteria states that healthcare should reflect the involvement of service-users, and enable choice and individualised care.

Moreover, whilst McColl-Kennedy, Hogan, Witell et al. (2017) perceive coproduction as the involvement of service-users in the design of service and the reconfiguration of healthcare staff; they also perceive coproduction as when service-users "comply with basics" (McColl-Kennedy et al., 2017, p.57) (taking medication, implementing treatments) and the cocreation of value, at the point of delivery/consumption (Lovelock and Young, 1979, Vargo and Lusch, 2004, Lusch and Vargo, 2006, Prahalad and Ramaswamy, 2004a, b) or "co-implementer" (Voorberg et al., 2015, p.1347). This is relevant in terms of goal identification and achievement, and the authors also cite healthcare and LTCs as one example. Despite the limitations of their single case study, McColl-Kennedy et al. (2017) concluded that the most significant factors which drives individuals to coproduce are those associated with Bandura's "Self-regulation theory" (self-observation, judgemental process, self-reaction (Bandura, 1991, p.249). These are the intrinsic and circumstantial motivations which align to existing individual belief systems; the extent to which service-users developed a relationship with service-providers; and the accessibility of information and shared-decision making. A relevant finding was that those individuals and groups, who should be encouraged to participate in coproducing activities are often those as excluded and disadvantaged from coproducing, on the basis of their socioeconomic status and personal characteristics and attributes (Etgar, 2008, Beresford, 2019).

This reflects the idea of a "normative purpose" (Vanleene et al., 2017, p.115), and the expected hierarchical relationship between health professionals and service-users. Furthermore, the concept of "circumstantial support" (Vanleene et al., 2017, p.116), is also the support provided by health professionals, in terms of information and treatment. This promotes the value of the relationship, interaction and communication between the service-user and service-providers (Makoul, 2001, Kaminsky et al., 2009). It also suggests that terms such as “compliance” and “adherence” cannot be oversimplified to service-users “doing as they are told” or simply following instructions. The definition of compliance (Haynes, 1979) is the degree to which someone deviates from prescribed care, and makes the assumption that the health care provider always has superior knowledge. This potentially leads to service-users who do not “comply” being perceived as deviant, and may lead to undermining the potential for positive relational exchange with service-users (Sointu, 2017). This also challenges the authority given to healthcare professionals, where hidden “strategic actions” (Outhwaite, 2009, p.470), when a service-provider uses manipulative communication techniques, to ensure that the service-user “chooses” the intervention, they believe is most therapeutic (Habermas, 1984, in , Baxter, 2001, Vandenburgh, 2004, Greenhalgh, Robb and Scambler, 2006, Outhwaite, 2009, Scambler, 2015).

Therefore, when examining the contributions of service-users to the coproduction of healthcare it is also important to consider several factors. These include service-users’ “operant resources” for example, health literacy (Ewert and Evers, 2014, Palumbo, 2015, Mackey, Doody, Werner et al., 2016, Palumbo et al., 2016, Palumbo et al., 2019) and their “operand resources” (socioeconomic position and social capital); the extent to which these influence their behaviour in relation to their health outcomes; the challenges posed by adequate or inadequate healthcare provision; the assumption that service-users are or can become expert, about, their illness or that of their families (Brandsen and Honingh, 2016), as defined by health professionals; and the power/hierarchy dynamics which can make the opportunities for coproduction less equitable (Bovaird, 2007, Palumbo, 2015, Palumbo, 2016, Palumbo et al., 2016, Palumbo and Manna, 2018).

This is in contrast to the perspective which argues that in coproducing the design and delivery of services, service-users will be empowered, which facilitates a more equal relationship with professionals and clinicians, and better delivery of healthcare (McColl-Kennedy et al., 2017, Elwyn et al., 2019). This is important when considering the needs of individuals living in a context of socioeconomic deprivation, which recognises the unique challenges facing these individuals, when delivering their own healthcare (Greenhalgh, 2009). Greenhalgh (2009a) suggests that this needs to consider the structural inequalities, which might prevent their ability to engage in "self-management".

The idea of coproduction within healthcare, especially within the NHS, may also be difficult for service-users to navigate This is specifically in terms of the degree to which they can influence their choice of care; government rhetoric promotes choice and service-user participation, when for many care provision is a non-negotiable issue (Beresford, 2019), unless they have the "operand resources" to pay privately. It is argued that a further shift in socially constructed power relationships is still required, particularly within healthcare from a bio-medical model to one of "relationship-centred care" (Tresolini, 1994, p.13). Professionals are in conflict with service-users as power relationships change; there is an expectation that they will relinquish paternalistic control, as service-users become proactive in their healthcare decisions (Trede and Higgs, 2003).

Despite the paradigmatic shift within business and management, much of the public services literature views coproduction processes as still bureaucratic and formal, led through a professional model (Bovaird, 2007, Bovaird and Loeffler, 2012, Bovaird et al., 2015). Service-users are still perceived in a "passive" role (Bovaird, 2007), despite the view that strives to suggest that coproduction reflects the democratisation of service design (Evers, Ewert and Brandsen, 2014).

However, it is also questionable if equity is possible within a coproducing relationship, due to the professionalisation and bureaucracy within healthcare, and the assumptions around the operant and "operand resources" of service-users (Hibbert et al., 2012). Again, this is based on the assumption that service-users have the skills and knowledge required to coproduce (Hibbert et al., 2012) and the idea that service-users are "experts by experience" (Fenge, Fannin and Hicks, 2012, p.456) by offering non-professional viewpoints due to their previous experiences of care within specific health services (Mayer and McKenzie, 2017).

Fundamentally, this suggests that the coproduction of care facilitates equality between service-users and service-providers; and is a panacea to solve all problems through the involvement of service-providers and service-users (Boyle and Harris, 2009). This is problematic given the paternalistic power dynamic inherent within the NHS. Bevir, Needham and Waring (2019) suggest that the aim of coproduction is to rebalance the political tension of power relationships, however they identify that there are few critical appraisals which interrogate theories of coproduction or question the assumptions on which these theories are based. Therefore, it is imperative to uncover the contextual barriers and enablers of the coproduction of health barriers; and critical to ensure that participants are recruited from areas considered highly socioeconomically deprived (Holland - Hart, Addis, Edwards et al., 2019). This is also a way of recognising the importance of support within the community (social capital), and why a useable definition of coproduction will ensure that barriers to understanding and communication, of the concept, are addressed.

It is also imperative to understand the interplay between social status, social capital, chronic illness, and the implementation of care (Vassilev et al., 2011, Vassilev et al., 2014). Effective coproduction of care which will enable service-users to experience more individualised care, (Freire and Sangiorgi, 2010, McColl-Kennedy, Vargo, Dagger et al., 2012), and recognises concepts of care which are not limited by existing definitions such as "self-care" and "self-managing" (Vassilev et al., 2011).

However, there is a paucity of literature exploring socioeconomic status, despite coproduction studies which explore mental health and ethnicity (Boyle and Harris, 2009, Lwembe et al., 2017). There remains a perception of an unequal power dynamic, highlighting the dichotomous relationship between service-user and healthcare providers is required (Dunston, Lee, Boud et al., 2009, Durose et al., 2017, Mayer and McKenzie, 2017), and it this which is worthy of further investigation and exploration.

2.5.5 Reflection and discussion of the coproduction literature

This NR explored the origins of customer participation within private sector firms and service industries. A “paradigm shift” occurred with a progression from craftsmanship, mass production, mass consumerism, to the importance of the involvement and experience of customers, coproduction, as key to successful businesses/services. However, attempts to define coproduction are problematic, this review demonstrates there is no consistent definition of coproduction, and it remains a nebulous term. The theory of coproduction was discussed within a significant body of diverse literature, which included many complex concepts and frameworks. Within this literature assumptions are made about the ability and motivation of service-users to coproduce. Uncertainty remains regarding the differences between definitions of coproduction, cocreation and participation. However, the overarching guiding principles of coproduction are aimed at beneficent approach to service-user participation, and the creation of value.

The conclusion of many primary research studies and systematic reviews is to suggest further empirical studies are required to contribute to, what is perceived as a weak evidence base (Loeffler and Bovaird, 2016, Brandsen and Honingh, 2016, Nabatchi et al., 2017, Rezaei Aghdam, Watson, Cliff et al., 2020, Amorim Lopes and Alves, 2020, Salisbury, 2020), and because of the paucity of robust outcome measures in primary coproduction research (Oertzen, Odekerken-Schröder, Brax et al., 2018). This is extremely relevant in relation to the contemporary healthcare literature, as research exploring coproduction and LTC focuses upon those which have far greater scientific capital (Bourdieu, 2004, Nairn et al., 2019) such as rheumatology, cancer, renal and diabetes (Elwyn et al., 2019). Furthermore, whilst the engagement of service-user coproduction is consistently identified as dependent upon socioeconomic status, there are few primary research studies (Salisbury, 2020) which explored coproduction within a context of inequality or deprivation fully.

A limitation of the much of the literature, was the focus upon the coproduction of services, where service-users are involved in the planning, design and delivery of services, as opposed to the actual coproduction of their own healthcare (Palmer, Weavell, Callander et al., 2019). Even the systematic review by Ocloo et al. (2021) excluded any reviews which explored decision making or treatment and reflected the focus of PPI in research. Moreover PPI, as opposed to coproduction, is underpinned by the assumption that that the voice of the service-user is genuinely heard (Vadiee, 2012, Ocloo and Matthews, 2016, Brand et al., 2020). It is also suggested that those service-users involved with PPI activity, have higher socioeconomic backgrounds; more “operant” and “operand” resources; and personal agendas which both enable and motivate them to participate (Etgar, 2008).

This also highlights the paucity of literature coproduction of healthcare, at the “point of care” or implementation (Voorberg, Bekkers and Tummers, 2013, Voorberg et al., 2015, Palumbo, 2015, Palumbo, 2016, Palumbo et al., 2016, Palumbo and Manna, 2018), which is not PPI or the “expert patient” (Department of Health (DoH), 2001). Much of the literature exploring healthcare within the “home” focusses upon about the experience of care workers delivering acute care in service-users homes; end of life care; healthcare of the older person; residential healthcare homes; or children (Shepperd and Iliffe, 2005, Lupton, 2013, Hasson, Nicholson, Muldrew et al., 2020). Moreover, definitions of healthcare settings do not include specific references to the domestic home (WHO, 2009); and the Care Quality Commission (Care Quality Commision, 2021) only recognises the home as a place where care is undertaken, related to who is delivering that care, for example, domiciliary care services, extra care housing services, shared lives and supported living services (Care Quality Commission, 2021) rather than informal carers, such as family and friends.

This NR demonstrates that the coproduction of care, should acknowledge the socioeconomic position and social capital of service-users. It requires that service-users and service-providers, with different types of expertise can collaborate equally, with open channels of communication, and achieve mutually agreed goals, by trusting each other's expertise. Consequently, this places the emphasis away from "compliance" to empowering service-users to be more accountable for their own care (Ewert and Evers, 2014). This interpretation of coproduction acknowledges the assumptions which underpin service-users' intangible, tacit skills knowledge and skills (Dolfsma, 2011) and their agency to act as responsibly and accountably (Bettencourt et al., 2002).

Paradoxically this interpretation also identifies an abstract version of a service-user, who is competent to fulfil the demands of a mutually beneficial (Bovaird, 2007, Bovaird and Loeffler, 2012, Bovaird et al., 2015, Loeffler and Bovaird, 2016), equal and equitable relationship, without conflict. This portrayal of the service-user infers that only those with the appropriate resources (SDH) (Vargo and Lusch, 2004, Lusch and Vargo, 2006) education, income and social capital (Bourdieu, 1984, 2005, Grenfell, 2012) are capable and motivated to engage in a coproducing relationship (Etgar, 2008, Thijssen and Van Dooren, 2016, Realpe and Wallace, 2010). The paucity of literature which considers the context of service-users (Bovaird, 2007, Bovaird and Loeffler, 2012, Bovaird et al., 2015) suggests greater insight is required to understand the social and cultural context (Etgar, 2008, Thijssen and Van Dooren, 2016, Eriksson, 2019), and why coproduction may become a place of conflict. Further inquiry, to explore fluctuation in the engagement and motivation of service-users, is necessary to ensure that the provision of future healthcare services meet their actual needs (Realpe and Wallace, 2010, McColl-Kennedy et al., 2012, Lehrer et al., 2012, von Thiele Schwarz, 2016).

Piller et al.(2010) suggest that when coproduction does occur, there is a reversal of previous market relationships, which indicates a shift in balances of power. However, the literature reviewed demonstrates that the discourse, activities and expectations associated with coproduction remain fragmented, and the evidence presented still reflects a paternalistic, hierarchical power relationship in favour of service-providers. This view is equally relevant within the healthcare literature; the overarching perspective is that to genuinely benefit from value creation and relational exchange through a coproducing relationship, there must be minimal hierarchy (Bovaird, 2007, Palumbo, 2015, Palumbo, 2016, Palumbo et al., 2016, Palumbo and Manna, 2018, Salisbury, 2020), or “power distance” (Chan et al., 2010, p.52). Chan et al. (2010), echoes Bettencourt et al. (2002) in agreeing that service-user responsibility and accountability is a fundamental part of participatory activity and relationships, as they adopt new roles; however, service-users may feel threatened if this expectation is imposed upon them.

Many coproduction activities are perceived as an opportunity for positive relational exchange and the sharing of skills and knowledge (Batalden, 2018), however it may also induce stress and conflict (Lehrer et al., 2012, Jo and Nabatchi, 2016, Nahi, 2016, Osborne, Radnor and Strokosch, 2016, Osborne, 2018). This is relevant in terms of how service-users "co-construct" (Osborne et al., 2016, p.647) their experience, within the care service, particularly when interactions with healthcare professionals are limited to a few times each year. Other authors suggest that that service-users are already experts, with the required "operant resources" required to coproduce (Bettencourt et al., 2002, Hibbert et al., 2012, Jacob and Rettinger, 2011). This is challenging if there are instances of "problematic consumer conduct" (Hibbert et al., 2012, p.329), when customers and service-users do not have the "operant resources", or if they are not willing or able to take responsibility for their role in a coproducing relationship.

Furthermore, Park (2020) identifies reoccurring themes in much of the coproduction literature, where there exists an unavoidable power imbalance, and suggests that previous literature does not adequately explore the conflict and tension, which occurs in coproducing relationships. There are aspects of the healthcare coproduction literature which perpetuates a paternalistic perspective and assumes that service-users lack health literacy and self-awareness about their health issues; they are generally unwilling to engage or motivated to coproduce their care, and that they are actively disengaging. Whist service-users may not always be positively self-motivated to participate, assumptions cannot be made as to why they do not coproduce at the point of implementing care; further studies are required to explore these assumptions, and to uncover the barriers and enablers to the coproduction of care.

Theories of coproduction have emerged to explore the shift in the role of service-users as a core component of service delivery (Realpe and Wallace, 2010, Osborne et al., 2016, Osborne, 2018), however there is evidence to suggest that there is significant structural inequality, hierarchy and power struggles within coproducing relationships (Nahi, 2016, Park, 2020). Despite the dichotomous relationship between firms/public services and clients/customers/service-users, there are still beneficial resources that service-users may bring to the coproduction process (Durose et al., 2017). This is relevant as it demonstrates the need to recognise individual preferences and the determinants of behaviour; to cultivate lasting relationships with service-providers; and improve service-user satisfaction.

There are also number of systematic reviews, which attempt to conceptualise and define coproduction (Voorberg et al., 2013, Voorberg et al., 2015, Leclercq, Hammedi and Poncin, 2016, Palumbo, 2016). However, some of these also identify the inadequate evidence of operationalising concepts of coproduction through primary research. In particular, the exploration of coproduction, and the opportunities for coproduction at the point of delivery and consumption of care between "hospital" and "home", and the cocreation of value between healthcare service-users and healthcare providers (Voorberg et al., 2013, Voorberg et al., 2015). Nabatchi et al. (2017, 2016) also refer to this as "co-delivery", and suggest that an overarching concept of coproduction, with specific typologies and definitions can prevent confusion, and researchers will better study, assess and evaluate coproductive activity. Whereas other authors suggest that replacing coproduction and cocreation, with customer participation, will reduce confusion and prevent other nebulous, overcomplicated definitions (Dong and Sivakumar, 2017).

The dilemmas with concept of coproduction, particularly within healthcare, suggests that it is a “wicked problem” (Rittel and Webber, 1973, p.155). This is due to the complexity around definitions, terminology and interpretation; it infers that only those service-user with the appropriate “operant” and “operand resources” (Vargo and Lusch, 2004, Lusch and Vargo, 2006) such as education, income and social capital (Bourdieu, 1984) are capable and motivated to engage in a coproducing relationship (Etgar, 2008, Thijssen and Van Dooren, 2016). Much of the literature suggests that those living within a context of social deprivation for example, geographical location or socioeconomic status, may lack also the personal attributes, social position or opportunity to engage in coproducing relationships (Bovaird, 2007, Nairn et al., 2019, Nahi, 2016).

Whilst there were a number of studies which explored the concept of coproduction within healthcare (Literature Map and Appendix 5:Selected Papers for the narrative review), there were only 3 papers which discussed or mentioned coproduction and lymphoedema few studies explore this problem empirically (Thomas and Morgan, 2017, Dixon, Lar and Dean, 2021, Kendall-Raynor, 2015); and even fewer through a philosophical or theoretical lens (Woods, 2002, Meiklejohn, Heesch, Janda et al., 2013). Moreover, there is a paucity of papers which do not consider fully the implications of coproduction in populations where there may be an inequality in terms of “operant” and “operand” resources.

2.5.6 Conclusion of the Narrative Review

The aim of this NR was to describe how did theories of coproduction emerged, explore the strengths and limitations of definitions; expose the assumptions and gap within the literature, and look at how the NR contributes to existing coproduction theories, and offers new perspectives.

In conclusion, coproduction remains a nebulous concept and many of the included authors suggest that further research is required specifically to explore how customers/citizens/service users engage in a coproducing relationship. This includes where they are socioeconomically situated, their social capital, their existing skills and knowledge, and how they empowered feel to coproduce. This is particularly relevant from a healthcare context, especially related to the gap between what happens between “hospital” and “home”. Ewert and Evers (2014) see these spaces as geographically and metaphorically distanced from each other, and a place where conflict can arise due to expectations related to social capital.

Within the context of this PhD the focus is upon the operationalisation of the coproduction of care at the point of implementation and consumption and Voorberg’s definition of “co-implementer” (2015, p. 1347), can be interpreted as where value is cocreated, through “relational exchange” (Morgan and Hunt, 1994, p.22) and the transfer of “operant resources” (Vargo and Lusch, 2004, p.6) (Figure 2: Elements of coproduction relevant to the thesis). The goal of stengthening trust and commitment, is perceived as a critical to the preservation of a positive, collaborative, reciprocal relationship; which has the potential to improve outcomes, and increase the social capital between service-providers and service-users (Ostrom, 1996, Steen and Brandsen, 2020). Therefore, the definitions of coproduction, all encompass the following concepts; the exchange of "operand" and "operant" resources; shared decision making; accountability and responsibility; equality; trust and relational exchange, reflected in the work of Lovelock and Young (1979), Morgan and Hunt (1994), Bettencourt et al. (2002), Vargo and Lusch (2004), Lusch and Vargo (2006), Bovaird (2007) Jacob and Rettinger (2011), Bovaird and Loeffler (2012) and Voorberg et al. (2015). These themes emerged as elements of coproduction relevant to the thesis (Figure 2).

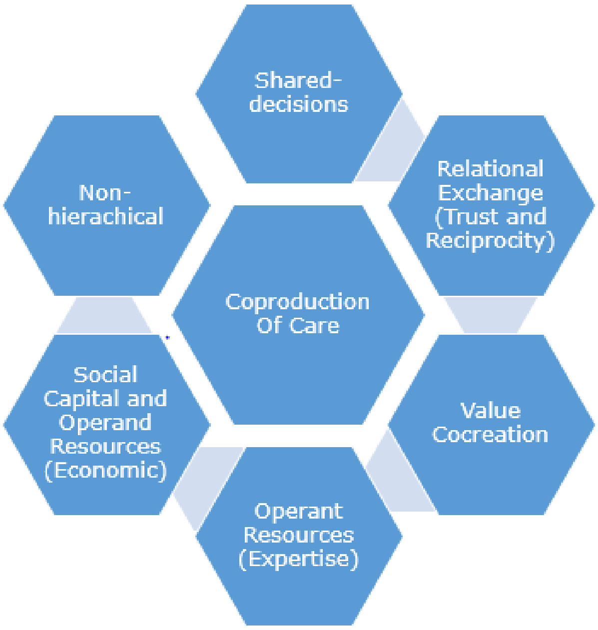


Figure 2: Elements of coproduction relevant to the thesis

It is apparent from the literature reviewed that the aspiration is to define coproducing relationships, as equitable partnership between service-providers and service-users, where their interaction, shared-decisions, transfer of "operant resources" and expertise leads to value creation. The extent to which this can be achieved was explored through this study and thesis. Further research needs to understand the social and cultural contexts of service-users (Bovaird, 2007, Bovaird and Loeffler, 2012, Bovaird et al., 2015, Eriksson, 2019); why coproduction is a place of conflict; and to explore fluctuation in the engagement and motivation of service-users (Lehrer et al., 2012), to ensure that the provision of future healthcare services meet their actual needs.

2.5.7 Relevance of the narrative review to the empirical study

The NR demonstrates that the concept of coproduction at the point of delivery and consumption as "co-implementer" (Voorberg et al., 2015, p.1347) or co-delivery" and "co-assessment" (Bovaird and Loeffler, 2012, p.1124) within healthcare. The conclusions of the NR also identify the paternalistic assumptions of coproduction, and the assumed attributes of those who are expected to coproduce. Furthermore when examining the contributions of service-users to the coproduction of health, it is important to address the issue of differences in their knowledge and skills, and the interpretations of dedication and commitment of service-users, in relation to their health outcomes (Bovaird, 2007, Palumbo, 2016).

The aims of the study were to explore how the coproduction of care is operationalised within a context of ongoing care, across hospital and home settings, for individuals living with a long-term condition (chronic oedema). This includes if and how socioeconomic position and social capital influences coproduction, between service-users and service-providers in this context; and if the social determinants of health and socioeconomic factors influence shared-decision-making strategies.

To address this, the PhD links prior research on social capital and service-user decision-making to the differences which may exist between what happens between the "home" and the "hospital". This extends to the health coproduction research agenda, which continues to focus on the relationship between service-provider and service-user, and critically examines the differences in the ways in which service-users contribute to their health outcomes outside of their interactions with health practitioners, for example, in the hospital setting (Realpe and Wallace, 2010).

The NR identifies an existing gap within the literature, in terms of the coproduction of care, and questions about how service-users implement care at "home", Furthermore, the challenges around definitions, within the contemporary coproduction literature and chronic oedema literature are both examples of a "wicked problem" (Rittel and Webber, 1973, p.155). Despite the existing definition of chronic oedema and lymphoedema (Moffatt et al., 2003), the prevalence of the condition is vastly underestimated, and is identified as a public health concern across the integrated care system (ICS).

This is relevant given that the conclusions from the NR propose that coproduction is also challenging for service-users who are not considered to be "experts" (Mayer and McKenzie, 2017, Palumbo, 2015, Palumbo, 2016), and whose social position may indicate structural inequalities of power. Moreover, a lack of scientific capital suggests a lack of health and organizational literacy within the public sphere, both of which are identified as prerequisites to coproduce care. This is a perspective which has not been fully explored in any of the existing literature, and which the PhD intended to address.

3 Philosophical Perspective Methodology and Methods

3.1 Chapter overview

In this chapter I discuss the choice of methodology and the philosophical perspective of the study. I discuss the rationale for the social constructivist perspective, the relevance of Bourdieu (1984), and the research design, methods, (overt non-participant observations; in-depth, face-to-face interviews and the clinic service-users' postcodes and their GP Practices); and how those methods are justified in terms of answering the research question. I also discuss the study design and study setting; the participant recruitment process; how I conducted the data collection; and the data analysis. I also outline the formal NHS ethical approval; ethical issues which needed to be considered (Good Clinical Practice); and my reflexive position as a nurse-researcher.

In this chapter I refer to Appendices 6-17

3.2 Philosophical position of the study: Social Constructivism

The aims of the study were to explore how coproduction is operationalised within the context of ongoing care across hospital and home for those living with chronic oedema, and how socioeconomic position and social capital impact on coproduction in this context. The conclusions from the NR, identified that structural inequalities of power, may influence how empowered service-users (Hoggett, 2001) are to engage in the coproduction of care.

Therefore, it was important that the methodological approach to the empirical study aligned to the exploration of the existing services; the coproducing relationship between health professionals and service-users; if and how coproduction occurs through the implementation of care, from “hospital” to “home”, in relation social capital and, “operant” and “operand resources” (Vargo and Lusch, 2004, p.6), and especially the social context of care (socioeconomic and SDHs).

3.2.1.1 Social constructivism

Social constructivist perspectives emerged through the philosophical, phenomenological and hermeneutical perspective of German philosophers, such as Husserl and Dilthey (Mackenzie and Knipe, 2006). Social constructivism is not perceived as a specific or exclusive philosophical perspective (Berger and Luckmann, 1966, Pfadenhaueris and Knoblauch, 2019, Jovanović, 2021), rather a “paradigm”, or several theories regarding interactions within the social world. This is particularly with regards to science, and the acquisition of knowledge as a social process (Guba and Lincoln, 1985, 2001, Detel, 2001, Dupré, 2004, Farrimond, 2013). This aligns to “moderate constructivism” (Hess, 1997, p.35), which is defined in terms of the social and cultural contexts, which shape the experience, reality and the socially constructed relationships of individuals within the social world. Therefore, this perspective was justified, given the ontological and epistemological position of social constructivist enquiry, and the underpinning philosophical and methodological approach, as related to the research primary objective.

The cultural context of care, and the social process of interaction, is a significant part of shared-decisions about health. This is because the social connotations of illness are bound heavily with perceptions of normality, deviance, criminality, cultural traditions, stigma, prejudice, status and power (Goffman, 1990, Link and Phelan, 1995, Conrad and Barker, 2010, Olafsdottir, 2013). Historically, the paternalistic bio-medical model of care (Tresolini, 1994), benefited healthcare professionals, in terms of "hidden strategic actions" (Outhwaite, 2009, p.470), whereby those in more powerful social positions (social, structural, cultural, economic and scientific capital) defined the accepted behaviours; and exerted power to those who are not able to avert this oppression because of their less powerful position (Bourdieu, 1984, Habermas, 1984, in , Baxter, 2001, Bourdieu, 2004, Vandenburgh, 2004, Greenhalgh et al., 2006, Outhwaite, 2009, Olafsdottir, 2013, Scambler, 2015).

The social constructivist perspective is also relevant with regard to the extent to which is aligns with Bourdieu's writing, particularly in terms of how individuals relate to the subjective and the objective, with the social world (Pouliot, 2007):

> *"as a constant dialectical process of creation,*
> *transmission and reproduction of "reality"*
> *(Jovanović, 2021, p.524)*

And social interaction which is influenced by habitus, social capital and the field. From a social constructivist perspective, the development of knowledge and innovation is perceived as a social process; that scientific knowledge is not completely objective, or a complete representation of truth or fact. It is also socially constructed within the context of the research process and relationships between researchers and 'science' (Detel, 2001, Collins, 2015, 2016), and that:

> *"knowledge is not absolute, but relative to cultures and contexts" (Jackson and Klobas, 2008, p.330)*

Collins (1996) suggests that a scientific approach remains the only satisfactory way to facilitate the identification and resolution of multi-faceted problems; this is because research through a social lens is perceived as less reliable (Collins and Pinch, 1998, Collins, 2014). This is also pertinent to the interactions between health professionals and service-users, in terms of "specialist expertise" (Collins, 2014, p.58) and "default expertise" (Collins, 2014, p.15). This standpoint is particularly relevant in terms of "scientific capital", within the field of chronic oedema, whereby healthcare professionals perceive a hierarchy of expertise; there are tacit rules about treatments, the transfer of knowledge between professionals, and factors which influence the relationships clinicians have with each other (Collins, 1974, Evans and Collins, 2010, Latour and Woolgar, 2013).

The social constructivist perspective is exemplified in the emergence of the different "schools" of chronic oedema therapy (Casley - Smith et al., 1998, Földi et al., 1989, Kasseroller, 1998, Leduc et al., 1998, Rockson et al., 1998); the descriptions of CDT and MLD techniques are detailed and elaborate in an effort to address the "chaos" described by Földi et al.(1989, p.505). The emphasis was upon their expertise perpetuating a structural, elitist and paternalistic position within the field, this is especially regarding the genetic and scientific advancements (Gordon et al., 2020, Keeley, 2017), despite the perception of minimal scientific capital within the public sphere (Nairn et al., 2019). The discourse is of a condition which lacks clear definition and robust clinical outcomes (Moffatt et al., 2003, Morgan and Moffatt, 2006, Morgan et al., 2012, Keeley et al., 2019, Moffatt et al., 2021b); creating a complex situation for service-users living with a LTC which cannot be cured; and expectations that they commit to a lifetime of treatment (Franks and Jarrett, 1997). This is worthy of discussion in relation to theories of coproduction, to explore this power dynamic, and the relationships between service-providers and service-users.

However, criticisms of a constructivist perspective argue that it is abstract and tautological (Roberts, 2017), and most obviously, does not account for knowledge we have not yet discovered (Freudenthal, 1984). This is relevant in terms of representing individual realities, which is also dependent upon the interpretation of the researcher. Furthermore, this questions whether it is possible for a researcher to commensurate a ‘subjective’ narrative (participants’) with an ‘objective’ interpretation (researcher) (Jovanović, 2021) within the research process.

This is a dilemma which has been debated by several authors (Berger and Luckmann, 1966, Lincoln et al., 2011, Dreher, 2016, Pfadenhaueris and Knoblauch, 2019, Jovanović, 2021). They conclude that a constructivist perspective seeks to bring together the objective and subjective, the inductive and the deductive; and that researchers have a responsibility to ensure the most appropriate methods are chosen to preserve authenticity and ‘voice’ (Lincoln et al., 2011, p.183) of the participants throughout the data collection. This also justifies undertaking a “paradigm perspective” mixed methods approach, which focuses upon the ontological and epistemological dilemmas when undertaking any research. In particular those which address context, values and reality, to understand the differences and similarities between the lived experiences of individuals (Creswell and Tashakkori, 2007, p.305).

A social constructivism is an appropriate methodological perspective (Bogna, Raineri and Dell, 2020), however it is imperative to recognise and address the challenges and limitations. This is to demonstrate how these are mitigated, when planning, undertaking, and analysing data within a study. This can be achieved through a "methodological perspective" of mixed methods which considers the entirety of the research process (aims, objectives, collection, analysis and interpretation of data) as a "paradigm-method"(Creswell and Tashakkori, 2007, p.304).

This perspective also acknowledges the position of the researcher within the study; a recognition of 'a priori' knowledge (Freudenthal, 1984); the influence of interactions with participants; interpretation of the data (Borbasi, Jackson and Wilkes, 2005); the authenticity of 'voice' (the participants and researcher) (Lincoln et al., 2011, p.183); and how the presence of the researcher may influence all steps of the research process. This is addressed by ensuring the 'trustworthiness' of the research, and addressing the epistemological issues, which arise through cocreated knowledge, and understanding through a subjectivist interpretation with the participants. Furthermore, this this can also be acceptably addressed by supporting qualitative data with quantitative data (Mojtahed, Nunes, Martins et al., 2014, Mackenzie and Knipe, 2006).

3.3 Methodology

The aims of this study were to explore how service-users operationalise the coproduction of care and implement their care within the "home". The study explored the differences between what happens across the "home" and the "hospital". It extended the health coproduction research agenda, by critically examining the differences in how service-users contribute to their health outcomes, outside of their interactions with health professionals (Realpe and Wallace, 2010). It examined a group of service-users who feel they have arbitrary access to the healthcare they need. This challenges the historical perspective of health professional and service-user relationships; and raised questions about why this may difficult due to their "operant" and/or "operand" resources.

Therefore, the study design and methods were chosen to best answer the primary aim, and objectives of the study. This was to articulate individual perspectives, through exploration of the dynamics of relationships, individual narratives, and contextualisation of the socioeconomic position of the study; and to capture the essence of phenomena, which enabled richer detail and contextualisation of the study findings (Becker and Geer, 1957).

3.3.1 Study Design

To undertake this study from a constructivist perspective, the study was based upon a mixed methods concurrent embedded design (Creswell and Plano Clark, 2011, p.73) (Figure 3). This was feasible, and justified (Onwuegbuzie and Leech, 2006) as only one phase of data collection was necessary for both and the qualitative and quantitative phases (Creswell and Plano Clark, 2011, p.73). Furthermore, mixed methods study can:

> *"involve the integration of the data at one or more stages in the process of research" (Creswell, Plano Clark, Gutmann et al., 2003, p.165)*

This is as an intuitive, appropriate, and pragmatic approach in terms of efficiency of time. Furthermore, in this study the qualitative component took precedence, which also aligns to a constructivist perspective (Creswell, Hanson, Clark Plano et al., 2007, Creswell and Plano Clark, 2011, Mojtahed et al., 2014). This enables the integration of findings and the emergence of any contradictions, or "disconfirming evidence" (Creswell and Miller, 2000, p.126)in addition to "thick descriptions" (Geertz, 1973, p.312), which reflect the in-depth detail of the phenomena. Furthermore, these methods facilitate "real world" research, which depicts and reflects the social construction of everyday life, the challenges individuals face and the strategies they use to mitigate their situation (Creswell and Plano Clark, 2011, Creswell, Klassen, Plano Clark et al., 2011, Craig et al., 2013).

This study focused upon exploration of the operationalisation of the coproduction of care, at the point of care delivery and implementation within their domestic setting, "home". The study design facilitated the exploration of the participants' social context and social capital, related to the socially constructed relationships, which develop between service-user within their "home" and their "hospital".

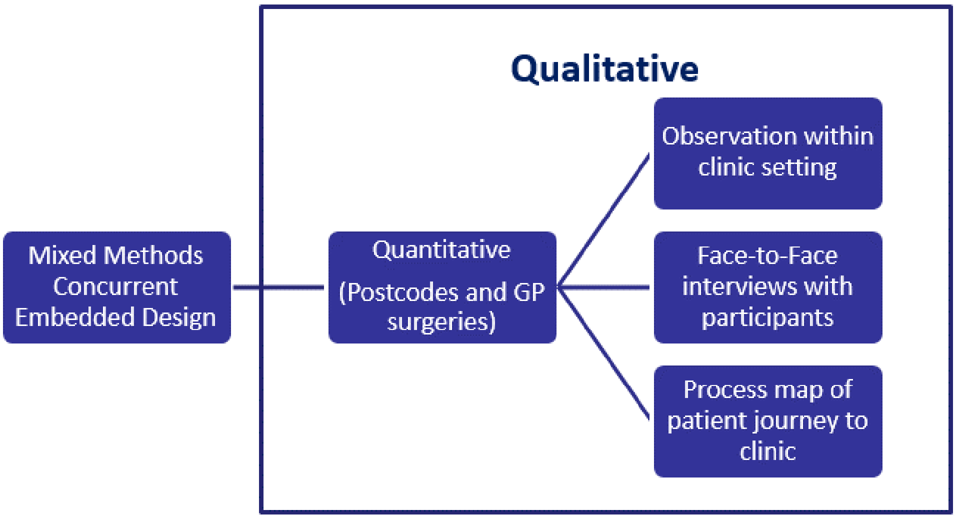


Figure 3: Mixed methods embedded design based on Creswell and Plano Clark, (2011, p.73)

This was particularly relevant in terms of the social construction of health (Olafsdottir, 2013) and the socially constructed meanings attached to disease, well-being and the SDH (Bourdieu, 1984, Radley and Green, 1987, Radley, 1989, Cockerham, 2005, Marmot et al., 2012, Cockerham, 2013b, Carey and Crammond, 2015, Crammond and Carey, 2016b, Cockerham et al., 2017). Qualitative research methods were used to explore the individual circumstances and experiences of the service-users, at two Lymphoedema Clinics within a regional service, and to uncover their lived reality and meaning of their experience (Creswell and Creswell, 2018). These were in-depth, face-to-face interviews and overt non-participant observation (Silverman, 2011). This enabled an exploration of how the coproduction of care was embedded within social contexts and networks, in terms of the cultural norms and expectations; and how cultural beliefs permeated opinions and decisions.

This was specifically relevant in terms of uncovering social meanings and the scientific capital associated with LTCs (Nairn et al., 2019); how the participants sought answers for what was "wrong" with their bodies and their relationships and interactions with their healthcare professionals. I achieved this by describing and interpreting the service-users perceptions of where they are situated within the social world, and their experience of access to care and choice, within the social contexts of the Lymphoedema Clinic and their "homes" (Creswell and Creswell, 2018).

In addition, quantitative data regarding postcodes and GP practices within geographical area of the study setting, were also collected. These methods were chosen because the aims of the study were to gain deeper insight into the dynamics and position of the study settings and contextualise the experience of participants. These methods of data collection facilitated an exploration of the phenomenon of study (Becker and Geer, 1957, Creswell et al., 2007, Kvale and Brinkmann, 2009, Silverman, 2013, Creswell, 2014b, Taylor, Bogdan and DeVault, 2015, Brinkmann and Kvale, 2015) and ensured a thorough comprehension of the context.

Moreover, the richness and completeness of the participants' narratives are enhanced, through using different qualitative methods; the findings from the observations enriched the findings from the in-depth, face-to-face interviews (Morse, 2009). This also addresses any potential limitations of a social constructivist approach by facilitating different individual perspectives, and what might be considered as the incommensurability of observing and interviewing. Furthermore, a reflexive approach to undertaking qualitative data collection, also recognises the potential for researchers to alter what they are observing or recording by "being there". Including this as part of the study data, and exploring the position of the researcher demonstrates rigour and trustworthiness within the research processes(Lincoln and Guba, 1985, p.218-219), as demonstrated later in this chapter (3.8).

3.3.2 Study setting

The study setting was within secondary care (NHS hospitals) and primary care (GP practices). The two Lymphoedema Clinics, within this study, are part of a regional multi-professional service, commissioned and managed at an East Midlands Acute NHS Foundation Trust Hospital. The service is also part of the National multi-professional Lymphoedema service, in conjunction with an NHS Foundation Trust in the southeast of England. At the time of the study, the Lymphoedema Clinics were located within the commissioning trust; an Acute NHS University Teaching Trust Hospital (Site 1); and an Acute NHS Foundation Trust Hospital in rural post-industrial town (Site 2). The service-users were spread over a wide geographical area and there are distinct socioeconomic differences between these two geographical areas, in terms of the "Indices of Social Deprivation" (NCC, 2015, Ministry of Housing Communities & Local Government, 2015). Whilst there is an outreach service within the chronic oedema service plan, the implementation of this is limited and inconsistent (Moffatt, Gaskin, Sykorova et al., 2019c).

The service is responsible for the assessment and management of children and adults diagnosed with chronic oedema, including primary lymphoedema, complex secondary lymphoedema, vascular anomalies, lymphovenous oedema, and lipoedema (a disorder of adipose tissue, which can coexist with lymphoedema) (Herpertz, 2001, Shavit, Wollina and Alavi, 2018, Paling and Macintyre, 2020), in conjunction with primary care services in the region. All treatment was delivered by the specialist, multi-professional lymphoedema therapists. The treatments include compression bandaging, compression garments, manual lymphatic drainage (MLD) (a specialised form of massage), simple lymph drainage (SLD) pneumatic compression pumps and kinesio taping. Clinical assessment data is captured using the specific quality of life measure for limb lymphoedema (LYMQOL) (Keeley, Crooks, Locke et al., 2010).

Permission was gained from the service leads to attend both Lymphoedema Clinics and undertake non-participant observations between clinicians; and to recruit service-users to participate in in-depth, face-to-face interviews. The study was advertised on the Lymphoedema Support and a Lymphoedema Network social media site (Facebook) with the expectation that some participants would self-select for the study.

3.3.3 Methods: Non-Participant Observation

Overt non-participant observation is a data collection method where researchers observe the phenomenon of interest and do not conceal their presence or role (Creswell, 2014b). This method is used to contextualise activity (what is done) within the setting; to observe the conversation and dynamics between service-providers and service-users; and to enrich the service-users' descriptions during the in-depth, face-to-face interviews.

Although the focus in this study was the service-user experience, it is appropriate to include the interaction and conversation between the SHPs and service-users, as this is where the initiation of a coproducing relationship occurred. The rationale for undertaking non-participant observations is to gain insight into the dynamic of the relationship between the SHPs and service-users, and if and how the coproduction of care takes place during the clinic consultations, in terms of the themes which emerge as elements of coproduction relevant to the thesis (Figure 2) which includes the exchange of “operand” and “operant” resources; shared-decision making; accountability and responsibility; equality; trust and relational exchange, reflected in the work of Lovelock and Young (1979), Morgan and Hunt (1994), Bettencourt et al. (2002), Vargo and Lusch (2004), Lusch and Vargo (2006), Bovaird (2007) Jacob and Rettinger (2011), Bovaird and Loeffler (2012) and Voorberg et al. (2015).

I could observe the activity within the “natural setting” of the clinic, and used my skills of observing as part of an, iterative and reflexive process to explore meaning (Creswell, 2014b, p.185). Although I am a registered nurse, I did not “belong” within the setting (Bloomer, Cross, Endacott et al., 2012), and I wanted to observe the social processes which occurred during the consultations. This was to acquire “thick description” (Geertz, 1973, p.312) in that the meanings, within the social interactions were identified and interpreted, rather than a solely descriptive account of the context of care (Silverman, 2011). This also emphasised the importance of “seeing voices” (Forsey, 2010, p.562), through listening to the flow and content of “speechmaking-noisemaking” (Forsey, 2010, p.563) to understand the meanings beyond the superficial, and described the context of experience (Ponterotto, 2006), as an authentic interpretation. Furthermore, this also enabled me to describe the complexity of the situation, in terms of the meanings and observed emotions which transpired during the interactions (Denzin, 2001). My focus was upon interpretation and representation of the relationships within the context of the clinic consultation, and through describing the context, interactions, and conversation, I ensured that the findings were:

> *"live in the setting" (Delamont, 2007, p.213).*

The process of collecting qualitative observational data usually involves using field notes, and memos, to record, describe and identify key aspects what is observed, framed in terms of the research question (Gibbs, 2018). Using field notes facilitates the intellectual effort required to ensure "thick description" (Geertz, 1973, p.312). These notes should also reflect the perspective of the researcher, and as an account of their interpretation. This was specifically relevant to the constructivist perspective of this study, (Gibbs, 2018); and the findings were presented in a way which aligns "realist tales" (van Maanen, 2011, p.45), as an authentic account of what occurred.

3.3.4 Methods: In-Depth, Face-To-Face Interviews

My aim was to undertake "in-depth" semi-structured, biographical face-to-face interviews, to ensure that the participants had every opportunity to describe their experience:

> *"to produce elaborated and detailed answers"*
> *(Rapley, 2007, p.15).*

The social interaction during the interviews is also a social construct, in terms of how the participant verbalises and articulates their story, and how they and the researcher communicate together (Mishler, 1991, Briggs, 2007, Brinkmann and Kvale, 2015). This includes where the participant and the researcher are each positioned, in terms of their cultural background and position within society. The aim was to understand the participant's viewpoint, and uncover the meanings which are from, and shaped by their experience (Brinkmann and Kvale, 2015). This is relevant as number of authors point to the interview being a social construction and this aligns to a social constructivist perspective.

My skills as a researcher were imperative, and I used these appropriately to encourage the participants' to describe their narrative in detail (Rapley, 2007), including non-verbal communication and cues. This was to observe, describe and interpret the context of the setting, and the detail of their experience. This included insight into the aspects of their "social world", which they perceived as important. The knowledge and insight which emerges, is facilitated through interaction and conversation between the researcher and participant. Brinkman and Vale describe this as the "inter-View" (Brinkmann and Kvale, 2015, p.4). The interview is the mechanism, the "instrument" which allows the participants story to be told (Turner, 1980, p.167). Moreover, in-depth, face-to-face interviews are a method which also enables participants to find meaning, and explore the context of their experiences (Hollway and Jefferson, 2008), through their interaction with the researcher. They facilitate the deeper exploration and interpretation of lived experiences, to guide a

> *"richer experiential process" (Becker and Geer, 1957, p.32)*

This is in addition to ongoing insight, understanding, meaning and discovery.

My aim was to achieve the optimum insight into the phenomenon of interest (Baker and Edwards, 2012). This was in terms of the saturation of pre-defined (deductive) and emergent themes (inductive), which add rigour to the thematic analysis (Fereday and Muir-Cochrane, 2006, Guest, Bunce and Johnson, 2006). Morse (1995) defines saturation as:

> *"collecting data until no new information is obtained" (Morse, 1995, p.147)*

However, it is also important to recognise that the concept of saturation may be perceived as incommensurable with a social constructivist perspective. This is that "saturation" might not be achieved, as each participant will have a unique experience. In addition, undertaking research, and data collection during a PhD will have a time limit, and therefore a pragmatic approach must also be taken. The most important aspect is then to ensure the rigour and quality of the interview process, the analysis, the authenticity of the narratives, and the participants' voices. Therefore, this was not reliant upon a specific number of interviews or observations (Baker and Edwards, 2012). When undertaking interviews, the researcher has a responsibility to their participants, to ensure that their voice is heard; this requires skill, and therefore interviewing can be perceived as:

> *"a craft, as a knowledge-producing activity, and as a social practice" (Brinkmann and Kvale, 2015, p.24)*

This is in terms of the quality of my practical skills as a researcher, and how these skills are practiced; how knowledge is produced through the process of the interview; how this is related to the research question, and the methodological and theoretical standpoint; how to address the ethical concerns; and the social effects and consequences which might be raised through the interaction and conversation.

This also depends upon how well participants can recall events; and my skill at interviewing should include using silence to enable the participant to take their time, using specific prompts to ask for examples, across a timeline. This facilitates the participant to report:

> *"concrete experience" or "specific memories"*
> *(Thomsen and Brinkmann, 2009, p.294)*

This is to reflect the participants' interpretation of those events or experience, their "story" and their multiple memories. Thomsen and Brinkmann (2009) suggest caution with regards to any generalisations, which can be made in terms of whether these interpretations are valid, as it must be accepted that these responses are the participants' autobiography; how they described, perceived and recalled events and experiences. This also recognises the importance of memory, and the validity of interviewee reports, as to whether there is a:

> *"reality outside the interview" (Brinkmann and Kvale, 2015).*

Researchers must acknowledge and accept that what is revealed during an interview may be a highly selective reflection of the participants' experience, and the recollection of significant experiences may be further constructed through the process of being interviewed (Gemignani, 2014).

Therefore, it was my intention to interview as a combination of “prober” and a “participant” seeking to empathetically and actively reach beyond the surface of the participants’ narrative (Brinkmann and Kvale, 2015, p.109), and to construct meaning from what the participant revealed. Through my interview technique, I facilitated the participants to take control of the direction of the interview, whilst asking questions at relevant and appropriate times. This was important because of the:

> *“power asymmetry” (Brinkmann and Kvale, 2015, p.37),*

Which can arise if the researcher has specific motives for conducting an interview, in a certain way. In my position as the researcher, I must be aware of and acknowledge, how my behaviour can influence the behaviour and responses of the participant, and that the “interview” is a construct and context, and not neutral ground.

3.3.5 Methods: Socioeconomic and geographical context of the study

In addition to collecting the in-depth, face-to-face interviews and the non-participant observations, the partial postcodes and address of the GP practices were collected to explore the socioeconomic context and geographical location of the setting. The aims of this were to:

- Contextualise socioeconomic position of the study setting, the number of participants living within the most deprived areas of the city.
- Identify the distribution of service-users attending the clinics at site 1

- Determine which GPs were referring the most service-users

The rationale for collecting this data, was related to the research question and socioeconomic and geographical position within this context of the coproduction of care. At the time of the study Site 1 location was ranked 8th out of 326 and within the lowest 10% of the most socially deprived areas within England (NCC, 2015). This was in comparison to Site 2, which was situated within a post-industrial, rural town district, which ranked 70th, and within the top 25% of the most socially deprived areas.

Moreover, within the Site 1 district, the rate of long-term illness and disability was higher than average for adults of working age; and the study setting ranked 12th for income, and 10th for employment within the most deprived areas (NCC, 2015). Furthermore, a prevalence study conducted in the county recorded a high prevalence of chronic oedema (Moffatt et al., 2003, Moffatt et al., 2017c, Moffatt et al., 2019c, Quéré et al., 2019) within the population. Therefore, to gain insight into the distribution of service-users across the city district, the clinic staff were asked to record all postcodes and GP surgeries, of the service-users attending clinic across the 18-month period of data collection.

3.3.6 Sampling and Recruitment Strategy

The sampling strategy for both the overt non-participant observation and semi-structured in-depth, face-to-face interviews was purposive sampling, which focused upon intentionally recruiting participants who experience the phenomenon of interest (Creswell and Plano Clark, 2011, p.173); and extreme case sampling, where participants are recruited on the basis that they are:

> *"unusual, troublesome or enlightened cases"*
> *(Creswell and Plano Clark, 2011, p.174).*

This aim of these sampling strategies was:

- To intentionally identify participants (Creswell, 2014a, 2014b), who were described by the health professionals, as having a challenging/enabled experience of living with chronic oedema
- To optimise the recruitment of this diverse and heterogeneous group service-users, including all types (primary/secondary/cancer/non-cancer) (Moffatt et al., 2003, Williams et al., 2005, Moffatt et al., 2017c, Moffatt, Keeley and Quéré, 2019b),
- Based upon the activity of the Lymphoedema Clinic specialist health professionals SHPS, the registered health professionals (doctors and nurses) who specialised in chronic oedema; and who worked at the clinics, and recruited the participants
- Based upon the availability of the clinics
- Dependent upon the eligibility and informed consent of the participants recruited.

The sample size was not considered an issue (Baker and Edwards, 2012, Palinkas, Horwitz, Green et al., 2015), as the intention was to use in-depth qualitative methods, however purposive sampling can be considered an example of selection bias (Jadad, Enkin and Jadad, 2007). In addition to the in-depth, face-to-face interviews and the non-participant observations, the postcodes and GP Practice of service-users attending Site 1 were documented by the clinic staff. The aim of collecting this data was to identify the distribution of service-users attending the clinics, to identify the service-users position on the Indices of social deprivation (Nottingham City Council (NCC), 2015, Ministry of Housing Communities & Local Government, 2015), and to contextualise socioeconomic context of the study setting.

3.4 Data Collection Processes

3.4.1 The participant recruitment process

In July 2017, when the ethical approval application began, I made initial contact with the lead registered nurse (RN) at Site 1 and Site 2. This enabled communication with the SHP teams, and I gained permission to visit the clinical area; to discuss the proposed study; to gain feedback from the clinic staff (SHPs) about the chosen methods and the recruitment process; and to discuss the feasibility of the research methods, given that the SHPs were working clinically. This also meant that the SHPs were involved at each significant stage of the proposal development, refinement, and during the Integrated Research Application System (IRAS) process and prior to agreement of the study by the Regional Ethics Committee (REC) and the Health Research Authority (HRA). This included the final eligibility criteria and inclusion criteria for the interviews and observations:

- Adults aged 18 and over
- Male and female
- Individuals with a diagnosis of lymphoedema and CO
- a diagnosis of CO/lymphoedema; including those with or without a wound or chronic wound including those

with skin and congenital disorders, cancer, inflammatory and immune system disorders, metabolic and endocrine disorders and diabetes,

- Ability to give informed consent

Exclusion criteria

- Those without fluent English for the interview component

This enabled the best opportunity to recruit from a diverse group of service-users living with chronic oedema. Entry to the study was entirely voluntary, and it was explained to the participants, by the SHPs, that their treatment and care was not affected by their decision to participate. The usual care team identified and checked whether service-users met the inclusion, and made the initial approach, and recruited all potential participants.

Posters advertising the study were also placed in each Lymphoedema Clinic consultation room; the SHPs within the usual care team initially approached the service-users and explained the purpose of the study, prior to entering the consultation room. The SHPs also gained verbal informed consent from the service-users, for me to observe the consultation. The SHPs also asked the service-users if they would be willing to participate in in-depth, face-to-face interviews, prior to entering the room, or during consultations. Service-users were asked to give their verbal consent to being observed during the consultations. This occurred when I was not in sight and ensured that the service-users were not under duress, and were not influenced or coerced into agreeing to participate and consent due to my presence.

Posters were also later put up at several GP surgeries selected, based on the results from the postcode data; and the study was advertised on the Lymphoedema Support and a Lymphoedema Network social media site, with the expectation that some participants would self-select for the study.

All the potential participants were given the participant information sheet at recruitment. The usual care team also purposively recruited a small number of participants by telephone; in these instances, the Participant Information Sheet (PIS) (Appendix 18) was sent to them via e-mail (by me, at the participants request), or given to them, at an upcoming clinic appointment; all potential participants were given a minimum of 24 hours to decide if they would like to take part in the study. Several of the service-users stated emphatically that they would like to participate during their clinic appointment, and their contact details were documented, at that time.

I contacted all recruited participants, within two weeks of their recruitment, and the date and time of the interview was arranged at the participant’s convenience, and in accordance with that the General Data Protection Regulation (GDPR) (Information Commissioner's Office, 2018). I only contacted recruited participants on two occasions, unless the participant contacted me by e-mail. Potential participants were given the choice as to the location of the interview; in an available clinic room at the Lymphoedema Clinics, at the potential participants’ home, or at another setting identified by the participant. Appendix 18 outlines the process of recruitment in the PIS.

All service-users, who consented to participate were asked if they would be prepared for me to contact them again for a follow-up interview, 3-6 months later. This was to increase the opportunity of reflecting the reality of participants' experience, as their treatment progressed, especially for newly diagnosed service-users, or those starting new treatments.

Table 7 identifies all the participants (anonymised) who were recruited to the study. The dates of the interviews have not been included to ensure confidentiality and anonymity of those participants interviewed. The table identifies that of the 50 participants recruited, 28 were interviewed and 22 were not interviewed. A total of 22 participants were observed in clinic (15) and during the yoga sessions (9). 20 participants were recruited by the SHPs by telephone, and I was present during 4 of these calls.

3.4.1.1 Table of all Participants recruited to the study

	Date recruited by SHP	Participant (anonymised)	Age Range	Site	Body site	How Recruited by SHP	Interviewed	Reason	Observed in clinic
1.	22/01/2018	Nel	56-65	Site 2	Both legs	Telephone	Yes		No
2.	22/01/2018	Keith	66-75	Site 2	Both legs	Telephone	Yes		No
3.	22/01/2018	Jeanette	66-75	Site 2	Both legs	Telephone	No	Declined interview	No
4.	29/01/2018	Jo	55-65	Site 2	One arm	Clinic	Yes		Yes
5.	29/01/2018	Rod	56-65	Site 2	Body	Telephone	Yes		No
6.	29/01/2018	Annie	66-75	Site 2	Both legs	Clinic	No	No response	Yes
7.	29/01/2018	Derek	76-85	Site 2	Both legs	Clinic	Yes		Yes
8.	01/02/2018	Karl	36-45	Site 2	Both legs	Telephone	No	Cancelled due to ill-health	No
9.	01/02/2018	Richard	56-65	Site 1	Both legs	Clinic	Yes		Yes
10.	01/02/2018	Hattie	66-75	Site 1	Both legs	Clinic	Yes		Yes
11.	05/02/2018	Faye	36-45	Site 2	Both legs	Clinic	No	Cancelled due to ill-health	Yes
12.	08/02/2018	Louise	36-45	Site 1	Both legs	Clinic	Yes		Yes
13.	08/02/2018	Lucy	36-45	Site 1	Both legs	Clinic	No	No response	Yes
14.	08/02/2018	Mary	56-65	Site 1	Both legs	Telephone	Yes		No
15.	21/02/2018	Tina	46-55	Site 1	Body	Telephone	Yes		No
16.	22/03/2018	Rebecca	36-45	Site 1	One arm	Clinic	No	Moved away from region	Yes
17.	22/03/2018	Donna	36-45	Site 1	Both legs	Clinic	No	No response	No
18.	22/03/2018	Linda	36-45	LSN	Abdomen /Pelvis	Self-selected (e-mail)	Yes		No
19.	22/03/2018	Taran	46-55	Site 1	Both legs	Clinic	Yes		No
20.	22/03/2018	Jane	56-65	Site 1	Both legs	Clinic	Yes		No

	Date recruited by SHP	Participant (anonymised)	Age Range	Site	Body site	How Recruited by SHP	Interviewed	Reason	Observed in clinic
21.	22/03/2018	Maureen	76-85	Site 1	One arm	Clinic	No	No response	No
22.	17/05/2018	Adrienne	36-45	Site 1	Both legs	Clinic	No	Declined interview	Yes
23.	17/05/2018	Maddie	36-45	Site 1	Both legs	Clinic	No	No response	Yes
24.	17/05/2018	Owen	46-55	Site 1	Both legs	Telephone	No	No response	No
25.	17/05/2018	Adrian	66-75	Site 1	Both legs	Telephone	No	No response	No
26.	06/06/2018	Gracie	25-36	Site 1	Both legs	Yoga	No	Declined interview	Yoga
27.	06/06/2018	Susie	56-65	Site 1	One arm	Clinic	No	Moved away from region	Yes
28.	06/06/2018	Judy	56-65	Site 1	Both legs	Yoga	No	No response	Yoga
29.	06/06/2018	Betty	56-65	Site 1	One arm	Yoga	Yes		Yoga
30.	06/06/2018	Cathy	66-75	Site 1	One leg	Clinic	Yes		Yes
31.	06/06/2018	Greg	66-75	Site 1	Both legs	Yoga	Yes		Yoga
32.	06/06/2018	Jenny	66-75	Site 1	Both legs	Yoga	Yes		Yoga
33.	06/06/2018	Julie	66-75	Site 1	Both legs	Yoga	No	No response	Yoga
34.	06/06/2018	Rachel	66-75	Site 1	Both legs	Yoga	Yes		Yoga
35.	09/07/2018	Shona	66-75	Site 2	Both legs	Clinic	No	Cancelled due to ill-health	Yes
36.	10/07/2018	Graham	46-55	Site 2	One leg	Telephone	Yes		No
37.	10/07/2018	Lloyd	56-65	Site 1	One leg	Telephone	Yes		No
38.	10/07/2018	Penny	56-65	Site 2	Both legs	Telephone	Yes		No
39.	10/07/2018	Bob	56-65	Site 2	Both legs	Telephone	No	No response	No

	Date recruited by SHP	Participant (anonymised)	Age Range	Site	Body site	How Recruited by SHP	Interviewed	Reason	Observed in clinic
40.	10/07/2018	Peter	76-85	Site 2	One leg	Telephone	Yes		No
41.	27/07/2018	Patrick	46-55	Site 2	Both legs	Telephone	No	No response	No
42.	27/07/2018	Maeve	56-65	Site 2	Both legs	Clinic	Yes		Yes
43.	27/07/2018	Malcolm	66-75	Site 2	Both legs	Telephone	Yes		No
44.	27/07/2018	Donald	66-75	Site 2	Both legs	Telephone	No	No response	No
45.	27/07/2018	June	78-85	Site 2	Both legs	Telephone	Yes		No
46.	12/10/2018	Christina	46-56	Site 1	Body	Clinic	No	No response	No
47.	12/10/2018	Matt	46-55	Site 1	One leg	Telephone	Yes		No
48.	12/10/2018	Debbie	56-65	Site 1	Both legs	Telephone	Yes		No
49.	12/10/2018	Rowan	66-75	Site 1	Body	Clinic	No	No response	No
50.	12/10/2018	Shirley	85+	Site 1	Both legs	Clinic	No	No response	No

Table 7: Table of all Participants recruited to the study

3.4.2 Data Collection : Overt Non-participant observations

The primary objective of the overt non-participant observation was to gain insight into the dynamics of the service-users' interaction and conversation with the SHPs, and an understanding of their experience of operationalising coproduction and implementing their care from "hospital" to "home", in particular the socioeconomic impact upon their daily life.

The overt non-participant observations were undertaken within the two Lymphoedema Clinics at Site 1 and Site 2, following the steps defined by Atkinson and Hammersley (1994), whereby I first gained access to the research sites, through existing relationships with the SHPs in Site 1, and a mutual professional colleague at Site 2. This began at the start of the formal ethical approval process, and I established communication and rapport, with clinic SHPs, prior to the start of the study. Once ethical approval was gained, I planned which clinics I would attend with the lead nurse SHPs.

The observations took place within clinics from January 2018 – August 2018; all the observations took place during nurse-led (SHPs) follow-up clinic appointments, and I did not attend any of the first clinic appointments. All service-users were asked by the SHPS, if they would consent to me observing their consultation, if they would also consider participating in the in-depth, face-to-face interviews, and were given the PIS, without me being present. I attended the clinic appointment, with the permission of the service-user, and I did not conceal my role as a researcher or a registered nurse, and the SHPs introduced me as a "nurse-researcher" or as "researcher, who is a nurse".

Overt non-participant observation enabled me to observe the actual delivery of care, the interactions and conversations, and to capture the narrative of the activity during the consultation. Although I was not involved in the delivery of care, I was involved in conversations and questions (O'Reilly, 2012). The service-users who agreed to me being present also had the opportunity to ask further questions about the study, with a minimum of 24 hours to decide whether to take part in the interviews.

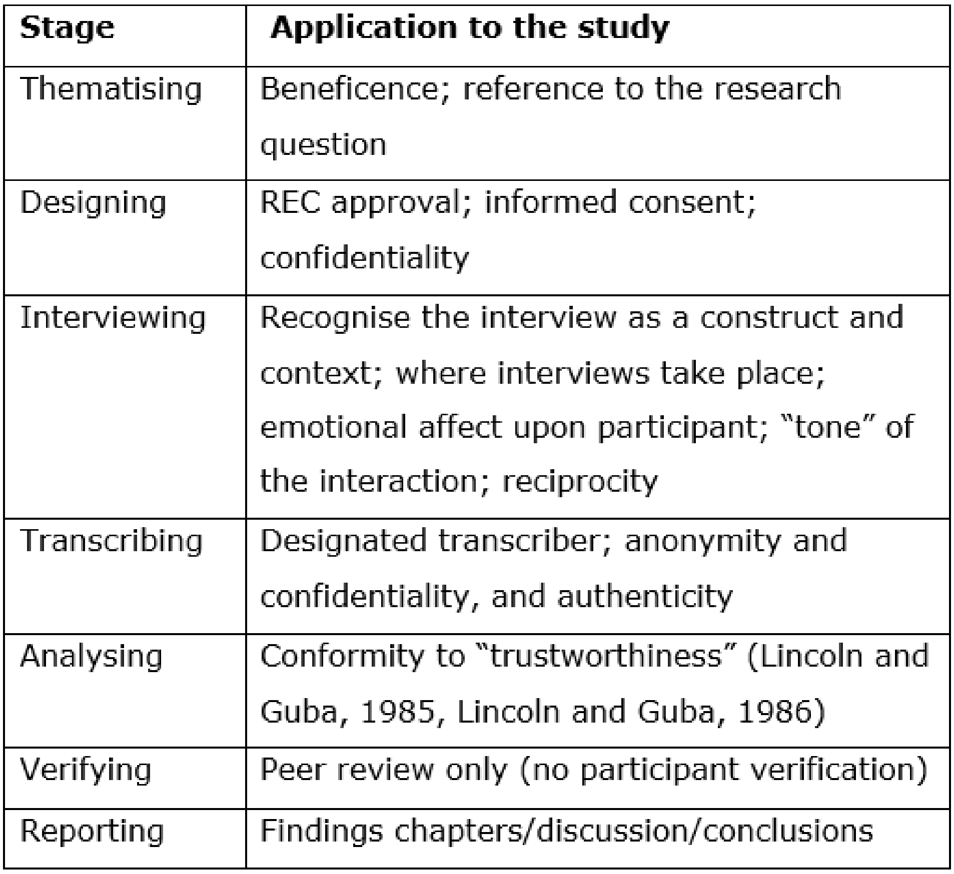
I attended several clinics on different days, across both sites, to ensure that I optimised opportunities to "sit in" with a diversity of service-users. In both of the clinic sites, I sat on a chair at an angle, facing the service-user, which enabled me to both listen and observe (Atkinson and Hammersley, 1994). I wrote most of my field notes up immediately after the clinic appointment, because I found it more appropriate to concentrate on what was occurring during the appointment, and to then reflect upon what I had observed. I noticed that the service-users watched me writing, and I was aware that this could influence what they verbalised. Furthermore, I did not always write what was said verbatim, however I paraphrased and ensured that the "voice" of the participants and the SHPs was present in my findings. This was achieved by documenting meaning, such as the tone of their voice, facial gestures, or if they voice altered because of an expressed emotion. This enabled me to observe the whole dynamic of the interaction.

3.4.3 Data collection: In-depth, Face-To-Face Interviews

The specific focus of interest was how the coproduction of care was operationalised at home when implementing their chronic oedema care; when the experience of implementing care is reported as complicated, time-consuming and uncomfortable. I was also interested in the socioeconomic impact of care, which included “out-of-pocket” costs, which are defined as unforeseen costs which have to be met by the participants, such as medications or clothing (Stringhini et al., 2010, Mercier et al., 2016a, Mercier et al., 2016b). Using interviews as a method facilitated the exploration of service-users experience of coproducing care through conversation between me and the participants, and sometimes their significant others. Furthermore, the purpose of interviewing participants later was to explore their subsequent experience, especially if the participant was a new service-user with a new diagnosis or had started new treatments.

Written informed consent was gained from all participants who were recruited to interview, and the Informed Consent Form (ICF) (Appendix 19) was signed and dated by the participant, before the interview commenced. I also asked participants if they would like to receive a summary of the findings from the study, as per the ICF. The participant was provided with the PIS, at the time of interview, and all details of the study were explained verbally to the participant. I asked the participants to confirm that they had sufficient time to consider participating; the opportunity to ask any further questions; and that their questions were sufficiently answered at the time of the interview. All participants, aside from one, requested that the interview take place within their own home. Therefore, one copy of the consent form was given to the participants, and one was placed within the Master File. No participants were interviewed within the clinic setting.

I prepared for the interviews by scoping the 7 practical stages suggested by Brinkmann and Kvale (2015); thematising, designing, interviewing, transcribing, analysing and verifying and reporting (Brinkmann and Kvale, 2015, p.23). How these were achieved, throughout this study, is detailed in Table 7, and they enabled me to bring together my methodological position, communication, interpersonal and interview skills.



Stage	Application to the study
Thematising	Beneficence; reference to the research question
Designing	REC approval; informed consent; confidentiality
Interviewing	Recognise the interview as a construct and context; where interviews take place; emotional affect upon participant; "tone" of the interaction; reciprocity
Transcribing	Designated transcriber; anonymity and confidentiality, and authenticity
Analysing	Conformity to "trustworthiness" (Lincoln and Guba, 1985, Lincoln and Guba, 1986)
Verifying	Peer review only (no participant verification)
Reporting	Findings chapters/discussion/conclusions

Table 8:7 Stages of the interview process (Brinkmann and Kvale, 2015, p.23).

I had prepared some questions for the topic guide (Appendix 20) using the chronic oedema papers (Mercier et al., 2016a, Mercier et al., 2016b, Mercier et al., 2019b, Taylor, 2021) which explored the socioeconomic context of chronic oedema. The topic guide was developed, and aligned to the aims and purpose of the study, including socioeconomic circumstances such as employment status; impact of lymphoedema on employment status and income; perceptions of the cost of lymphoedema healthcare; and any specific "out-of-pocket" costs due to living with chronic oedema, for example prescription charges, medical and non-medical goods not paid for by the NHS (Smith, 2005, Mercier et al., 2019a). These questions were developed in consultation with the clinic staff and through the PPI activity, prior to gaining ethical approval. Prior to starting each interview, I referred to my question plan; this was to ensure that I was prepared and started the interview asking the demographic questions about age, status (work and relationships). Throughout the interviews, I "listened" for how the "coproduction of care" was revealed, as the participants spoke about their experiences of shared-decision making and the implementation of care within the clinic and their home. I ensured that I appropriately maintained eye-contact, paraphrased, nodded and checked for understanding.

It was relevant to understand their access to healthcare and how far participants travelled to attend the Lymphoedema Clinic. This was if this affected their experience or perception of access; or the utilisation of lymphoedema healthcare due to geographical or financial issues. It was extremely relevant to understand their family and social dynamics, particularly in terms of the social support and social capital available to individuals and families, in terms of formal (social services/private social care) and informal care (family and friends); and in terms of if and how this enabled the operationalisation of care at home.

Moreover, the interpretation of the findings from the observations, together with the qualitative interviews enabled greater contextualisation; an in-depth, richer interpretation of the barriers and challenges specifically related to the operationalisation of coproduction of care, within the home. In addition, the PIS detailed the topics of interest, and therefore participants were aware of the potential subjects for discussion. Throughout the interviews I ensured that the focus was upon the participants' "narrative", and only asked questions when relevant, or if the conversation was waning. I tried to ask open questions, in a sensitive manner, which was appropriate to the conversation. Whilst all the clinic observations and interviews were conducted as separate processes, aspects of the participants' consultation were discussed during the interviews and were often prompted by the participants.

All interviews were recorded on a digital audio recorder; 29 interviews were undertaken and transcribed, which created a large amount of raw data (Mays and Pope, 1995, 2000).

3.4.4 Data collection: Postcodes and GP surgeries

The data collection sample was the total clinic population at Site 1, and this was to optimise the opportunity for staff to record the data, taking into consideration the additional workload. There were approximately 30 clinics per week, with between 3 and 8 service-users attending each clinic, therefore at least 7,000 clinic attendances over the 18-month period. The purpose was to identify if, and how many service-users were referred from the areas considered the most deprived, as per the Indices of social deprivation (ISD) (Ministry of Housing Communities & Local Government, 2015, NCC, 2015); the number of service-users from the GP practices within those areas; and if possible to determine which GP surgeries were referring the most service-users.

Furthermore, this identified GP surgeries as Participant Identification Sites (PIC), as this data was collected concurrently to the non-participant observations and the interviews. The aim was to visit the GP surgeries who were research active and part of the East Midlands NIHR Research Site Initiative (National Institute of Health Research, 2021). This is a scheme which provides support to GP surgeries and enables them to contribute to NIHR CRN-supported studies and increase their capacity and capability to be involved and deliver research. This was to increase the opportunity of recruiting participants diagnosed with chronic oedema who waiting to attend, or did not attend, a Lymphoedema Clinic.

The clinic staff were asked to document the full outward code, and first number of the inward code (i.e., NE9 5**) of all clinic attendees, including the full address of the service-users' GP practice. The reason for the partial postcode was because REC and HRA had only given ethical approval for the first number of the inward code. All the dates, postcodes and GPs were recorded on an excel spreadsheet, and I categorised all the postcodes, and filtered these into specific postcode areas, with the aim of identifying the highest and lowest number of service-users accessing the Lymphoedema Clinic.

I correlated the postcodes with the GP surgeries, which demonstrated the highest number of referrals, with the aim of identifying the distribution of service-users accessing clinics by their position on the ISD. I cross referenced the service-user postcodes against the GP's which featured most and least on the list, and then referenced this across to the East Midlands NIHR Research Site Initiative (NIHR RSI) (National Institute of Health Research, 2021) scheme list; and cross-referenced the list of RSI surgeries, to identify which surgeries would be most appropriate to include as PIC sites.

The SHP Team explained that they could copy the relevant details from the clinic lists on to the paperwork I provided to record the data, and they were asked to fill in as many as possible. I was attending the clinic at relevant intervals and able to collect the data each time I attended. I analysed the postcodes data concurrently during the study, to identify and contact GP surgeries as a PIC site, I could contact to recruit participants to the face-to-face interviews part of the study. I subsequently contacted 10 GP surgeries by telephone, to introduce myself, and then arranged dates and times to deliver the posters and the patient information sheet (PIS). The rationale for this was to increase the diversity of participants within the study, given that those living with a diagnosis of chronic oedema are known to be a heterogeneous group.

3.5 Data analysis methods.

Data analysis of the overt non-participant observations and the in-depth, face-to-face interviews was undertaken concurrently to the data collection. This was to ensure that I remained focused on the research questions; that I comprehended the phenomena under exploration fully; and reflected upon my skills, in the pursuit of good qualitative research (Silverman, 2014). All data sets were analysed and interpreted separately by me, and the results and findings contributed to answering the research question.

I used a combination of thematic analysis (Braun and Clarke, 2006, 2012) and techniques from thematic network analysis

(Attride-Stirling, 2001) to analyse data, for both the interviews and the observations. The justification for this approach was that thematic analysis is an open method, appropriate to most philosophical assumptions and useful for novice researchers (Hollway and Jefferson, 2008). The emphasis was upon coding the most meaningful aspects of the data, in terms of the aims and objectives of the study, and not solely the pattern of those themes (Braun and Clarke, 2006, 2012, Silverman, 2014).

The concepts of "operant" and "operand resources" were pivotal to my analysis and interpretation of meaning, within the context of the coproduction literature, particularly in reference to the theories of Lovelock and Young (1979), Morgan and Hunt (1994), Bettencourt et al. (2002), Vargo and Lusch (2004), Lusch and Vargo (2006), Bovaird (2007), Jacob and Rettinger (2011), Bovaird and Loeffler (2012) and (Voorberg et al., 2015). These were approached in terms of the perceived and described responsibilities of the health professionals and the service-user, from both the observations and within the interview transcripts.

During the analysis I compared the participants to identify their demographic and geographical similarities, and differences; I explored the diversity of the service-user group; and process mapped how service-users were referred and accessed the clinic. This was achieved through the service-users descriptions and interpretation of their experiences, and their account of reality (Baxter and Jack, 2008). This was an opportunity to reflect themes which emerged from and within the participants descriptions of their socioeconomic contexts, in addition to those themes which emerged from the transcripts (Brinkmann and Kvale, 2015).

During the analysis it emerged that the participants used the term "lymphoedema", rather than chronic oedema, therefore for consistency, this term will be used within the finding's chapters.

3.5.1 Analysis of the Overt Non-participant Observations

The aim of the analysis was to interpret the observational data from an "iterative-inductive" (O'Reilly, 2012, p.29) perspective, as this was a more fluid and flexible approach (Braun and Clarke, 2006, 2012, O'Reilly, 2012). Undertaking overt non-participant observation, led to a greater opportunity to gain insight into the dynamics of the relationship between the SHP and the service-users. I framed my analysis in terms of the themes which emerged from the interactions, and how these related to the cogent aspects of the relevant coproduction theories such as, "relational exchange", "operand"/" operant" resources, shared-decision making, responsibility, accountability and nurturing.

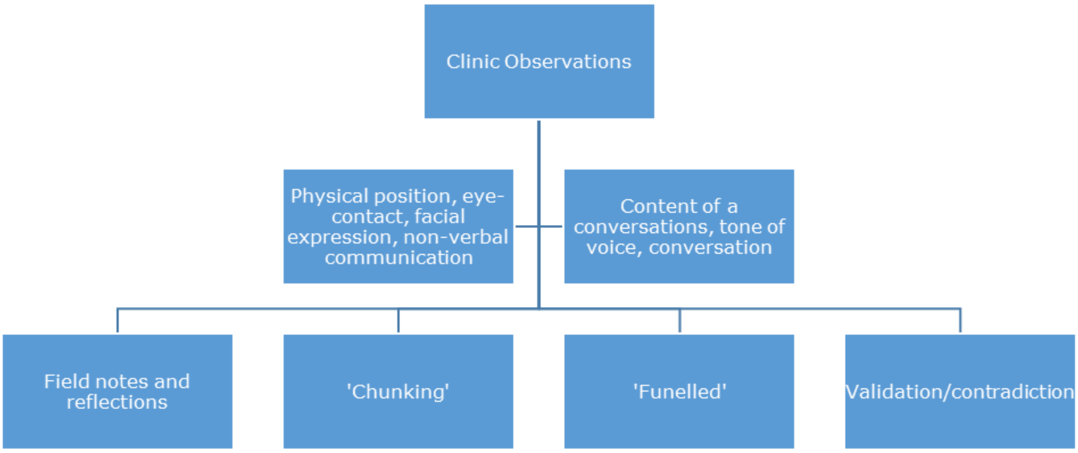


Figure 4: Thematic analysis process for the Clinic Observations

My thematic analytic process was as follows (Figure 4),

- I separated the data into what I observed (physical position, eye-contact, facial expression, and other non-verbal communication); and in terms of the content of conversations (tone of voice, how the SHP and the participant navigated their conversation together)
- I read through my field notes after each consultation and added further narrative by reflecting on the interactions.
- I reviewed my notes and highlighted relevant text, in terms of quotes, words and sections of text which are relevant to the research question, referred to as "chunking" (Roberts, Dowell and Nie, 2019, p.6).
- I examined how these "chunks" (Attride-Stirling, 2001, p.391) related to my study aims, and the relevant coproduction literature (relational exchange, "operand" and "operant resources", shared-decision making) and identified codes and themes which emerged.
- I "funnelled" (Hammersley and Atkinson, 2019, p.168) the "chunks" to prevent it from becoming anecdotal (Silverman, 2011), and to focus the themes and sub-themes which were written on post-it notes.
- Finally, once the data was analysed, I compared these with the themes, from the interviews and identified any areas of validation or contradiction.

3.5.2 Analysis of the In-depth, face-to-face interviews

All recorded interviews were professionally transcribed, in line with the university regulations; all interviews were typed verbatim and checked prior to analysis. For the purpose of analysis both the researcher's and the participant's talk was included; and transcripts included colloquialisms, pauses, corrections and overlapping speech to:

- Include any "ums and aahhs" and repeated words (no background noises, coughs, sneezes)
- Reflect any colloquial language and write a word as it was spoken for example. "yer" instead of "your" as there were distinct accents within the regional dialect
- Reflect times when there was cross talking [CT], [laughs] or [crying]

My rationale for this was that the East Midlands has a colloquial dialect, and the accents of some participants were salient, and an important aspect of the interviews and findings. I wanted to reflect a realistic representation of the participants' "voice" in the analysis and interpretation, to ensure transparency and authenticity of how, and what, the participants described (Bucholtz, 2000). Therefore, deciding on a method of analysis prior to the interviews guided the interview process and the transcription (Silverman, 2014). This followed an iterative process of listening to recordings, reading and re-reading transcripts, and "transcription checking" (Gibbs, 2018, p.136) to ensure that there were no obvious mistakes.

The interviews were semi-structured in that I asked a few demographic questions at the beginning of the interview, and then asked the participant to describe "their story", in their own words, specifically related to their experience of care within the Lymphoedema Clinic, and how they subsequently implemented this care at home

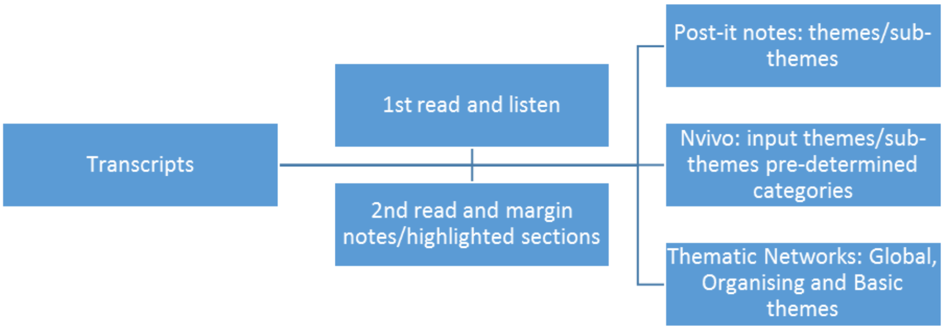


Figure 5: Process of thematic analysis and thematic network analysis of interviews

In terms of the steps which were undertaken (Figure 5),

- I read all paper copies and listened to each audio recording as I read the transcript again.
- I re-read all transcripts as paper copies and relevant statements and key words were highlighted, with prompts for analysis documented in the margins.
- I used a combination of deductive and inductive strategies (O'Reilly, 2012, p.29) to develop a coding frame.
- Concurrently, I undertook a deductive process, using Nvivo research software to develop a predetermined thematic coding framework (Appendix 21-23). This was developed using the overarching headings from the study protocol and participant information (coproduction, treatment, lymphoedema, identity, socioeconomic deprivation).
- Subsequent headings and sub-headings were those which emerged from the data
- I wrote single words, comments and questions on "post-it notes", and in the margins of the printed transcripts.

This was to prompt and highlight sections as a visual display of themes and key words, and to aid interpretation of the data.

- I collated all post-it notes together in themes, on flipchart paper
- All themes were then validated against the original transcript, during the iterative process of returning to the transcript and this was developed into the initial table of themes (Appendix 24). I organised these into statements and narratives, which led to the emergence of a narrative framework
- Once this process was completed the framework and the raw themes from the data were then cross-referenced against each other (Appendix 24 and 25). I expanded the headings and themes within the thematic framework analysis, to demonstrate how the themes interconnected.
- All coherent themes were refined (Elo and Kyngäs, 2008, Elo, Kääriäinen, Kanste et al., 2014), and this enabled me to define how they correlated, and revealed recurring "essences" within the text (Creswell et al., 2007).).
- I used thematic network analysis, to condense these into global, organising and basic themes (Attride-Stirling, 2001) (Appendix 25).

Appendix 24 and 25 demonstrates how this process was undertaken.

The process of analysis and coding was an iterative/deductive process; as demonstrated in Appendices 21-25; it included interpretation of the specifics and the overarching themes within the conversation, and whether the participants' discussions matched an existing category, and the information a participant was given prior to the interview (posters/PIS).

This also ensured that the analysis was comprehensive and prevented the interpretations from being pre-selected and/or anecdotal (Silverman, 2014). The process continued until no further themes emerged, and themes repeated, which I regarded as reaching “saturation” (Morse, 1995, Guest et al., 2006), taking a pragmatic approach, as discussed previously in this chapter (3.3.4). I regarded the transcripts as a “living conversation” (Brinkmann and Kvale, 2015, p.218), and I wanted to ensure that I articulated the meaning of individual experience accurately (Tufford and Newman, 2012). This was to ensure that during the analysis I did not reach either tenuous interpretations, or substantiating conclusions (Brinkmann and Kvale, 2015) which did not accurately reflect the participants meaning. This also acknowledged that it is frequently assumed that all participants can articulate and describe their experiences (van Manen, 2016, 2014), and that they fully understand and comprehend their experience during an interview (Tufford and Newman, 2012). This was pertinent because the study was undertaken from a constructivist perspective, and the focus was the lived experience and participants’ individual realities.

I used thematic analysis to initially code the interviews (Braun and Clarke, 2006, 2012, Nowell, Norris, White et al., 2017); and then thematic network analysis to synthesise the findings in a robust, rigorous and trustworthy manner, this was appropriate as many of the themes and subthemes were closely interconnected (Lincoln and Guba, 1986), as demonstrated in Appendix 25. To add to the rigour to the process, several transcripts were also analysed separately, by two of my academic supervisors, and agreement and consensus achieved, on our interpretation. I chose not to return the transcripts to the participants for “respondent validation” (Gibbs, 2018, p.132). My rationale for this was that I did not want to detract from the meanings and emotions I interpreted from the transcripts, and to ensure that they reflected accurately the authenticity of the moment.

3.5.3 Analysis of the postcodes and GP surgery data

In terms of the analysis of the data, I initially used a detailed postcode map of the region; however, as I started this process, I realised that the postcode boundaries also crossed local authority districts (LADs). This was of relevance as the LADs, and not the postcode, determined the position of an area on the ISD. Therefore, because the city is divided into local authority districts (LAD), which cross postcode boundaries areas, I was unable to use the postcode map accurately. Instead, I filtered the service-user postcodes, and the GP postcodes using GeoPunk (GeoPunk, 2021). GeoPunk is a website which identifies the exact location of postcode districts, local council areas, and roads in England Scotland and Wales (GeoPunk, 2021). I analysed each postcode, as positioned within the LAD and checked where the LAD was positioned, according to the 2015 ISD. This was a complex process and necessary because I only had access to the partial postcodes. Furthermore, some postcodes covered two LADs and used I GeoPunk to confirm their exact position. This enabled me to document each of the postcodes in an excel spreadsheet with the relevant LAD.

3.6 Ethical Approval: Good Clinical Practice, Ethical issues and confidentiality

3.6.1 NHS ethical approval

Formal NHS ethical approval was required for this study as the study participants were NHS service-users. Prior to submitting any participant information to IRAS (Health Research Authority (HRA), 2017), draft versions of the PIS, ICF and posters were sent to the SHPs within both of the Lymphoedema Clinics at Site 1 and Site 2. Prior to submission for ethical approval PPI activity was undertaken in line with the requirements of the IRAS application and in terms of Good Clinical practice (Health Research Authority, 2017, National Institute for Health Research (NIHR), 2019) with the local Lymphoedema Support Group and the SHPs. Copies were also sent to the Research and Innovation PPI lead at Site 1, who disseminated them to the Trust’s PPI group for comment. The SHPs at both Lymphoedema Clinics, and the service-user fed back that they were satisfied with the content of the documentation, and that they were written and understood in “plain English”, and all wording aligned to the Health Research Authority (HRA) (2020) templates, which changed due to the introduction of GDPR (Information Commissioner's Office, 2018) in May 2018. The service-user also expressed that they considered this important and relevant research, which they believed was not currently available. Receiving this feedback enabled the design of a “real world” study (Creswell et al., 2007, Creswell et al., 2011) which considered the needs of the day to day running of a busy clinical area.

The study received ethical approval by Proportionate Review at a regional NHS Research and Ethics Committee, in

November 2017. The study did not commence until the 22nd of January 2018, when all approvals were given by the NHS organisations Research and Innovation departments. The study data collection was paused in August 2018, when a substantial amendment application was submitted and then agreed in September 2018. This was required for the change of Chief Investigator. All procedures were followed, and documentation to support this process can be seen in Appendix 6-17.

3.6.2 Good Clinical Practice, Ethical issues and Confidentiality

The aim of the study was to explore how coproduction is operationalised in the context of care across the interface between hospital and home for people living with an LTC, and the role of resources and social capital. However, in explaining this to participants I needed to ensure that I used the most straightforward language which explained the purpose of the interview clearly. It was made explicit within the participant information sheet, and through the process of informed consent, that participating meant being asked questions of a personal or intimate nature (Brinkmann and Kvale, 2015). This meant that building trust and rapport with the participants, within a short period of time, was important as some questions could unintentionally evoke emotional distress. Therefore, all participants were informed that they could stop the interview at any point, and should they wish to continue, would be given time within the interview to gain composure. They were also informed that they could decline answering any further questions which might cause distress or terminate the interview. Due to the risk of inconvenience, in terms of time and venue, participants were asked where they would prefer to be interviewed.

Interviews are considered to be a “moral inquiry” (Brinkmann and Kvale, 2015, p.84) and I had moral and professional obligations, both as a researcher, and also a registered nurse. This was relevant because the participants disclosed subjects and details about their personal life which they might not be discuss in everyday conversation (Johnson, 2001). However, none of the participants verbalised feelings of intrusion or inconvenience. Moreover, I also had to consider the ethical implications of self-disclosure; I ensured that I only shared “appropriate” experience of caring for those with lymphoedema, and that it did not include any prescriptive advice. It was important to be aware of the challenges my role as a researcher may pose in terms of “the Hawthorne effect”, described as a change in the behaviour due to being observed and interviewed, and within the context of the interview (Sedgwick and Greenwood, 2015, Muldoon, 2017, Wickström and Bendix, 2000). I accepted that this was an inevitable part of the interactive process of qualitative inquiry, and why it was important for me to retain a reflexive position throughout data collection (Koch and Harrington, 1998, Borbasi et al., 2005, Finlay and Gough, 2008).

Moreover, an important consideration relates to unintended consequences, such as the process of observation or interview becoming a therapeutic experience for the participant. When participants revealed personal details and experiences, there was a potential therapeutic benefit to the participants. This was due to the opportunity to fully express their experience, and the revelation of new understanding. Therefore, the findings also demonstrated the beneficent effect of the purpose of this study, and the experience of participating (Farrimond, 2013). This was to increase knowledge and awareness of the complexity of coproducing and implementing chronic oedema care, even if this did not directly affect all of the participants in the study. This was explained to the participants during the process of informed consent, and the response of many was that they believed this to be an important study, regardless of it directly benefitted them. They stated that they did not want other people diagnosed with the condition to experience the same challenges that they faced.

3.7 Trustworthiness: Data collection and Data Analysis

Part of the beneficence of my study was to ensure the fidelity and trustworthiness of my research conduct (Farrimond, 2013, Lincoln and Guba, 1986). Therefore, whilst I disclosed that I was a nurse to the participants, I explained that I was not there in the capacity as their nurse; however I was professionally bound Nursing and Midwifery Council Code of Professional Standards (2018). I explained that the observations and interviews were treated confidentially. If a participant disclosed information believed to place the participant, or anyone else at any risk, I explained that I was obliged to report this to the appropriate persons, for example criminal activity or a safeguarding concern (Straughair, 2011).

Furthermore, I ensured rigour and quality in the process of data collection, interpretation and analysis of the findings, by aligning the strengths and limitations of my methods (Fereday and Muir-Cochrane, 2006, Sandelowski, 1986, Creswell and Miller, 2000) in terms of their definition of "Trustworthiness"

(Lincoln and Guba, 1985, p.290). It was important to consider the extent to which the analysis and findings reflected the reality of the experience of the participants within the context of the interaction and through my interpretation. I remained aware of all of these in terms of the limitations of my study.

Criteria	Strengths	Limitations
Credibility of data processes (internal validity):	Use of interviews and observations concurrently "Nurse-researcher" Diversity of participants: SHPs and service-users Use of verbatim quotes Non-participant observation throughout the data collection period Comparison between inferences from observations and interviews; "deviant" cases (2 participants at interviews)	No access to first appointments "being" a nurse and a "clinical evaluation lens"
Transferability: (External validity)	"Thick description" from observations and interviews Analysis of the interviews interpreted with comparison/ applicability of the studies within the literature review settings within more than one organisation (Site 1, site 2, participants' homes)	Very specific to one long-term condition Specific to a specialist clinic Specific to one geographical locality

Dependability: the methodological process of inquiry	"transcription checking" (Gibbs, 2018, p.136) Use of thematic analysis and thematic network analysis to develop codes, categories and themes from the interviews and observation. Adherence to the data collection timetable	Transcripts were not given to participants to read Transcription undertaken by a professional transcriber
Conformability: (objectivity)	Use of a reflective journal during data collection Analysis undertaken with supervisory team	No respondent validation (Gibbs, 2018, p.132)

Table 9: Criteria for trustworthiness (Lincoln and Guba, 1985, p.218-219) adapted from Teddlie and Tashakkori (2009, p.296)

Therefore, I demonstrated trustworthiness (Lincoln and Guba, 1985, p.218-219) (Table 9) by using the guidance from the NIHR Good Clinical practice (GCP) (Health Research Authority (HRA), 2017). This enabled me to manage the ethical considerations regarding confidentiality and the anonymity of participants; the data I collected; and the documentation I created throughout the study.

- I used the GCP templates to develop standardised documents for within the Master files, and the two site files.
- All documents within these study files were treated as confidential and held securely in accordance with the University regulations.
- To ensure the anonymity of the participants, I assigned each a study identity code number and a pseudonym.

These were recorded as a separate confidential record of the participant’s name, date of birth, and Participant Study Number.

- I ensured the anonymity of the SHPs, by using a code and did not reveal their identity when paraphrasing their statements.
- When the participants or SHPs referred to a person by name, I replaced their name with asterisks
- I used the identity code number on study documents and pseudonyms of the participants within the thesis.
- All paper forms adhered to the University’s and the Nursing and Midwifery Council’s record keeping standards (NMC, 2018) and GDPR (2018).
- I adhered to The University Lone Working Policy when participants were interviewed within their own home, or an alternative location.

In accordance with the REC/HRA ethical approval, only the usual care team were permitted to access the electronic service-user records and clinic lists. These held the participants’ sources of identifiable personal information. All participants recruited were informed that the content of the interviews was confidential; and recruited participants were assured that their anonymity would be protected, and that details of the interview would not be disclosed or divulged to members of their usual care team. They were made explicitly aware that the interviews would be recorded onto Dictaphone, and that these recordings were uploaded to a secure online platform, as per the university policy.

In addition, permission was sought through NHS REC to use transcribing services accredited by the University. All interview files for transcription were uploaded onto a file shared by the researcher in "Dropbox", as permitted by the University, and conformed to data protection regulation (GDPR). Once downloaded by the transcriber, they were deleted from the platform and then deleted from the device

I chose not to give the transcripts to my participants for review, this was again because I wanted to ensure the fidelity of the interviews (Farrimond, 2013); that they were an authentic reflection of the interview, and our interaction. This ensured that the data collection, analysis and interpretation aligned to the constructivist perspective because it reflected the lived experience and individual realities of participants at the time of the interviews (Creswell and Plano Clark, 2011), rather than the possibility that the participants would want to change or reinterpret what they had described.

3.8 My reflexive position as a nurse-researcher

Ensuring reflexivity and reflecting upon my position as the researcher was an integral aspect of the data collection, analysis and interpretation process. My interactions with the participants and SHPs enabled an exploration, and uncovered themes which emerged from the accounts of their experience (van Manen, 1997, Bonner and Tolhurst, 2002). This was specifically in terms of my presence, as a researcher; interacting with the participants and the SHPs (Bonner and Tolhurst, 2002); as an intrinsic actor in co-constructing the context with the participants (Hamill and Sinclair, 2010); and my subjective experience with the participants, were all part of the research process (Tufford and Newman, 2014).

I was aware that my existing knowledge and beliefs shaped my interpretations, and therefore a reflexive approach made me aware of the preconceptions, at the beginning of the research process. This enabled me to develop a strategy to address this prior, during and after the observations and interviews, recognising and mitigating the potential “duality” in my role (Borbasi et al., 2005, p.499). Moreover, my “a priori” experience and knowledge as a nurse, meant that I did not need to learn the clinical and cultural language and the setting (O'Reilly, 2012), and I did not need “learn” rules of the setting (Hughes, 1989).

This is specifically relevant in nursing and healthcare culture, due to the use of colloquialisms and abbreviations, and nursing routines. In this study service-users also adopted this language, which I interpreted as the development of their “operant” resources regarding their understanding of lymphoedema care, within the context of the setting. This enabled me to listen more consciously and recognise new insights into the phenomenon of their experience, as I did not need to interrupt or ask questions. However, I also had to be aware of the criticisms of a constructivist perspective, that my interaction, and my “a priori” knowledge could also challenge my ability to interpret any findings in a way that maintained the authenticity of the participant’s narrative. I had to ensure that what I was interpreting was “subtle realism” as rather than the pursuit of “truth” (Mays and Pope, 2000, p.51). Furthermore, I conducted this in a way that did not undermine my philosophical position.

This focus enabled me to acknowledge the interpersonal and social context of the observations and the interviews; and the interpretations of meanings which occurred within that context (Brinkmann and Kvale, 2015, p.218). Moreover, my a priori knowledge was relevant specifically because I am nurse, and my awareness of my position was relevant to the analytical process (Ho, Chiang and Leung, 2017). However, the idea of "bracketing", or separating my knowledge (Hamill and Sinclair, 2010, p.16), as part of a social constructivist approach, was challenging (Koch, 1999). I was an intrinsic part of the research process; interpreting the data, and therefore I could not completely detach my interactions from the essence of a phenomenon (Sloan and Bowe, 2014).

I addressed the challenges of "bracketing" (Hamill and Sinclair, 2010) my knowledge through "reflection-in-action" (Schön, 1983, p.62) during, rather than after the interaction. This ensured the rigour of my methodological practice (Borbasi et al., 2005), and the credibility and trustworthiness of my data collection processes, interpretation and analysis (Lincoln and Guba, 1986). This was especially relevant in terms of the observations; although I was a "non-participant", I remained part of the interaction, and my analysis included my reflexive position in the field. This was also relevant from a social constructivist perspective, in terms of exploring the participants' meaning, individual learning and the reality of living with lymphoedema; how:

> *"Scientific beliefs and facts are socially created"*
> *(Kukla, 2000).*

O'Reilly (2012) describes the reflexive practice of participant observation as an "embodied activity" (2012) as researchers are present in the setting. Therefore, meeting the service-users within clinic was valuable, as I had the opportunity to gain insight to their experience during their interaction with the SHPs, which was not completely captured in subsequent interviews. It also enabled me to develop a rapport much more easily with those participants I interviewed as I had met them previously.

This also reflected the “field relations” (O'Reilly, 2012, p.100) I developed through my interactions with the participants, and facilitated a meaningful relationship with the participants, within the context of the interviews (Borbasi et al., 2005, Boellstorff, Nardi, Pearce et al., 2012). Furthermore, when the SHPs introduced me as a nurse, I realised they were legitimising my presence. I began to do this too to legitimise my role as an “insider-outsider” (Bonner and Tolhurst, 2002, p.7). These interactions enabled commensurability (Magee, 2011, p.15) and reconciliation of my identity, as a nurse and a researcher (Bonner and Tolhurst, 2002, Bloomer et al., 2012, O'Reilly, 2012). Therefore, I gained deeper insights into the dynamics of the relationships between the participants and the SHP, which enabled me to contextualise “what happens” when coproducing care within the clinic appointments.

Throughout my time within the clinics, I noticed differences between the two sites, particularly the recruitment of participants to the in-depth, face-to-face interviews; recruitment was greater when I was present in the Clinics at Site 1, and greater when I was not present at Site 2. I was aware that this was bias because of a prior professional relationship with the SHPs, at Site 1. This expedited my access to Site 1 more easily, and led to a more relaxed relationship from the outset of the study.

In terms of the interviews, I began by asking each participant the same questions, to open the conversation and put the participant at ease. This led to the participants talking more readily about what they want to discuss, and through describing their “story”, many of the questions I wanted to ask were answered. I used silence and pauses, rather than over talking, and actively listening to ensure I was consciously aware, to prevent myself from “drifting”. I encouraged the participants to freely describe their experiences, and was then able to ask, clarify or qualify what they described more appropriately and sensitively. Furthermore, when I realised I asked a leading question, I rephrased the question, or engaged in a more relaxed a conversational approach to minimise the “the Hawthorne Effect” (Sedgwick and Greenwood, 2015, Muldoon, 2017, Wickström and Bendix, 2000), or a change in their responses due to the context of the interview. In doing this my confidence and skill as a researcher increased, as I recognised the interviews as a social interaction, rather than a clinical appointment, and made the concerted effort to reflect upon my presence within the interaction.

This led me to reflect upon “bracketing” (Hamill and Sinclair, 2010), within the in-depth, face-to-face interviews, and my position within the field (Koch and Harrington, 1998). Whilst I was not able to “bracket” my knowledge and preconceptions, reflecting enabled me to strategically prepare more for subsequent interviews (Ahern, 1999). This was especially important in relation to instances when I was conflicted, for example when service-users asked me clinical questions about their lymphoedema. I ensured that I was prepared with an answer which reflected my accountability as a nurse, but not “your” nurse.

I was aware that the conditions within the context of the interview were relevant to the phenomenon under study (Baxter and Jack, 2008). For example, interviewing participants within their own homes enabled me to observe and interpret the location of their homes, and the types of accommodation they inhabit. However, I approached the interview process with an open mind, acknowledging my beliefs and position, and conscious of any assumptions or value-judgements; I did this to be fully prepared to hear the participants “story” (Starks and Trinidad, 2007). Furthermore, I improved my interview technique by listening back to interviews, and re-reading my “out-of-the field diary” (Delamont, 2007, p.213), which I used to document my reflexive experience throughout the data collection, in addition to my PhD journey overall.

4 Observational findings

4.1 Chapter overview

This chapter discusses how I accessed the Lymphoedema Clinics; the exploration of the overt non-participant observations and the interactions within the clinics, between the service-users, and the SHPs; and the service-users at the Yoga sessions. I describe the clinic observation findings, under the themes "Sharing "operant resources", "Relationship building" and "We are detective": spoken and unspoken conflict" and how social capital is observed during the interactions. Finally, I conclude with the analysis, interpretation and discussion of the observational findings.

Within this chapter I include a section where I discuss the methods, analysis, findings and relevance of collecting the postcodes and GP practices, and explain the relevance of this data, within the context of the study.

4.2 Access to the clinics

My initial access to the clinics was straightforward and I believed this was because I had an existing and established professional relationship with some of the SHPs from both sites, and I developed a good working rapport with other members of the SHP Team. This was as a result of a previous nursing and research role, and the effort I made to negotiate which clinics would be the most appropriate for me to attend, and the best dates and times to access the clinic consultations. This included deciding with the SHPs the best way for them to introduce me to the service-users.

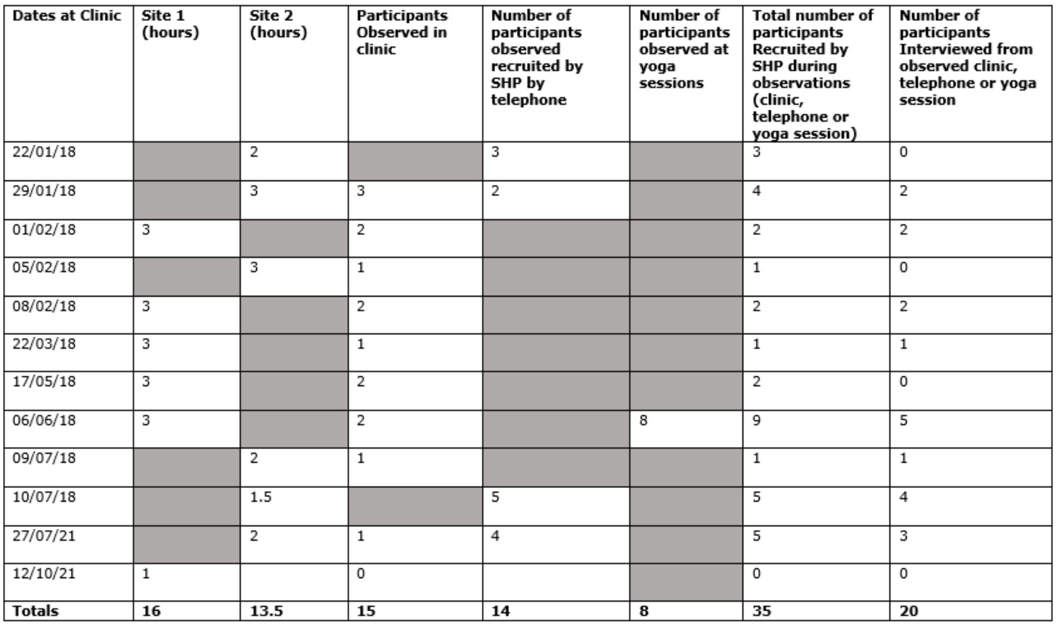
Throughout the period of observational data collection, I only attended follow-up appointments at both sites. Despite being cordial with me, the senior SHPs at Site 1 asked me questions about the study in a tone and manner, which I interpreted as indicating that they were suspicious of my intentions. I was later informed by a less senior SHP, that it would not be possible for me to observe the consultations for new service-users at Site 1, even though there had been an opportunity for the two senior SHPs to explain this to me. The reason given was that they would be much too “busy”, both in terms of space in the consultation rooms, and time constraints. Moreover, the appointments for new service-users were led by more senior SHPS, who I had met in my previous roles. I accepted this, and recognised it as “gatekeeping”, whereby a I was prevented from having access by a member of staff with status within the organisation (O'Reilly, 2012).

I chose not to challenge this, as I did not want to undermine my positive relationships with the other SHPs, however this interaction enabled me to recognise the hierarchical relationships between some of the SHPs within the Clinic 1. In addition, because I was not present for any of the service-users first appointments the less senior SHPs made a point of explaining what usually occurs as standard practice. There were no “gatekeeping” issues at Site 2; however due to the location of the Clinic and the dates I intended to observe, it was not possible for me to attend first appointments.

My aim was for the SHPs to purposively recruit participants, which led to their selection bias in choosing participants for me to observe and interview. This was apparent because the SHPs were quite open about wanting me to interview participants they perceived as “interesting”, “complex” and “challenging”. They made it explicit that this was in terms of the opportunity for me to interview those with chronic oedema, who they considered were “rare”; or difficult to treat, because of the complexity of their condition; or if they perceived the service-user as “challenging”, in terms of their engagement and implementation of treatments. The SHPs verbalised that they wanted me to understand the challenges they faced, when caring for these service-users, and the challenges that it posed for them as clinicians. On a few occasions, they expressed that it was a “shame” if I “missed” a service-user in clinic, because I was observing in another room, or if I was not present that day.

Table 10 outlines the number of hours I spent in the clinics; the participants I observed, recruited and interviewed. However, I did not observe all of these participants during their clinic appointment; each appointment lasted approximately one hour, and therefore it was difficult and inappropriate to move between rooms, until each consultation had finished. I observed a total of 15 participants in the clinic setting (across both sites) and observed 8 participants during the yoga session

At Site 1, 12 participants were recruited by the SHPs separately to the clinic observations, and of these 6 were interviewed (one participant self-recruited via the Lymphoedema UK Support Group advert on Facebook). A total of 16 hours observation was undertaken at this location, I observed 12 participants in clinic, of which 5 were interviewed. I also observed two, hour long “seated yoga” sessions which were held in a separate room, away from the clinic. The first was not was included in the data collection, and no participants were recruited. The SHP recruited 7 participants who attended the second yoga session, and 5 were interviewed. At site 2, 13.5 hours of observation was undertaken, I observed 6 participants during their consultation (Table 10). The 4 participants recruited to the study, which are not reflected in the table were recruited by the SHPS by telephone, however I did not observe these calls.



Dates at Clinic	Site 1 (hours)	Site 2 (hours)	Participants Observed in clinic	Number of participants observed recruited by SHP by telephone	Number of participants observed at yoga sessions	Total number of participants Recruited by SHP during observations (clinic, telephone or yoga session)	Number of participants Interviewed from observed clinic, telephone or yoga session
22/01/18		2		3		3	0
29/01/18		3	3	2		4	2
01/02/18	3		2			2	2
05/02/18		3	1			1	0
08/02/18	3		2			2	2
22/03/18	3		1			1	1
17/05/18	3		2			2	0
06/06/18	3		2		8	9	5
09/07/18		2	1			1	1
10/07/18		1.5		5		5	4
27/07/21		2	1	4		5	3
12/10/21	1		0			0	0
Totals	**16**	**13.5**	**15**	**14**	**8**	**35**	**20**

Table 10: Hours of non-participant observation in the Lymphoedema Clinics

The layout and the position of each clinic was an important aspect of this study. Neither the clinic at Site 1 nor Site 2 had their own dedicated, permanent space. Both clinics were situated in a space which is part of or “belonged” to another service or was usually an inpatient service. Furthermore, conversations with the team revealed that they are part of a prestigious National Centre of Excellence, working relationships with genetic, vascular and paediatric teams for complex disease. However, most referrals to the clinics were from local GPs; a lesser number through referrals from consultants within secondary services, and some “out of county” referrals, for more complex disease.

4.2.1 Site 1:

This clinic was initially located in separate, conjoined rooms along a busy corridor of the hospital. The first clinic room was used as the office space; three administrative staff worked in here, and the room had a few lockable filing cabinets. All service-users had to knock on the office door, to inform the administration staff of their arrival. The space available for service-users to wait for their appointment was on the corridor, and opposite and adjacent to one of the "front door" medical admission units.

The absence of a formal waiting area was arresting, and there were several oversized chairs along the wall of corridor. This set it aside from all the other clinic settings within the hospital, which all had a space or room within their department, clearly identified as a waiting area. The corridor was used as a "short-cut" for hospital staff moving service-users, treated in the medical admissions unit, around the hospital on trolleys and wheelchairs. Therefore, it was not only a busy area in terms of hospital traffic, but also in terms of limited space. This meant that it was often difficult for the trolleys to move past the chairs (and often wheelchairs and mobility scooters) unless the service-users waiting for their Lymphoedema Clinic appointment moved "out of the way". In addition, the position of the chairs made the service-users, waiting for their clinic appointments, appear to be "on show", and this was apparent in the way I observed passers-by staring.

Within the administration office room there was an interconnecting door, which led to clinic room 1, and the same again between clinic rooms 2 and 3. Each room had a door onto the corridor, and a window with frosted glass, towards the back of the room. All clinic rooms had a hand wash sink and were set up in the same way; with a desk and chair; a high backed, comfortable chair, and a medical couch for service-users. The rooms also had several metal cupboards with supplies, and the large windowsills were also piled with further supplies.

Part way through the data collection period, the clinic was given notice to vacate all the rooms, because of plans to expand the medical admissions area. This led to uncertainty in terms of where the clinic would move; the first move was to another hospital site 4.2 miles away, across the other side of the city. This was a “Nightingale” ward; a traditional style in-patient ward, designed as one large room, with high ceilings and multiple windows, allowing nurses to view all of their patients (Hurst, 2008). The atmosphere was the complete opposite at the hospital ward; it was a large and spacious area, with natural light. A few of the curtained bed spaces were used as the consultation areas, as there were no individual rooms for staff to use. In addition, the waiting area was a windowed room at the bottom of the ward. In this location, the whole ward belonged to the clinic and was visibly much less cluttered, as there was adequate apace and storage for all the equipment and supplies.

Service-users entered the ward through a telecom call system, and then moved to the reception desk at the front of the ward. This was a much more private space and I observed that the service-users appeared to engage more readily in conversation with each other, however this was possibly influenced by my presence. However, there was much less privacy in terms of the individual consultation areas, because the clinic was on a ward, rather than in separate rooms. The conversation between SHPs and service-users was audible and echoed because of the large open space.

The clinic remained in this location only for a few months, before they were moved onto another clinic space within an existing orthopaedic outpatients' clinic. This meant reverting to a similar setting to the separate clinic rooms, the only difference being that the waiting area was in the middle of the clinic. In addition, it was a separate unit and no other hospital "traffic" passed through the area. Finally, after a few months, the clinic moved out of the hospital setting, and to a building which was previously a health centre, and over 10 miles away from the acute hospital setting. This setting was for the sole purpose of the Site 1 Lymphoedema Clinic. The SHPs expressed a feeling that the move to this setting, gave them a greater sense of ownership within the space. Space within the clinic rooms and waiting room was much more appropriate. The location, and service-user car park meant access to the clinic was much easier, whether service-users used public transport or their own vehicles. No observations were undertaken at the orthopaedic outpatients' clinic or the community GP/health centre, as this move occurred after the data collection period.

4.2.2 Site 2:

The Lymphoedema Clinic at Site 2 used 3 cubicle spaces in an existing physiotherapy clinic. This was a large, open plan area, with curtained "bed spaces". All the lighting was artificial as the windows in the area were small, with opaque glass; the area felt quite oppressive because there was minimal natural light. In addition, the clinic was on a lower floor, giving the sense of being in a "basement". The clinic space was a busy area, full of activity and noisy, as the Lymphoedema Clinic was continuing alongside other physiotherapy clinics. The service-users had to move through two reception areas, to reach a very small waiting area. This often became hectic, especially if the service-users, for both the physiotherapy and the Lymphoedema Clinic, used wheelchairs, mobility scooters or other mobility aids. The space they occupied in the physiotherapy clinic was similar to the Site 1; the space behind the curtains was extremely limited with a desk chair, clinical couch, and extra chairs were brought in from outside the curtain space when necessary. There was some medical equipment, but most of this was at the end of the room, in cupboards. The SHPS explained that some service-users attending for primary and follow-up consultant/nurse consultant appointments, were also seen in clinic rooms within a dermatology clinic, two floors above. However, no observations were undertaken in this location, due to the clinic schedules, which were often cancelled during the data collection period.

4.2.3 Clinic Activity

The activity between both sites was practically the same and in the same order. The SHP was usually sitting adjacent or opposite to the participant, or on their knees on the floor, if the service-user had lymphoedema of the lower leg. The consultation began with general “small-talk” if they had met before, or introductions, if the service-user had not met the SHP previously. Although I was not present for any first appointments, I was informed that all new service-users were assessed using LYMQOL (Keeley et al., 2010), a quality of life measure for those with limb lymphoedema. This was to establish the initial effect of lymphoedema upon their life.

The consultation started with questions from the SHP to learn how the service-users was “getting on”, followed by a systematic process of reassessment. This included weight; observation of the affected swelling; checking against what was written in the notes from the previous consultation; and checking any blood or investigation results since the last appointment or other appointments in primary/secondary care. The primary objective was to address any immediate issues, such as skin breakdown, infection; any concerning reasons as to why any swelling had worsened or spread, for example, lymphoedema had spread from the upper legs to the abdomen; or if there was a concern about a potential malignancy, such as metastases (spread of cancer). The main emphasis was upon evaluating the care “so far” and re-measurement of the affected limbs (arms and legs) with the Perometer, to record the current swelling; take measurements; decide upon a treatment plan; the new “made-to-measure” compression garments and/or wraps were ordered; and a further appointment was made.

In most cases the SHP was on their knees or chair, applying wraps, bandages or compression garments. At the end of the consultation some service-users and their carer/family re-applied their own garment, rather than the SHPs reapplying them, however these were younger and/or more able-bodied service-users. Service-users were informed that they would receive their garment by post, and some had follow-up appointments to “fit” the garment.

4.2.4 Yoga sessions:

Prior to formal data collection the SHP had contacted them to see if they would agree to me attending their Christmas party, to tell them about the upcoming study, and what it would involve. I viewed this as an opportunity to gain some feedback about their thoughts and ideas, prior to data collection. All the service-users at the yoga sessions were members of the local lymphoedema support group, and explained that they enjoyed the opportunities to meet, and the support they found on their social media page (Facebook). During the party some of the participants, suggested that I should join them at their yoga session. The yoga sessions were arranged by one of the SHPs, through charitable funds, and led by a qualified yoga instructor who guided the participants through a seated session. The sessions lasted approximately 40 minutes.

I formally observed a later yoga session when all appropriate approvals were in place, and once the data collection had started. All the participants commented how much they enjoyed the session. This was in terms of relaxation, socialising and being with other people who live with lymphoedema. The participants all said that would attend the session again; especially those who were not already part of the support group. Some expressed feeling disappointed that the yoga was not available more regularly because of a lack of funding and praised the SHP for working hard to raise the current funds. I observed that it was a positive experience, and a genuine sense of community.

At the second yoga session, many of the participants were eager to tell me their experiences of living with lymphoedema, and how they came to access the service. Several of them said that:

> *"No one knows about us even my doctor didn't have an idea" (Mary)*

This helped me to identify questions I intended to ask during the interviews. The SHP explained that I was recruiting to the study, and that she would take the details of anyone who wanted to take part. By the end of this session the SHP recruited 7 of the 12 participants, and I interviewed 5. After the yoga sessions I observed the participants chatting amongst themselves, pulling up trouser legs or pointing to their affected body part, and I heard them sharing their lymphoedema experiences. This was a relevant finding as I had already undertaken a few interviews where participants, who were not part of the regional support group, explained their sense of loneliness and isolation.

4.3 Clinic observations Findings

The findings from the observations (Figure 6) provide an insight into coproduction in a healthcare setting that focus on self-management and coproduction at home. These led to the emergence of 3 main themes:

- Sharing information and “operant resources”
- Building relationships: relationship-centred care
- We are Detective: spoken and unspoken conflict

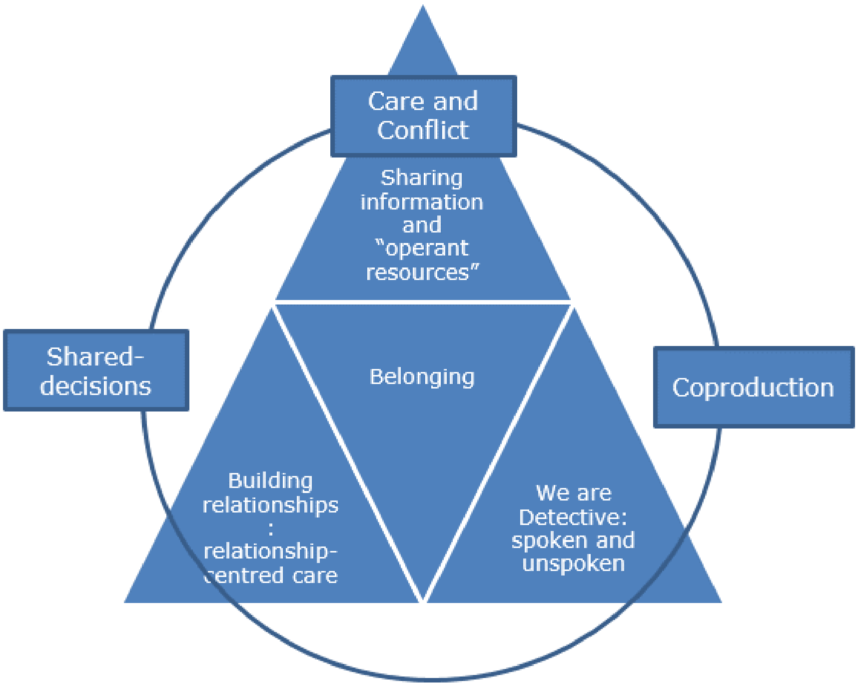


Figure 6: Findings from the clinic observations

4.3.1 Sharing "operant resources"

Information sharing was an important aspect of the interaction between the SHPs and the participants. Although I did not have opportunity to see a first appointment one of nurse SHPs explained that this can often be quite an emotional experience for participants, and that because of this it is important to understand how they have been referred to the clinic. She stated that the SHPs must be prepared to explain a great deal of information. In addition, the SHP stated that participants often present at clinic after years of living with lymphoedema, but without any diagnosis or care within the primary care setting.

This was one of the problems they perceived due to a lack of consistency in the way service-users were referred to the service, and demonstrates a lack of scientific capital (Bourdieu, 2004)and "organisational health literacy", (Brach et al., 2014, p.274) in how service-users navigate the system of referral.

These first appointments were usually significant longer, with both a doctor, and a nurse. They explained that many service-users were devastated and/or relieved by their diagnosis, although few were prepared or comprehended immediately what living with lymphoedema involved, especially the treatment regimens.

Most of the interactions began with introductions, especially if it was the first time the service-user met a particular SHP, and then “small-talk”, and general discussions. This often demonstrated their familiarity, especially if the SHP and the service-user asked each other about specific aspects of family life. Most of the consultations had a very friendly, up-beat, and jovial atmosphere, and this demonstrated the familiarity and social capital which evolved through the interaction. Especially those service-users who had been attending the clinic for many years. The SHP usually then directed the interaction by asking the participants about their experience since the last appointment, which was usually between three to six months prior. A smaller number of the participants were being seen every one to two weeks due to the severity of their lymphoedema, and/or complications/co-morbidities.

The SHPs checked any recent investigations and blood results, and any other appointments within primary or secondary care, that they could access on the in the patient notes or on the hospital’s digital systems. The discussion mainly focused upon the progress of their lymphoedema; whether the participants perceived any significant changes, for example, if their swelling had improved with the prescribed treatment; or if they had experienced any episodes of infection and cellulitis. Preventing infection was often a focus of discussion during many of the consultations. This usually included questions about their mood and how they were feeling generally. The interaction at this point was very pragmatic and clinically orientated, in terms of "top to toe" assessment, which included documenting, measuring, filling in forms and completing paperwork. This involved a visual assessment, with the SHP focussing, listening and observing the service-user, and "checking-in" on how their assessment compared with the participants' descriptions. This enabled (with or without significant others present) an open conversation, with the SHP responding and acknowledging the daily reality of life for the participants.

The SHPs' focus shifted to exploring the priorities and goals, both short-term (days and weeks) and long-term (months/years). This involved a discussion of the service-user's expectations; checking what they perceived as realistically achievable goals; and how these goals could be achieved together, including factors such as medication and diet. Often participants' goals were influenced by their fears of developing infection or cellulitis, and conversations often focused upon strategies, such as taking prophylactic antibiotics, having a prescription for different antibiotics and accessing emergency care if symptoms did not improve. It was an opportunity for the SHP to suggest if other healthcare professionals needed to be involved, such as occupational therapy, podiatry, orthotics; or if their assessment suggested the need to be seen by one of the doctors in the clinic, and any further investigations, particularly blood tests were required.

This was when the SHP fully explained what was involved in the continuation, or next stage in care, including any changes in treatment plan and the SHP was prescriptive and action focused. This was especially for those participants who required further investigations, due to abnormal or unexpected results from investigations and blood tests; or those who had symptoms of concern related to a previous cancer diagnosis.

This aspect of the interaction demonstrated a more hierarchical and paternalistic approach by the SHPs, even though all goals were motivated towards shared-decision making, sharing information and agreement, between the participants and the SHPs. One example of this was at Site 2, when June had presented with some concerns about an increase in swelling to her arm (following treatment for breast cancer). Her blood results were also slightly out of range, and the SHP stated that she would contact her oncologist to discuss an earlier date for her follow-up outpatient's appointment. The SHP calmly delivered this information, and explained what could be achieved through working together, and agreeing upon a plan. Other examples of this included the exchange of information regarding aspects of care which have proved to be helpful, for example using diuretics (Derek, Maeve) or the specific types of garments which were best tolerated (Lucy, Amy).

For some participants the consultation had an emotionally therapeutic quality, for other participants the consultation was a very pragmatic interaction. I noticed that a small number of participants at Site 1 were "in and out" of the appointments; these were women (Maddie, Louise,) in paid employment and/or had young children. Maddie described how

> *"I don't have time for my legs" (Maddie).*

She had a great deal of responsibility in her professional job, and her focus was to *"stay well", "get on with life", "look after my legs",* and enjoy time with her family, especially their international holidays. She explained that she wears her compression garment *"all year round"* aside from when she is on holiday, because *"leaving them off"* that made her feel *"normal"*. Louise also expressed how she needed to keep well and keep working to look after her young family. She also stated that her lymphoedema used to bother her, and now she accepts having it is part of her life; she appeared to present a "matter-of-fact" outlook towards living with the condition, however the SHP later explained that it had taken both Louise and Maddie a few years to feel this acceptance, and come to terms with her condition.

It was apparent that during the consultations that the SHP relied upon the participants contribution, to *"see the whole picture"*. An important and integral part of the consultation emerged as *"getting to know"* the participants, to gain an understanding of how lymphoedema affects their life. This enabled the SHPs to suggest individualised treatment plans, which were the appropriate and realistic. Sharing information meant that the SHPs could also understand what the participants considered was most important aspect of their life; whether their treatment regime, or any agreed adaptations to their plan, for example not wearing garment on holiday. The emphasis was upon the SHPs to support participants to find practical strategies to deal with their lymphoedema, and to mitigate any challenges due to the agreed adaptations. Moreover, this also emerged as a way that the SHPs developed a genuine relationship with the service-users. The effort of the SHP was the instigating factor for the development of social capital between them.

It also involved directing participants to seek out information about lymphoedema from "reliable" sources for example ILF, British Lymphology Society (BLS), Lymphoedema Support Network (LSN); asking them to recognise and record what works and does not work; and to document times when their lymphoedema feels worse or better. This was an important aspect of the consultation, because their next appointment was usually in six months, and the SHP, needed to ensure that they were equipped with all the resources they needed to manage their care at home. This also suggested that the onus of responsibility was upon the service-user, to encourage them to be more aware of themselves, and take a proactive approach to their own care.

4.3.2 Relationship building

During the observations it was clear that many participants expressed the sentiment of

> *"I'm so pleased that I am seeing you" (Hattie)*

This seemed to be both in terms of accessing the service, and the reciprocal exchange of seeing that member of the team. It was a sense of both relief and anticipation in seeing their SHP. Many of the participants saw the SHPs only once every six months, and less if their "usual" SHP was not available. This was the opportunity to tell the SHP everything that had occurred since their last appointment. However, when I was present, many of the SHPs encouraged the participants to re-tell their "story" of living with lymphoedema, and how they came to access the clinic.

Richard was attending the clinic following recurrent episodes of cellulitis, after sustaining a serious leg injury. He had developed chronic oedema of both legs, which was a contributing factor to his retirement due to ill-health. Richard was interviewed a few weeks later and spent most of his appointment retelling the events which led to the development of his lymphoedema. These included his cardiac problems, alcohol dependency; and subsequent surgical complications when he broke his leg in an accident. It was clear from the way he spoke that he was angry, resentful and devastated by these events. He described these as being the *"doctors' fault"* (orthopaedic surgeons). He deflected blame away from the SHPs and was eager point out that his subsequent problems with lymphoedema were not their fault. Richard wanted me to see his disfigured leg and confirm that it *"looks bloody awful"*.

However, the SHP made attempts during this interaction to redirect his focus, by affirming that reducing his alcohol intake over the last few months had improved his blood tests results, and that his lymphoedema and swelling had lessened. It seemed that this was the SHPs way of encouraging Richard into think more positively, and whilst not forget the past, focus on future goals. The SHPs also validated the participants' experience before and after accessing the clinic. In many of the consultations they would interject with comments such as:

> *"You had been living with symptoms for a long time" (SHPS2)*
>
> *"Your swelling was really extensive when you first came to us" (SHPS1)*
>
> *"It's looking so much better than it did when you first came" (SHPS2)*

These statements were also often verified by the participants

> *"I was in a really bad way I was getting desperate" (Hattie)*
>
> *"I found out the lymphoedema was just part of it "cos I had all different things going on" (Richard)*
>
> *"It's such a relief to find out what was wrong "cos it's so much better since coming to see ****" (Jo)*

Many of the participants spoke about the SHPs as if they were a *"saviour",* referring to them as *"my nurse"* and that they could not imagine how "bad I would be" if they had not been referred.

There was a significant amount of physical activity for the SHPs, during the consultation whether operating the perometer, or getting down on their knees to assess the participants affected limbs. I observed that this was an opportunity for the SHPs to multi-task, and thus create an atmosphere where the SHP and service-user could converse. During these interactions I noticed the SHP always looked up and initiated eye contact; this and the tactile quality of their work, gave the impression of a holistic, relaxed therapeutic intervention, aside from the formality of the consultation. Whilst there was little discussion from the SHP, especially when they were concentrating on activity, I observed this as an optimum opportunity for the service-user to describe *"how they were getting on"*; or to go into detail about specific issues they may be experiencing, and feel that the SHPs were genuinely listening to their concerns.

Whilst the consultation involved a thorough physical assessment of the lymphoedema, participants were also examined for any skin changes or swelling that had not been noticed by the service-user. The discussion focused upon agreeing actions, in terms of agreeing together what the next steps of care should involve. In most of the consultations, I observed a dynamic whereby the SHP behaved in a nurturing and caring way; reassuring, encouraging; allaying fears; and relationship building.

This was a complex aspect of their interaction, and I also perceived that it could be being emotionally demanding for the SHPs. There were several participants who described other aspects of their life which were contributing to feelings of stress, isolation and marginalisation. Rebecca attended for re-measurement of her compression garment. She described feeling quite anxious because she was in the process of moving a great distance, back to her hometown. This was her last appointment with the team at Site 1, and she described feeling increasingly anxious about her transition of care, from the Lymphoedema Clinic to her new consultant. Her apprehension was twofold; firstly, because she had been diagnosed and treated for breast cancer and secondly, because she had been diagnosed with lymphoedema, following treatment of her affected breast and armpit. Her greatest anxiety was for her young child, as her relationship with her child’s father ended when she received her cancer diagnosis. She described this as a devastating experience and had spent the last few years trying to rebuild her life. Being diagnosed with lymphoedema was another setback, and increased her worries about the cancer returning, and what would happen to her son, if she died.

During the consultation, the SHP listened to her concerns, and I observed her using counselling skills such as listening, appropriate touch, paraphrasing, and encouraging Rebecca. The SHP reassured Rebecca that they had made the referral to the new clinic and would also give her a letter to take to her new GP. The SHP explained that she can call the clinic, if the new clinic needs more information. The SHP was clear to delineate between the current and new care provision. In addition, the SHP also encouraged her to seek advice from her new GP, especially if she developed any other symptoms. Rebecca expressed that she wished she could *"stay under you"* because "you know me and all the things I worry about". The SHP allowed Rebecca the time to express how she was feeling and supported her by asking her about the details of the move. This seemed to help Rebecca, who seemed very agitated at the beginning of the consultation and much less so by the time she left. I observed the therapeutic relationship, and the value of their relational exchange and social capital, in how Rebecca tangibly relied upon the SHP for emotional support in addition to the lymphoedema care. The SHPs seemed to be aware of how they communicated with the participants, and often qualified their statements to me before and after the consultation, when the service-user was not in the room, stating:

> *"She's been through such a lot" (SHPS1, talking about Lucy)*
>
> *"He needs a lot of encouragement and reassurance I have to try and help him look forwards" (SHPS1, talking about Richard)*

> *"She suffers with depression, and it can be very difficult to help her think about her future"*
> *(SHPS2, talking about Faye)*

Many of the observations undertaken demonstrated the familiarity between the SHPs and participants, especially regarding the exchange of information about non-medical aspects of their life including family, children, and special events. This demonstrated the extent of the relational exchange and the social capital between them. This was most evident during the consultation I observed with Hattie. Hattie and her husband went into detail about the emotional lifelong journey she experienced when she was finally diagnosed with primary lymphoedema, her 60s. Hattie emphasised:

> *"We do everything together" (Hattie)*

Hattie was attending in-between her usual appointments as she was having issues with the swelling in her legs, and this was beginning to worry her again. Hattie explained her life before meeting her husband had been very difficult and traumatic, and the shock of a *"proper"* diagnosis had left her with so many questions. Hattie explained that this was something she always felt able to talk about with her SHPs. During the consultation I observed how difficult it was for the SHP to measure Hattie's legs and arms, especially because she was so unsteady on her feet. Hattie went onto express her frustration at being *"so wobbly",* due to not having proper shoes; she had an upcoming family wedding, and she was worried that she was not going to be able to attend.

> *"I don't want to miss out again because of these damned legs" (Hattie)*

The SHP reassured her that there was a small improvement to the swelling in her legs, and that she was going to request some more blood tests

> *"Have a chat with Dr ****** to make sure that you are on the right dose of your medication". (SHPS1)*

This highlights the worries that many of the participants had when attending clinic, the insecurity of being told that something else was *"wrong"* or that there lymphoedema was worsening. Many of the participants expressed that their worries were aligned to being able to "get on with life", as opposed to concerns about their morbidity and mortality.

A key finding from the observations was the number of participants who described feeling marginalised and isolated, because of their lymphoedema. I observed this sentiment in terms of how the SHPs also felt about their work and position. Several times, across both sites, the SHPs made comments such as

> *"We know nobody knows about us it can be very frustrating" (SHPS1)*
>
> *"They think we are just a leg ulcer clinic but we should not really have patients with wounds" (SHPS2)*
>
> *"Our patients have real difficulty even finding us" (SHPS1)*

In addition, the SHPS also recognised the how difficult life was for many of their service-users; this was not specifically about their health literacy or understanding the treatment options.

This was more a reflection of their socioeconomic position, and their SDH. A few of the SHPs reflected a feeling of a loss at what to do and how to help.

> *"It's really hard because we know their lymphoedema is just not going to improve" (SHPS1)*
>
> *"Life is really difficult for him at the moment" (SHPS2 talking about Keith)*
>
> *"I have been really worried about her and I phoned their GP I was that worried" (SHPS2 talking about Faye)*

They also explained that some of the participants experienced significant financial difficulties, and that they were often asked to provide evidence or help fill in forms for Personal Independence Payment (PIP) assessments or state benefits. During these consultations many of the participants were so worried by their symptoms that they wanted to do whatever they could to *"look after"* themselves, even though many of the participants expressed to the SHPs their difficulties when implementing their agreed care at home.

4.3.3 "We are detective": spoken and unspoken conflict

One of the most significant observations during my time within the clinic was what the SHPs said before and after participants entered the consultation. The SHPs would often state that there was a service-user who was *"good for you to meet",* at the beginning of clinic. I realised that this usually meant a service-user with a "challenging" form of lymphoedema, which was if it was part of a genetic condition or rare disease (Moffatt et al., 2019b, Gordon et al., 2020); or that the service-user was perceived by the SHPs to be “challenging” in terms of their resistance to engaging with treatment; or difficulties in implementing their care at home, due to financial or psychological issues (depression and anxiety).

I recognised that the SHPs perceived this as an opportunity for me to see the impact of lymphoedema; the implications for the individual participants, and the challenges that caring for these participants also posed to the service. SHPs were committed to recruiting participants to the in-depth, face-to-face interviews, and often suggested that I should observe their *“worst patients”*, in terms of difficulties with symptom control or their engagement with their treatment. This made me recognise the issues they had with the perceived lack of scientific capital; if I observed their most complex cases, I could then also report their challenges in delivering care. There were a few participants whose appointments lasted longer than usual, and a significant amount of time was spent negotiating the care to be implemented at home. Therefore, the SHPs focused upon agreeing care which they thought the service-user could realistically achieve. This was not always easy, especially if the SHP was trying to encourage a new line of treatment, and there were times when their facial expressions (frowning, raised eyebrows, slightly pursed lips) suggested they were frustrated, however, they remained highly professional in their manner and interaction with their participants.

During most of the consultations the participants were open with the SHPs, explaining the care they were able to undertake at home, and what they did if they developed an infection, which most of the participants expressed as their greatest fear. In addition, most of the participants were aware that their condition was not curable but were eager to seek solutions or treatments which might keep their affected area "well" (Maddie, Louise, Rebecca); this included discussing times when they decided not to wear their compression garments (Hattie, Maddie), or when it was challenging to undertake the care, they needed at home (Faye).

Faye was a 32-year-old woman with complex health morbidities and had secondary lymphoedema to her legs. She attended the clinic at Site 2 with her partner and was seated in a wheelchair. Faye was very anxious and tearful, and explained that she was having *"a terrible time at home"*; she was waiting for her new PIP payment, and whilst waiting her Disability Living Allowance (DLA) had been suspended. At the time of the study the Department of Work and Pensions (DWP) was moving transferring to a new system of state payments. Faye and her partner, who supported her with her care needs at home, were forced to move to an alternative rented property because their current house was very damp. Faye was worried that her housing benefit would also be suspended. The SHP listened and suggested that if Faye needed any letters of confirmation, that *"her team"* could provide these, and spent some time listening and talking through some actions.

The SHP asked Faye about her legs, and Faye stated that she had not really been thinking about them "with everything else going on". The SHP tentatively asked her about what she had been doing and what might make looking after them easier. The SHP also asked Faye about her mental health, and Faye replied to expressing concern that she was beginning to feel depressed again:

> *"Which made me very ill I don't want to go back to that ever again but I am worried about mesun" (Faye)*

Together they decided to continue with the current treatment, and arranged a follow-up appointment in 3 months instead of 6 months. The SHP also reiterated to Faye that she was to call them if there was anything further evidence she might need for her PIP and recommended contacting her GP to discuss her low mood. After the appointment the SHP expressed that she was extremely worried about Faye; that even with the support of her partner, she found living with lymphoedema emotionally and financially demanding. The SHP also stated that she was going to phone Faye in a few weeks*, "to check that she's ok"*. All the SHPs, across both clinics, reiterated the same:

> *"We always follow-up" (SHPS2)*

Especially if they were concerned

> *"That something else is going on that they're not telling us about" (SHPS2)*

There were several other participants who also found the financial aspect of their care challenging and expressed this during their consultations.

At Site 2, Derek and his wife described how the swelling in his legs had worsened, and his ability to mobilise or *"get about"* was increasingly difficult. When the SHP said

> *"I think it's time for us to think about you having the bandages again Derek I really don't think they are going to improve unless we give them a go what do you think" (SHPS2)*

Derek was reluctant start CDT because travelling to clinic three times a week was too expensive, rather than because he minded wearing the bandages. He refused hospital transport because of the risk of being picked up too early, as he had to travel by ambulance due to his poor mobility. By the end of the consultation Derek had agreed to *"give it a think",* however the SHP was concerned that unless this was treatment that Derek could receive in his own home, he would agree to attending the clinic.

There were instances when the SHPs attempted to negotiate care with patients, who they perceived as a "challenge" to engaging with care and treatment. Diane was a middle-aged woman who had been suffering from secondary lymphoedema to her lower legs for many years and attending the Site 1 clinic for approximately 4 years. She declined when the SHP asked her if you would be interested in being recruited to the interviews but agreed for me to observe her clinic consultation. Diane's legs looked swollen and red, her feet did not fit properly into her shoes, and she struggled to walk. She entered the room cheerfully, however when she sat down, she started looking in her handbag, and without look up at the SHP said

> *"Look, before we start I know it's bad and my own fault but I have to live with it I know I avant been doing what I should ave bin doing an that me legs is probably worse its ma own fault as am just too busee" (Diane)*

Whilst the SHP assessed her legs, she asked Diane what her reasons were for not wearing the compression wraps. Diane responded by stating again that she was *"too busy"* then started reminiscing about life with a local high-profile sports team in the city, and that it was her job to look after the Junior Team's archives. The SHP continued to assess Diane, and made some suggestions about alternative treatments, and about implementing some of the recommended self-care; she suggested that a course of CDT might be appropriate. Diane's response was that

> *"I've 'ad it before it takes that it ages to work and me legs just got bad again there's no point". (Diane)*

Diane argued against the suggestions, and contradicted the advice in a dismissive manner, whilst looking across at me and shaking her head and rolling her eyes, and then smiling at the SHP when she looked up. The SHP asked Diane what she would like to do, to which Diane responded that she had given up because nothing works, and that she would carry on using the wraps:

> *"When I remember to put them on" (Diane)*

And winked at me.

The SHP suggested another appointment in 1 month, because she was concerned that her leg was at risk of skin "breaking down" and encouraged Diane to call the clinic if she had any problems in between. After the consultation the SHP commented that Diane "is a difficult one", and I interpreted this as both in terms of how Diane communicated with her SHPs, and in terms of treating Diane's lymphoedema. The SHP stated that they have several service-users who know what they need to do but find it impossible to implement that care. She commented that

> *"it's like being a detective, you're trying to find out exactly what's really going on because if we know we might be able to help if they don't get the help they need it will only get worse until we struggle to find a way to manage it" (SHPS1)*

An example of this was when I observed the consultation with Lucy, at Site 1, and who was recruited to an interview. Lucy stated:

> *"It's all I can do to wear jeggings, never mind stockings" (Lucy)*

She explained that she was feeling very low, everything in life was going wrong, and life at home was very difficult, especially now the DWP were looking into her PIP award. Lucy had not attended her last appointment, and it was longer than 6 months since she had been to clinic. Her SHP stated that lymphoedema did appear to be slightly worse and was more noticeable in her thighs. Lucy appeared to be very nervous and shaky, looking down, and on the verge of tears. The SHP suggested re-measuring, to order some new compression garment and that Lucy should return to clinic a month after her garment has arrived, for a "check-in". Lucy laughed, and expressed that she felt a:

> *"Bit of a lost hope" (Lucy)*

The SHPs gently asked Lucy, to describe how she was feeling, suggested that it might be worth returning to her GP if she was feeling in a lower mood than usual. Lucy looked at me and disclosed that she had experienced a traumatic childhood, was diagnosed with cervical cancer when she was 17; that most of her problems were due to a late diagnosis and the extensive treatment she needed. She explained that wearing compression reminded her that she is “damaged”, and she believed she had reached a point of rebuilding her life, but everything was “going wrong again”. For Lucy, wearing skinny jeans was her compromise, as she said they were as tight as her compression.

The consultations I observed demonstrated the development of social capital and extensive communication skills that the SHPs used to encourage the participants to implement their care. Furthermore, the SHPs recognised and acknowledged the real challenges the participants faced. I observed the SHPs working hard to share-decisions with the participants. However, the participants either wanted to follow the exact advice of the SHPs, or they were unable to implement the prescribed treatments, due to factors separate to their health literacy and understanding regarding their lymphoedema. The relationship between SHPs and the participants appeared to be open, as many of the participants disclosed their challenges, even if they needed encouragement from their SHP to share their experience. However, some of the participants appeared to be reluctant to disclose exactly what they thought.

The SHPs expressed their frustration, and at times I observed that they had to mentally prepare for appointments, as they were emotionally demanding, and the effort of negotiating care with some participants was seen to be challenging. The SHPS verbalised that there were other reasons for these challenges. Like detectives, uncovering these challenges and barriers was their responsibility, as healthcare professionals. This was to help prevent the deterioration, to work together and increase the opportunities for improvement of the participants’ lymphoedema.

4.4 Observational findings: Analysis and interpretation.

Undertaking the observations within clinic gave me significant insight into the spatial position of the clinics, the experience of the SHP working within that space, and of the dynamics of the relationships between the participants and the SHPs. This is discussed in terms of the access to the clinics; the sharing of "operant resources" and where conflict arose; how the relationships developed between the SHPs and participants, in terms of shared-decisions and social capital within the "field" (the clinic)(Collyer et al., 2015, p.690); and the role of the SHPs as detectives.

4.4.1.1 Hidden position of the clinics

The physical position of both the clinics was remarkable because neither occupied their "own" space within the two hospitals. Both were clinics, which was part of the regional service. Although both clinics were situated within a permanent clinic space, this did not "belong" to the lymphoedema service. The service configuration is important because it is commissioned by one NHS Trust, and at the time of the study, hosted in two other acute services. These were issues affected the services' embeddedness, as staff are employed by the commissioning hospital, which influenced their capacity to negotiate adequate space. This contributed to the impression that the lymphoedema service was "hidden", with a lack of permanence, and of a service hidden away in parts of the hospital that their participants reported as "difficult to find". This was ironic because the service is part of a national centre of excellence, with a formal association to a reputable service within the southeast England.

This also aligned to the recurring theme from the literature which suggests that chronic oedema is a hidden condition; a of lack of scientific capital, also corresponds to a lack of “organisational health literacy” (Brach et al., 2014, p.274) for either service-users or healthcare professionals, to navigate the healthcare system; and which lacks social capital, affecting affects those living with this LTC (Williams et al., 2004, Morgan et al., 2005, Keast et al., 2015, Mercier et al., 2016a, Mercier et al., 2016b, Humphreys et al., 2017, Nairn et al., 2019). This was relevant in terms of the frustration the SHPs expressed, around the clarity of their role, and the remit of the service level agreement, and in terms of appropriate referrals, for example patients referred with leg ulcers.

This included the challenges of dealing with what might be the “real” issues for participants, for example, financial, social and psychological issues, which limit their engagement, and the challenge of discharging participants from the clinics. This was particularly the case when the SHPs stated they were worried that “something else is going on”, suggesting their own fears about the limits of treatment and projecting this onto the participants. This also aligns to the literature by Moffatt et al. (2019a) which identifies the emotional burden upon SHPS, of dealing with limited clinical outcome measures (Moffatt et al., 2021b, Moffatt et al., 2021a); the anxiety that professional uncertainty caused and their fatalism in terms of what they were trying to achieve, with and for the participants.

Furthermore, the impact of not having their own space, led the SHPs to describe their feelings of isolation, and the lack of ownership of the space, as inconsistent and inconvenient. The location of the clinics led to a sense of being positioned in the “only space available”, which the SHPS described as “one of those things” with a defeatist acceptance that there was little they could do to influence the situation. This was even more evident given that the clinic in Site 1 moved three times, within two years, until it moved to a permanent space, out of the City and on the border of another local authority district and county. The move of this clinic reflects recent government policy, and the transfer of care to community settings, rather than within secondary care (Moffatt et al., 2019c)

4.4.1.2 Social capital and belonging

There is a plethora of literature which recognises the paucity of service provision for lymphoedema; this includes the lack of education, knowledge and skills available amongst some community and GP nursing teams (Moffatt et al., 2003, Williams et al., 2005, Fu et al., 2013, Ridner et al., 2012a, Muldoon and Charles, 2013, Todd, 2013a). Examples from this study demonstrated situations where some participants perceived they were left to “self-manage” their care, even though they had significant input from the SHPS, or their significant others were taught those skills (Hattie, Faye). The responses from some of the service users, like Diane, who believed that inevitably the treatment fails, and therefore the care proposed was not a solution.

Many of the participants described experiences which confirmed that their fears of infection and getting worse were the drivers and motivation for implementing their care. This related to the SHPs and the participants dealing with the uncertainty and limits of treatment. The participants recognised the commitment of the SHPs in trying to help and support them, and this created a sense of solidarity and social capital, however care at home was not always possible without the support from their family, friends and carers (significant others). This seemed to be one of the motivations for the SHPs encouraging the participants to contact them between appointments, and maintain supportive relationships, and the greatest potential for the operationalisation of the coproduction of care, and the development and function of social capital.

The concept of social capital also emerged in terms of the participants descriptions of the isolating aspects of living with lymphoedema, and how the SHPs actively encouraged the participants to join the support group, Facebook or attend a yoga class (funded through fundraising activities by the clinic). This was a way to increase their social networks, and gain support and opportunities for learning from each other. The activities, such as the yoga sessions and swimming sessions, were interpreted as a way of increasing non-formal access to the SHPs, in a more equal relationship, and as a way of addressing the perceived structural and hierarchical relationships perpetuated by the bio-medical model of care.

Furthermore, this was not as a hidden “strategic action” (Outhwaite, 2009, p.470), but a genuine attempt to mitigate the perceived lack of social capital amongst the participants. This reiterated the idea that these were opportunities for positive “critical encounters” (Payne et al., 2008, p.90), as the participants reported that this activity increased their social networks, and also their sense of belonging and wellbeing. Notably, this was even if they perceived it had minimal effect at “improving” their lymphoedema. However, the SHPs also saw this as a positive outcome; if the activity was perceived by the participants as therapeutic intervention, it might lead to positive physical, and psychological health outcomes and benefits (Summers and Tudor, 2000, Reeves et al., 2014). This study demonstrated that some of the participants recruited were actively finding ways to improve their experience of living with lymphoedema (Moffatt et al., 2021b).

This was described by the SHPs as particularly important because of the recognised challenges regarding the absence of robust clinical outcomes for lymphoedema (Moffatt, Keeley, Hughes et al., 2019d), other than reduced subjective experience swelling, or improved quality of life. Several participants exemplified sharing "operant" resources; such as the other factors they believed affected their swelling, such as sleeping in bed, elevating their legs, hot or damp weather; and how much activity they had undertaken in previous days. Furthermore, many participants perceived reduced swelling as an important outcome, because they believed it also reduced the risk of serious infection, and increased mobility. This demonstrated the SHPs' commitment to therapeutically supporting the participants and extended beyond the confines of the clinic setting, especially because the clinical setting was not conducive to delivering the care they wanted to provide.

These findings also emphasised the way in which the SHPs observed fulfilled the nurturing role within a coproducing relationship, as suggested by Lovelock and Young (1979). The positive aspects of the SHPs relationships with the participants, were aimed at developing trust; understanding the drivers and motivators for the participants health behaviour; consideration of the contexts in which the participants were living (SDH); creating opportunities to share skills and knowledge ("operant" resources), which included learning from the participants; supported the participants to implement care, which would hopefully improve their symptoms; working with the participants to evaluate their care; and determine and discern what care can and cannot be easily implemented at home. By creating a place of safety, belonging and trust, I observed "strong bonding" social capital (Ferlander, 2007, p.120), which is normally observed in less formal relationships, as the participants shared candidly about how difficult it was to implement their care at home. This included criticism of some aspects of their lymphoedema care, particularly the lack of perceived choice of "made-to-measure" compression garments available to them through the clinic. Many of the participants described that there were "lovely" garments now available, but that they could not afford to buy them as their cost was prohibitive.

4.4.1.3 Power dynamics

Whilst there was a clear and open exchange of skills and knowledge and "operant resources" (Vargo and Lusch, 2004, Lusch and Vargo, 2006) it seemed that most of the participants looked to the SHPs for clear guidance about their lymphoedema care. This was an example of the bio-medical hierarchical relationship, whereby the participants perceived the SHPs as having "specialist expertise" (Collins and Evans, 2007, Collins, 2014) and stated this explicitly, or inferred this during the conversations by frequently referring to being "under the care" of the SHPs. However, this also reiterated the concept of formal, vertical social networks or linking social capital, which reflects a paternalistic power dynamic (Ferlander, 2007, p.123), demonstrating the dichotomous relationship, when compared with "strong bonding" social capital (Ferlander, 2007, p.120). The participants often sought a medical solution for what seemed an emotional or psychological issue; the calm, empathetic approach of the

SHPs, belied wider issues, which could not be addressed by medication or a bio-medical model of care.

Moreover, this hierarchical position seemed to be the foundation of their relationship and offered reassurance to the participants. It reflected the transfer and accumulation of knowledge through their exchange, and appeared to be where value was cocreated (Morgan and Hunt, 1994, Prahalad and Ramaswamy, 2004a), as the participants developed more knowledge and the “operant resources”, the skills and knowledge, were transferred within the coproducing relationship.

The more the participants learned about their lymphoedema, the more expertise they developed, as they became socialised into the “world” of lymphoedema (Brandsen and Honingh, 2016). This was reflected in the articulate way they spoke about their lymphoedema how it developed, their diagnosis, the treatments they had tried, and descriptions of how they addressed the everyday challenges of living with their condition. Importantly, expertise was defined by the participants and the SHPS in terms of “successful” or “unsuccessful” treatments, for example whether there was a reduction in swelling, or if participants tolerated a new compression garment/wrap. Gaining this insight led to more knowledge, and more expertise.

Paradoxically, there were also times when the SHPs were confounded by the limitations of the interventions and were not always able to provide the participants with an adequate rationale or answers. Furthermore, it reflected that the SHPs were also dealing with professional uncertainty, (Moffatt et al., 2019a) or the anxiety of delivering difficult information, due to the lack of robust clinical outcomes. It is also possible that this was heightened because they were being observed, and because the SHPs recruited the participants, they selected service-users they perceived would be “helpful” for me to see.

Most of the participants recognised that due to the extent or progression or their lymphoedema, cure was not an option, and the chances of improvement were uncertain. A successful outcome was the prevention of deterioration, the absence of infection or any reduction in swelling, between each appointment. This was perceived by the participants as an indicator of how successful they were was at implementing their acquired and “expert” skills in their care, at home. This was particularly the case for those participants whose consultations were short, and it was a reflection of either their agency in “knowing what to do”, and explaining this to the SHPs; or their lack of agency and a desire to escape the scrutiny of the SHPs.

4.4.1.4 Relationship-centred care and conflict

I observed the transfer of knowledge between the participants and the SHPs as a critical aspect of the consultations, as it indicated where the participants developed their trust in the SHPs. For most of the SHPs, their perception of a trusting relationship seemed to be what enabled them to work together with the participants, and share the decisions about care. During the consultations I observed the way the SHPs and the participants communicated; the conversation was informal, and they often pre-empted what each other was going to say or prompted each other to continue an explanation. This aspect of care is aligned to the coproduction literature (Morgan and Hunt, 1994, Lovelock and Young, 1979, Bovaird, 2007, Wu et al., 2013), which emphasises the importance of trust, especially when there is the likelihood of a long-term relationship with a service-user. The dynamics of the relationships I observed were focused upon the SHPs encouragement of the participants to develop their confidence on implementing care at home, and through the acquisition of skills and knowledge. This was a means to delivering relationship-centred care (Tresolini, 1994), and increased their social capital as they encouraged the participants to maintain hope, even when their hope seemed lost.

This was suggestive of socio-emotional communication and relationship building (Vinall-Collier et al., 2016), as the participants came to “know” their SHPs. It was also an example of the nurturing and maternalistic approach to the care given by the SHPs, and further examples of a vertical bonding social capital (Ferlander, 2007). The dynamic of their relationship was complex, and centred around the SHPs giving reassurance, information giving, coaching, encouraging, and acting as a conduit to “affective resources” (Whiteford, 2017, p.185) in terms of therapeutic interventions, such as yoga and swimming.

These could also be interpreted as hidden “strategic actions” of the SHPs, which ensure that the service-users understand the benefits of the proposed therapeutic interventions, especially if the service-user was reluctant or hesitant about the SHP suggestions (Habermas, 1984, in , Baxter, 2001, Vandenburgh, 2004, Greenhalgh et al., 2006, Outhwaite, 2009, Scambler, 2015). However, any strategic actions could also be perceived as the SHPs attempt to increase the service-users’ accountability and responsibility (Bettencourt et al., 2002) for coproducing and implementing their care. This was in terms of optimising opportunities for the participants to share-decisions, and gain confidence to make choices with the SHPs, even if the choices were perceived as limited. The SHPs attempted to do this through learning more about the participants, and encouraging them to actively communicate by asking questions, sharing their thoughts and problems, and explaining how they adjusted their life where necessary. This transfer of knowledge created more opportunities for the SHPs to understand what was really happening when the participants described difficulties in implementing the agreed care. In addition, they rebuffed any perceived resistance to treatment, by proposing it in a way which was acceptable to the participants.

The participants, and their significant others, frequently described implementing the required care at home as time-consuming, difficult, frightening, and expensive. In these instances, the SHPs encouraged and facilitated the participants to express their feelings and emotions, about this and then suggested options which would be most realistically achieved by the participants. The SHPs delivered individualised care and hoped that it was implemented and tolerated. The SHPs clearly recognised the tensions which arose in their relationships with the participants, and therefore the most important aspect of care delivery was agreeing a plan together; shared-decisions which were acceptable to the participants, and which helped them to feel more in control, and which allayed their fears as much as possible.

This was especially important in those instances when suggestions were met with resistance (Derek, Lucy, Diane), This appeared to be an unconscious strategy by participants to negate their responsibility, when the affected area is "not behaving” like the rest of their body (Synofzik et al., 2008) reinforced the idea that “nothing really can be done”. This had implications in terms of operationalising the coproduction of care, as participants tried to regain control and manage a condition which they perceived to be uncontrollable. This further highlighted the emotional difficulties which the participants expressed when implementing that care within their own home. The negotiating skills of the SHPs were aimed at encouraging participants to follow prescribed treatment. However, there was never a sense of “giving up” on them, even when the SHPs described them as “very challenging” or when they described caring for those participants who genuinely very complex disease.

This also highlighted the SHPs’ frustrations and sense of injustice about the lack of scientific capital or recognition of lymphoedema, and in particular the lack of “organizational health literacy (Brach et al., 2014, p.274) which led to arbitrary ways in which the participants accessed their care. The SHPs expressed desperation about how to find solutions collectively and individually for their service-users, even when they knew worsening symptoms or complications occur due to factors beyond their control.

There were times when this created conflict in their relationship, especially in terms of the service-user as “co-implementer” (Voorberg et al., 2015, p.1347); and the assumption that sharing and accumulating knowledge always enabled the participants to operationalise their care, outside of the clinic setting. Despite optimising the opportunity for positive relational exchange and the sharing of skills and knowledge (Batalden, 2018), the SHPs explained where, and how the most stress and conflict arose within the coproducing relationship (Jo and Nabatchi, 2016, Nahi, 2016, Osborne et al., 2016, Osborne, 2018).

It was obvious that within most of the consultations that the SHPS had to ask probing questions to gain information about the participants. However, I observed that this was not always easy or straightforward; even when the SHP demonstrated adept communication and interpersonal skills. Furthermore, the SHPs perceived they worked as “detectives” (Zerwekh, 1991, Kaminsky et al., 2009, Whiteford, 2017, Ahlsen et al., 2018, Rubin, 2020) and used their skills and knowledge to elucidate the key enablers and barriers to the participants implementing their care at home. I observed the SHPs using their intuition, expertise, and tacit knowledge to understand their participants, without also making gross assumptions. It was obviously challenging when a participant did not share or explain their issues, whether related to their care, or their lived experience.

Therefore, the detective work was more about “what was not being said” and persevering with questions to build a picture of what was “going on” for the service-user. The SHPs asked sensitive and empathetic questions; probing to delve deeper to find answers. The behaviour of some participants during these conversations could be considered to be an example of “problematic consumer conduct” (Hibbert et al., 2012, p.329); when participants are not implementing care at home, whatever their reason. This became a source of conflict which also antagonised the hierarchical power dynamic at the clinic. In these instances, the SHPs responded by actively trying to understand the participants’ story; they recognised that this was an emotive experience; considered how the service-user responded by paraphrasing their responses; and attempted to de-escalate the interaction.

4.4.1.5 Conclusion

In conclusion, the findings from the observations exemplified the dichotomy of coproducing relationships within healthcare when there is conflict in terms of how that care could be implemented at home. The value of the relational exchange and sharing of “operant” resources, which developed over time, enabled the participants to gain trust and confidence in the SHPs. This increased the social capital between them, despite this being a vertical social network or linking social capital, which reflects this power dynamic (Ferlander, 2007, p.123) . This was even when participants were not entirely confident about their implementation of care at home, or if they perceived that the treatment options were limited, and outcomes were not deemed “successful”. The SHPs nurtured a positive relationship with the participants. This centred upon developing trust, understanding the drivers and motivators for their health behaviour, and considered their socioeconomic contexts (SDH), and their emotional and psychosocial issues, through their “detective” work.

This demonstrates the relevance of Bourdieu (1984), in terms of how the participants’ habitus and capitals influenced their health behaviour and implementation of care at “home”. The subsequent transfer of knowledge and skills created more opportunities for the SHPs to understand what was really happening, and the difficulties that the participants described.

The hierarchical relationship which exists within the NHS cannot be negated or avoided, no matter how positive or aspirational the SHPs and participants are regarding the potential for equality within their relationship. Despite the structural issues regarding the coproduction of care most of the participants highly valued their relationship with the SHPs; and the SHPs attempts at the genuine coproduction of care were not perceived as a token gesture (Ocloo and Matthews, 2016). It was aimed at building trust, demonstrated loyalty and reciprocity (Bovaird, 2007), relied upon commitment, and especially upon the participants accepting responsibility (Morgan and Hunt, 1994, Bettencourt et al., 2002). In the instances where this happened, value was co-created (Ramirez, 1999), and the process of coproducing care was successful, even if the implementation of care at home was a challenge. However, challenges persisted on the occasions whereby the SHPs perceived that the participants could not or did not accept responsibility for their care.

4.5 Socioeconomic context: findings and conclusion Postcodes and GP Surgery

By the end of the data collection period, the staff at the Site 1 collected postcodes from the 1st of February 2018 to the 20th of March 2018 (434), and then the 15th of October 2018 to the 20th of October 2018 (44). The total number of attendees recorded by the staff at Site 1 was 478. Given that during the data collection period there were potentially a minimum of 7,000 clinic attendees, it must be acknowledged that the sample of service-users' postcodes was limited. At the time of data collection, the limited findings of the postcodes and GP Surgeries, indicated grouping of service-users within geographical areas considered as socially deprived on the ISD. However, no assumptions could be made as to whether the service-users were socially deprived, because they resided in these areas.

Although it appeared that I was able to identify specific GP surgeries, who referred the most service-users, I realised that some of the service-users attending the clinic were recurrent attendees. The absence of the last two letters of the postcode meant that this was not clear and could not be assumed. However, the clinic staff documented the attendees and they reported that there were frequent times when this was not undertaken, because of it was time-consuming. This was because they had to access the notes or the electronic system to find the GP surgeries and this was significantly adding to their workload. Furthermore, the clinic staff explained that they were not always able to prioritise collecting the data, due to the move of the clinic to other locations and the time pressure this created.

In conclusion, at the time of the study the service-users attending clinic, and living within the postcode areas of the City (Site 1), resided in a geographical location which was within the top 10% of the most socially deprived cities of the UK (NCC, 2015, Ministry of Housing Communities & Local Government, 2015). Although I also collected the demographic information on the 28 participants who consented to interview, it was not possible to make any assumptions about the socioeconomic position or levels of social deprivation of the participants; or whether their immediate circumstances, as opposed to their geographically locality, were evidence of being socioeconomically deprived. In addition, whilst the postcode data matched the geographical position of the clinic attendees and the participants who were interviewed, a more in-depth study is required to determine their socioeconomic position in terms of factors such as income, class, education and housing.

The main conclusion of the limited findings of this aspect of the study, is that they support what is already known about LTCs, the SDH, and health inequality (Marmot et al., 2012, Carey and Crammond, 2015, Crammond and Carey, 2016b, Cockerham et al., 2017), in terms of the geographical context of service-users.

5 Findings of the In-depth, Face-to-Face interviews

5.1 Chapter overview

This chapter provides details of interview participants and summarises the qualitative findings from the In-depth, face-to-face interviews study, to providing a framework for subsequent chapters.

5.2 The participants

My aim was to explore how coproduction was operationalised within this context of ongoing care across hospital and home settings, for individuals living with a long-term condition (chronic oedema), and how socioeconomic position and social capital affects coproduction in this context.

The usual care team recruited 50 participants to the study, by the usual care team, and 28 participants consented to interview; 29 interviews were undertaken, as one participant was interviewed twice. All interviews, apart from two, took place within the participants' own domestic setting. These were all approximately an hour long, or until no new themes or new information was revealed (Guest et al., 2006). These participants were recruited from both Site 1 and Site 2 Clinics, and at the time of data collection (NCC, 2015, McCormick, Aderson, Kightley et al., 2017) they all lived in areas considered to be significantly socially deprived. The reasons for the 22 other participants not continuing to interview were that they:

- did not answer their phone
- they stated they no longer wanted to participate

- they were too unwell to participate, or they changed their mind

During most of the interviews the participants stated that they believed the research topic to be important, because of their experience of the lack of awareness about lymphoedema.

5.2.1 Table of Participants

Name	Affected body part	Age	Employment status	gender	When identified by participant	Primary or secondary lymphoedema	Name of condition as described by participant	Access to clinic	status	Site	Observed in clinic
Linda	Abdomen/ Pelvis	36-45	Paid employment	Female	Following surgery	Secondary granulomatous	Lymphoedema	Via a different consultant team/clinic	Single	LSN	No
Lucy	Both legs	36-45	Unable to work	Female	Following cancer/cancer treatment	Secondary (radiotherapy and lymph node removal)	Lymphoedema	Via GP	Single	Site 1	Yes
Matt	One leg	46-55	Unable to work	Male	Cellulitis	Secondary (morbid obesity and recurrent cellulitis	Lymphoedema	Via a different consultant team/clinic	Divorced	Site 1	No
Taran	Both legs	46-55	Carer	Male	Swelling	Secondary morbid obesity and injury	Lymphoedema	Via emergency admission	Married	Site 1	No
Tina	Body	46-55	Retired due to ill health	Female	Cellulitis	Secondary morbid obesity and Crohn's disease)	Lymphoedema	Via emergency admission	In a relationship	Site 1	No
Betty	One arm	56-65	Retired	Female	Swelling	Secondary radiotherapy and lymph node removal)	Lymphoedema	Via a different consultant team/clinic	Married	Site 1	No

Name	**Affected body part**	**Age**	**Employment status**	**gender**	**When identified by participant**	**Primary or secondary lymphoedema**	**Name of condition as described by participant**	**Access to clinic**	**status**	**Site**	**Observed in clinic**
Debbie	Both legs	56-65	Retired due to ill health	Female	Following surgery	Secondary (morbid obesity)	Lymphoedema	Via a different consultant team/clinic	Divorced	Site 1	No
Jane	Both legs	56-65	Unable to work	Female	Swelling	Secondary to cancer treatment	Lymphoedema	Via GP	In a relationship	Site 1	No
Lloyd	One leg	56-65	Paid employment	Male	Swelling	Primary	Lymphoedema	GP and emergency care	Married	Site 1	No
Mary	Both legs	56-65	Retired due to ill health	Female	Swelling	Secondary Reduced mobility due to auto immune condition	Lymphoedema	Via GP	Married	Site 1	Yoga
Richard	Both legs	56-65	Retired due to ill health	Male	Cellulitis	Secondary (injury)	Oedema	Via GP	Married	Site 1	Yes
Cathy	One leg	66-75	Retired	Female	Swelling	Primary Lymphoedema	Primary Lymphoedema	Via GP	Divorced	Site 1	Yes

Name	Affected body part	Age	Employment status	gender	When identified by participant	Primary or secondary lymphoedema	Name of condition as described by participant	Access to clinic	status	Site	Observed in clinic
Greg	Both legs	66-75	Retired	Male	Swelling and leaking	Secondary to poor venous return	Lymphoedema	Via GP	Married	Site 1	Yoga
Hattie	Both legs	66-75	Retired due to ill health	Female	Swelling	Primary	Swelling	Via GP	Married	Site 1	Yes
Jenny	Both legs	66-75	Retired	Female	Swelling	Secondary to varicose veins and DVT	Lymphoevenous oedema	Via a different consultant team/clinic	Married	Site 1	Yoga
Rachel	Both legs	66-75	Retired due to ill health	Female	Swelling	Secondary to varicose veins	Lymphoedema	Via a different consultant team/clinic	Widowed	Site 1	Yoga
Shirley	Both legs	85+	Retired	Female	Varicose veins	Secondary to varicose veins	Swelling	Via GP	Widowed	Site 1	No
Graham	One leg	46-55	Paid employment	Male	Swelling	Primary	Lymphoedema	Via emergency admission	In a relationship	Site 2	No
Jo	One arm	56-65	Paid employment	Female	Following cancer/cancer treatment	Secondary to cancer treatment	Lymphoedema	Via GP	Married	Site 2	Yes
Maeve	Both legs	56-65	Paid employment	Female	Swelling	Secondary to DVT	Lymphoedema	Via GP	Divorced	Site 2	Yes

Name	Affected body part	Age	Employment status	gender	When identified by participant	Primary or secondary lymphoedema	Name of condition as described by participant	Access to clinic	status	Site	Observed in clinic
Nel	Both legs	56-65	Retired	Female	Swelling	Primary	Lymphoedema	Via emergency admission	Married	Site 2	No
Penny	Both legs	56-65	Self-employed	Female	DVT/PE	Secondary to DVT	Primary Lymphoedema	Via a different consultant team/clinic	Married	Site 2	No
Rod	Body	56-65	Retired due to ill health	Male	Swelling	Primary (interstitial)	Lymphoedema	Via GP	Divorced	Site 2	No
Keith	Both legs	66-75	Retired	Male	Swelling	Secondary cellulitis	Lymphoedema	Via GP	Widowed	Site 2	No
Malcolm	Both legs	66-75	Retired due to ill health	Male	Varicose veins	Secondary to varicose veins	Lymphoedema	Via a different consultant team/clinic	Single	Site 2	No
Derek	Both legs	76-85	Retired due to ill health	Male	Swelling	Secondary cellulitis	Cellulitis	Via GP	Married	Site 2	Yes
June	Both legs	76-85	Retired	Female	Following cancer/cancer treatment	Secondary to cancer treatment	Lymphoedema	Via GP	Married	Site 2	No
Peter	One leg	76-85	Retired due to ill health	Male	Following cancer/cancer treatment	Secondary to cancer treatment	Lymphoedema	Via a different consultant team/clinic	Married	Site 2	No

Table 11: Table of face-to-face interview participants

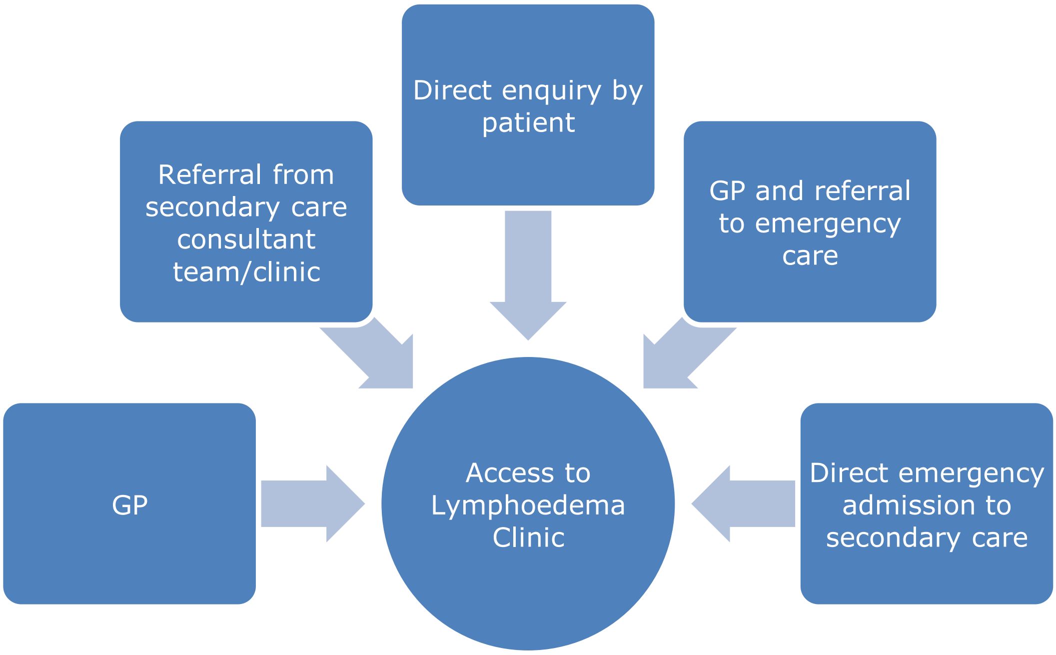


Figure 7: Process map of participants accessed the Lymphoedema Clinics

The participants interviewed in this study (Table 11) described how their access to the Lymphoedema Clinic was arbitrary. By process mapping their descriptions (Figure 8), it was clear that many had accessed multiple episodes of care within their local emergency department and/or visits to their GP, before any referral to the Lymphoedema Clinic was made. For some this occurred over years, or "by chance". It was evident that no clear pathway for participants was in place (Moffatt et al., 2018, Thomas and Morgan, 2017, Humphreys and Thomas, 2017), as shown in Figure 7.

It is also relevant to note that in this study that over the half (61%) (Figure 7) of these participants were under 65 years of age, which is lower than the average age of participants, in some of the contemporary studies (Moffatt et al., 2003, Moffatt et al., 2017b, Quéré et al., 2019). This is particularly relevant given the trajectory of chronic oedema/lymphoedema of those diagnosed at a younger age.

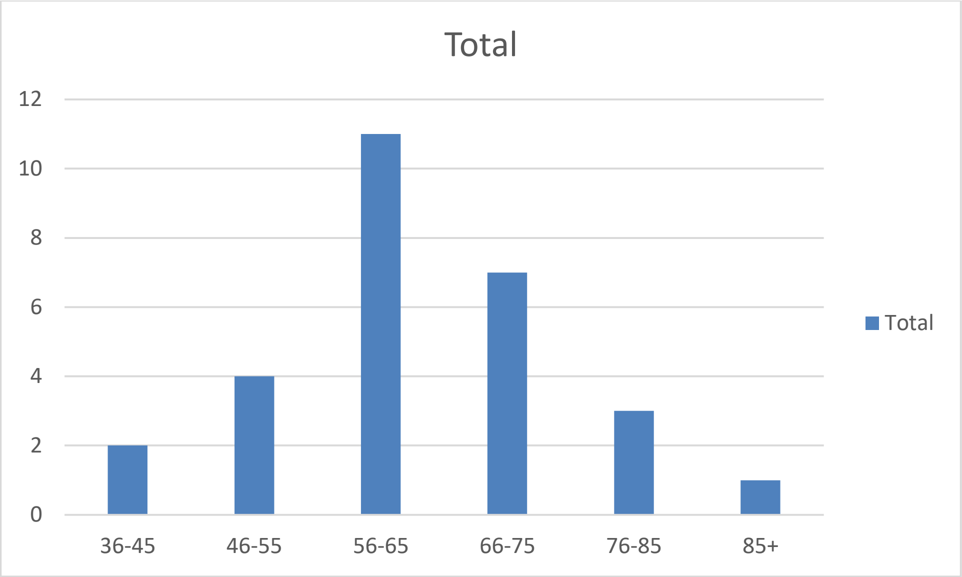


Figure 8: Age of the participants recruited to interview

No participants were recruited directly from GP surgeries, and one participant was self-recruited through the Lymphoedema Support Network, who advertised the study on their social media "Facebook" page. None of the participants recruited or interviewed were considered vulnerable (NHS England North, 2014); as outlined in the REC committee's decision for ethical approval, the inclusion criteria for recruitment, and consent process. All participants were over 18, and assessed as having the capacity to complete informed consent. 5 participants stated they received a diagnosis of primary lymphoedema and 23 received a diagnosis of secondary lymphoedema.

5.2.2 Interview Participants demographics

From the participants demographics some important findings emerged.

- Figure 9, demonstrates how most of the participants presented with 'swelling' (Site 1 and 2), followed by cellulitis (site 1) and cancer (site 2).
- Figure 10 shows how the number of those affected by lymphoedema of the legs correlates with retired due to

ill health, retired and unable to work. Suggesting that bilateral lymphoedema of the legs has a significant impact upon their ability to remain employed (all these participants stated they had worked in paid employment).

- Figure 11 demonstrates the body site affected and how the participants described the presentation of lymphoedema.
- Figure 12 demonstrates the distribution of the participants across each site and how their lymphoedema presented

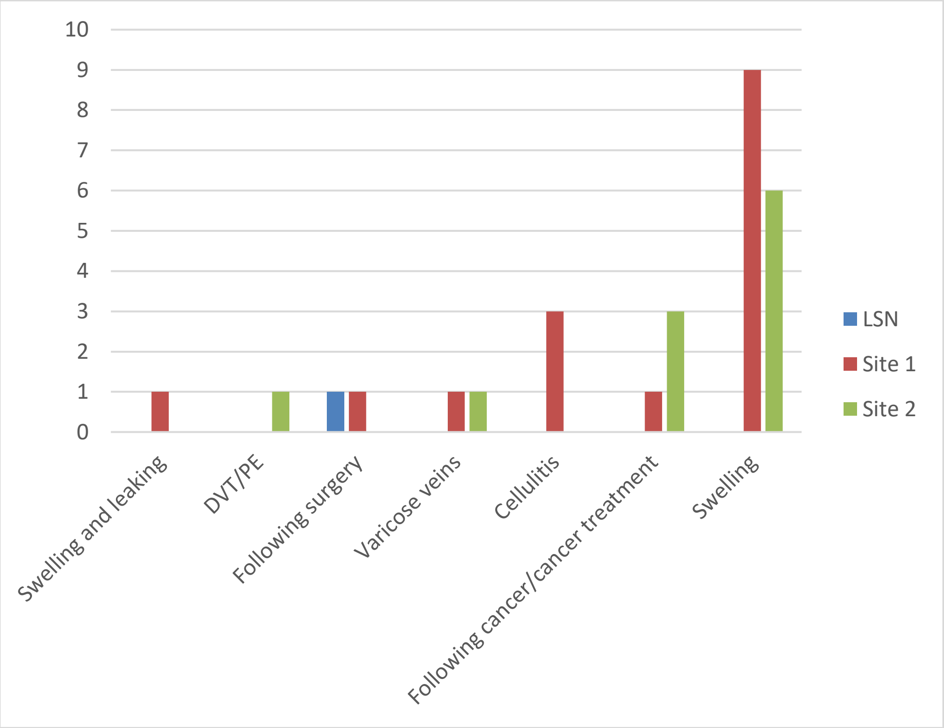


Figure 9: Recruitment Site and presentation of lymphoedema

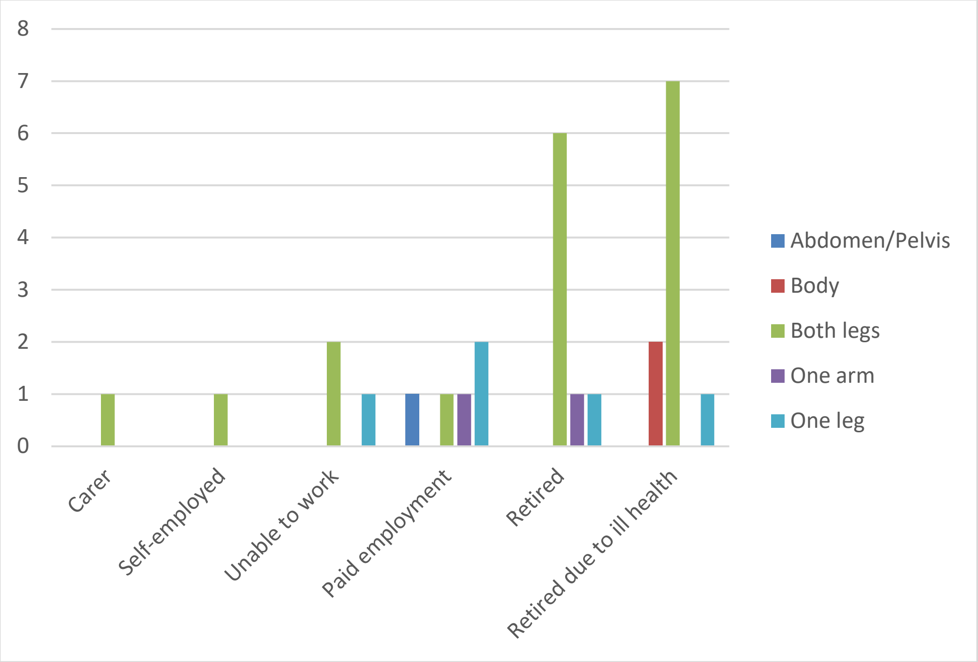


Figure 10: Employment and body site affected by lymphoedema

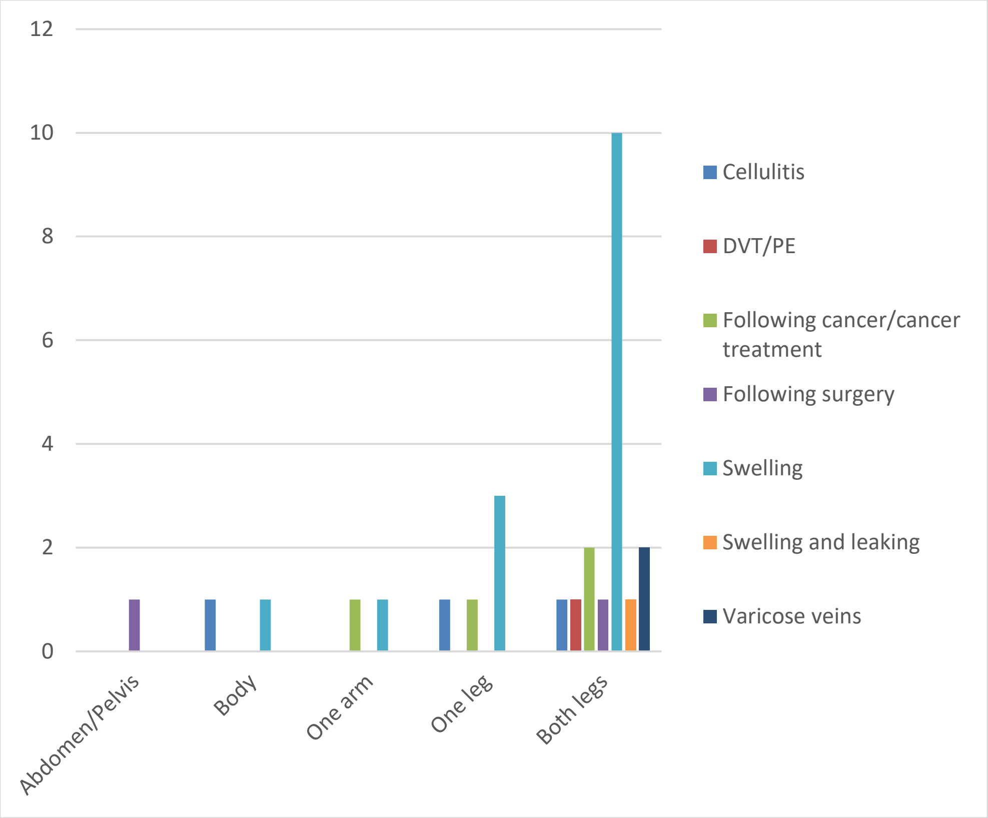


Figure 11: Body site affected and presentation of lymphoedema

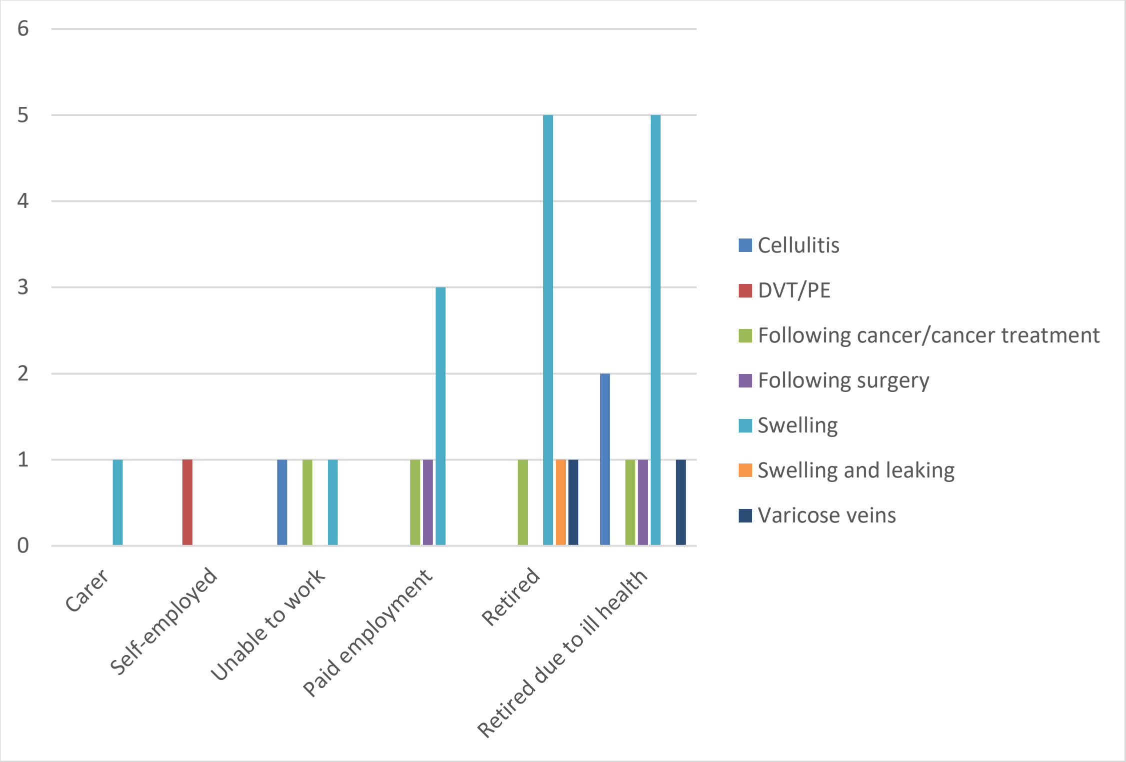


Figure 12: Employment status and presentation of lymphoedema

5.3 The Coproduction of Chronic Oedema Care

The overall the analysis of the interviews led to 3 chapters of findings and identified three interconnected aspects which reflected the participants' experience of engaging and coproducing care (Figure 14). These defined the Coproduction of Chronic Oedema Care:

1. Developing Expertise: Identity and Biographical Disruption; Goals for Management; "Operant Resources"
2. Interface with Healthcare Professionals: Finding a Way When There Is No Path; Relational Exchange; Context of The Healthcare System
3. "Operand Resources": Working and Not Working, The Hidden Cost: Economic and Social Capital

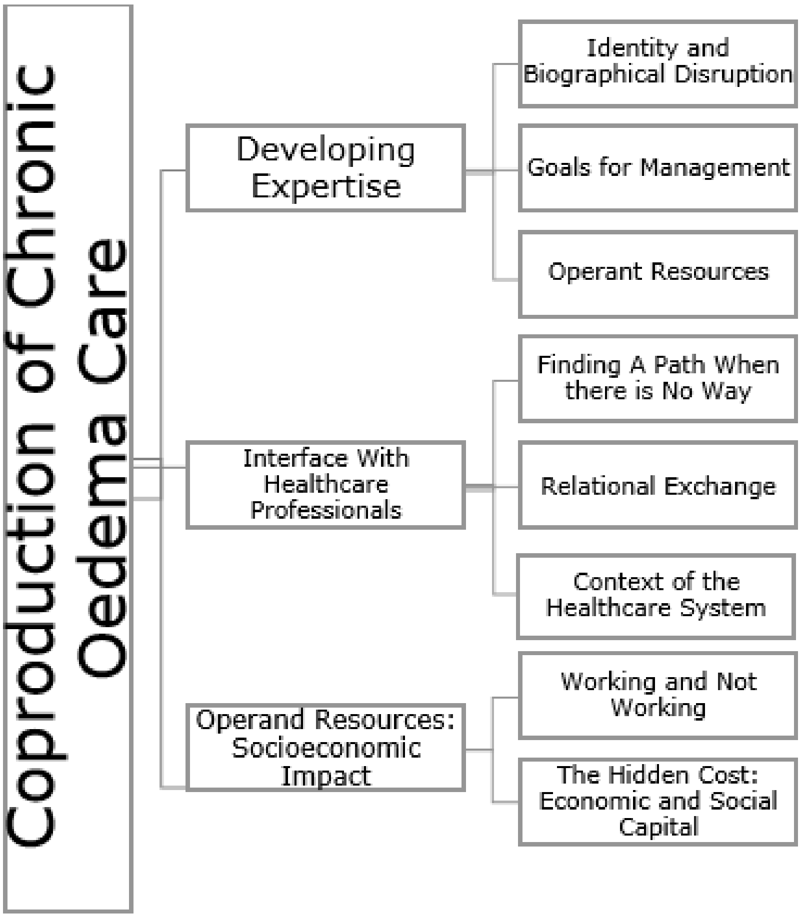


Figure 13: The Coproduction of Chronic Oedema Care Themes and sub-themes of the in-depth, face-to-face interviews

6 Developing Expertise

6.1 Chapter overview

Within this first section of findings, a clear overarching theme emerged regarding the participants experience of Developing Expertise illness. This section explores the themes and sub-themes of:

- Identity and Biographical Disruption: Loss and Stigma; "This is war": manifestations of coping with illness
- Goals for Management: Pragmatic solutions: mobility, safety and independence; Restrictions to choice and control:
- "Operant resources": Skills and knowledge; Finding solutions; Routines and rituals; Resisting help: maintaining normality

Exploration of these themes (Figure 13) demonstrates how these findings are relevant in terms of how the participants operationalised their care, from "hospital" to "home", and how self-perception and identity affects the strategies for managing their care within the domestic setting. The experience of illness is positioned within a frame of what it means to be "normal" and "functioning", and how this affects their goals for management.

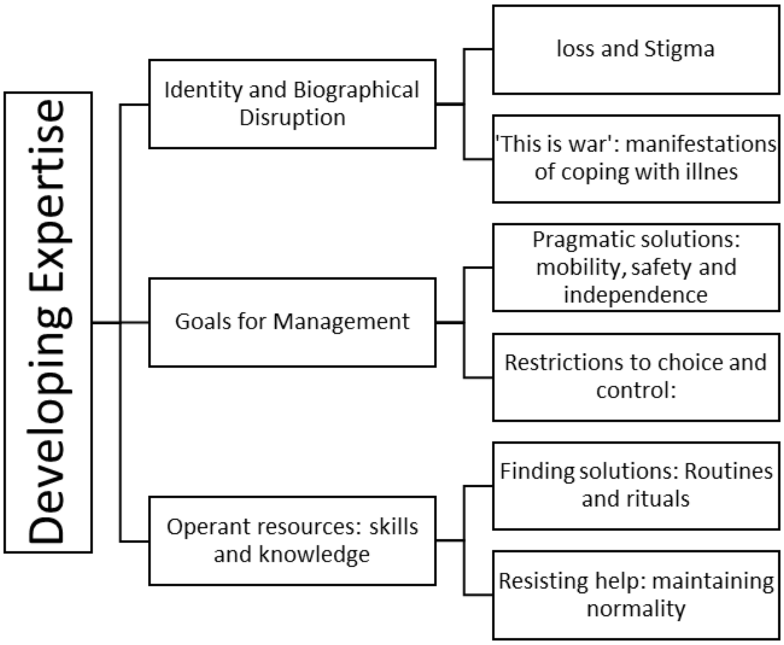


Figure 14: Theme 1: Developing Expertise

6.2 Identity and Biographical Disruption:

The participants' self-perception was a theme which emerged, throughout the data collection period, as participants waited for investigations, diagnoses, treatment; and described their experience of living with Lymphoedema. The participants described their experience within the frame of "normal" and "functioning", which emerged as activities which were important to them. This was an intrinsic aspect part of the importance they placed upon their role (work and family) and their interpretation of societal expectations. The potential to improve, and their personal responsibility placed upon their engagement and motivation to cope with their health, contributed to maintaining their credible place within society. This was regardless of how they described their socioeconomic status or because of any limitations around their treatment or access to support (social capital).

Many participants described their initial awareness of lymphoedema as feeling "different", a swollen body part or feeling of heaviness in their limbs. For some this started in childhood (Helen, Cathy) or was an abrupt event due to infection or acute swelling (Matt), or cancer/cancer treatment related (Lucy, Betty, Jo, Peter, June). Regardless of how their lymphoedema presented, the overarching narratives emerged of a life, and body, separated in terms of "before and after", with no sense of what this meant for their future:

> *"Oh absolutely gosh I had no I had no way of knowing erm what my life would have been like" (Cathy)*

This sense of separation was even more pronounced at the point of diagnosis, and the realisation that lymphoedema was a condition they must live with for the rest of their lives. Nel, a 65-year-old, retired schoolteacher, revealed she had a rare genetic condition, which caused her lymphoedema:

> *"Even growing up er it became I didn't know I had it" (Nel)*

For many of the participants the physical manifestation of lymphoedema was an observable antithesis to the defined concepts of physical health and wellness. Many participants, regardless of how their lymphoedema developed, described their own remorse and frustration at not recognising their early symptoms:

> *"When you get the shadow and think I'm sure my leg is a lot fatter [laughs] it's ridiculous because you think I'm going to the doctor and saying my leg looks fatter [laughs] (Maeve)*

Or were self-critical because they did not access help sooner, due to normalising their symptoms and comparing themselves to their family members:

> *"I had always had bad legs because my mum used to say you're going to be like your gran with big legs" (Rachel)*

For some this represented a complete change in their identity and for many this was expressed as grief, anger and/or sadness at the loss of their former self:

> *"So quite you know physically active you know walking going everywhere yeah going everywhere but after that it's just er sort of basically totally changed now" (Taran)*

This was even more pronounced because of the feelings of embarrassment and shame about their appearance; the sense that their body was changed and no longer resembled the form they recognised as themselves. For June it was:

> *"The embarrassment of two different shaped legs and I don't want people to know … on the front of appearance I look fine" (June)*

Moreover, these participants also described feelings of disgust in terms of how they perceived their body. Mary articulated what many participants described:

> *"You know [laughs] because you know it's quite it makes you feel almost dirty and I know that's daft" (Mary)*

Nearly all the participants described the swollen parts of their body in derogatory terms such as bulky, warty, hard, "leaking" and smelly. Many of the participants described their physical state as a mass of overwhelming and enveloping skin and flesh:

> *"So I started to blow up I began to look like the Michelin man … the legs I loathe and over the year's erm they've just got bigger and bigger and bigger" (Debbie)*

Moreover, the descriptions of their physical appearance were always closely associated with the connotation of "fatness" (adiposity) and the problems this created for the participants. Many of the participants within the study, described themselves as "fat" and expressed that they "needed" to lose weight. Furthermore, they found it difficult to accept the physical changes which occurred because of lymphoedema:

> *"To try and keep me weight down and I'm not a lazy person" (Graham)*

Some of the participants described how, prior to their own diagnosis, they had also made assumptions about others who they perceived as "just fat" (Tina):

> *Because it's a hidden illness same as Crohn's people just don't think there's anything wrong with ya basically they think you're fat (Tina)*

This was evident in many of the interviews, for example Debbie explained that her son:

> *"**** is convinced that I've got it because I'm overweight now don't get me wrong I know that my weight doesn't help" (Debbie)*

These perceptions are then verified, because of how the participants described their own bodies, and in terms of how other people looked, stared and made hurtful comments:

> *"it's got a very psychological thing to it the body image because … every single bloody person I came in contact with said what av ya done and I thought oh my God so much for the nobody'll notice" (Penny)*

Or that they become a source of amusement and mockery:

> *"And you see when they're walking it wobbles and they said me leg looked like and they were just giggling about it so [laughs] it was it wasn't embarrassing or upsetting it was just comical Er I mean I didn't take it as an insult or anything" (Matt)*

Although Matt verbalised that this was amusing, his body language and facial expression did not suggest that he found it amusing, it seemed that he laughed but did not feel "in" on the joke and recognised that he was the object of the joke. Furthermore, even wearing compression garments (stockings and sleeves) caused self-loathing:

> *"It's so disheartening I mean it's and it makes you look even more freakish you know people talk about oh you have to learn to love your body I absolutely hate my legs (Debbie)"*

For many participants the idea of improving cosmesis was problematic, because of what they perceived had happened to their body already, particularly the fear that they are beyond restoration:

> *"So I'm sort of back in a catch 22 situation"*
> *(Taran)*

This was relevant when the participants spoke about the challenge to reduce their swelling and lose weight, and vice versa. This was frequently described when they were doing their utmost to persevere with their treatment plan. In addition, the participants blamed themselves, and agonised that having lymphoedema was their fault:

> *"I wonder if I'd have continued to wear my support tights whether I would have actually ended up with it" (Maeve)*

Many participants described that their current situation was not how they envisaged their life and missed their former "self"; a profound sense of loss around of what should have been.

6.2.1 Loss and stigmatization of the self.

Through the descriptions of self-stigmatization, a sub-theme emerged; the imagery that the participants' former body (before) metamorphosed, and was replaced by a deviant body, which cannot be controlled and does not conform. Many of the participants referred to an "otherness" and described affected body parts as inanimate objects such as "tissue paper", "balloons", "lump of lead" and "fire extinguisher". Some participants used metaphors to describe this change, and often referenced the affected parts of their body as a separate entity, such as “the leg” rather than “my leg”. Moreover, describing their body as an inanimate object enabled the participants to partly reconcile their self-blame; that their body was beyond control because it’s not really part of “me”:

> *“Two tree trunks for legs … If I could have a leg transplant I’d have one” (Debbie)*

Furthermore, participants often described that trying to manage treatments, and their management plan was like being:

> *“Between a rock and a hard place” (Keith)*

Or trying to gain or maintain control of their changed or changing body. Accepting the changes was much more challenging, especially when their body was behaving in an unpredictable way:

> *“And it’s almost like crazy paving just as if like the tissue’s that thin that it just breaks open” (Mary)*

Or if most feared symptoms returned. The participants often described their bodies as if it was invaded by an “outside force” (Bury, 1982, p.173) or distinguished a physical or imagined boundary between the affected and non-affected parts of their body:

> *“I’ve explained to people at work it’s like “avin a bucket deep enough for yer leg to go into filling it with boiling water … it’s like I’m walking with a fire extinguisher” (Graham)*

For many participants this change in appearance and the behaviour of their body was perceived as a physical and metaphorical battle.

6.2.2 "This is war", manifestations of coping with illness

Living with lymphoedema as a daily "battle" or "war", emerged as a compelling theme. The battle was in terms of every aspect of their care. Many described that the battle began even before diagnosis, and then as they fought against the changes in their body, the management of their swelling and other more serious complications:

> *"It's just bin such a erm er just been such a hard battle [laughs] erm and I think I sort of realised that it was probably gonna carry on you know it wasn't just gonna be til ma next appointment" (Linda)*

For Linda the battle was in relation to their referral to SHPs, finding answers and the challenge of waiting between appointments for more information. Participants explained that this was often very stressful during the early stages of diagnosis. However, after diagnosis came the shock and realisation that their life had changed and for some, was evermore defined by their lymphoedema because it can never be cured.

From the point of diagnosis, the real battle was to prevent all aspects of life with lymphoedema from worsening. This led to many of the participants to face their "battle" with a stealth like determination. For others the battle was very physical, in terms of a determination to undertake tasks which were once easy and taken for granted, such as getting out of a chair or bed easily; or continuing with “normal” activities such as exercise, washing, dressing or housework.

For some the battle was related to their treatment plans, especially trying to get into compression garments and applying wraps. This was often physically exhausting due to the effort required to apply them. This was problematic when participants had existing comorbidities, particularly arthritis and required the help of others:

> *“… because putting this strapping on is not a one is not a self person job erm I have family that are prepared to do that” (Matt)*

The participants with a diagnosis of cancer had a different perspective, in that they described that their battle started before the lymphoedema. They described that fighting is what must be done, and that living with lymphoedema is no different; the struggle goes on. Furthermore, the meanings which underpinned the concept of fighting inferred that it was against a losing battle; potentially anything they do might not change what happens in the future. This was important in terms of their motivation to undertake the required self-care and treatments, they agreed with their SHPs; and make decisions about care and how this was then implemented at home. This was particularly relevant because only a small number of the participants in the study were attending clinic on a weekly, or monthly basis. Most participants were only seeing their SHP once every six months, and therefore care was mostly undertaken within the home setting.

For many the idea of a battle was underpinned by their fears about an unpredictable future. Therefore information, education, and support were essential; to enable them to come to terms with the physical magnitude of lymphoedema, and to help in terms of future. Whilst working and agreeing goals with their SHP was important, how they were undertaken at home represented the metaphorical battlefield. This was what really influenced and framed their goals for management.

6.3 Goals for management

The participants explained their goals for management in terms of what was discussed and agreed between the SHPS and the participants during their clinic appointments. These were underpinned by 2 main factors: maintaining function (working, mobility and footwear, and choice); and mitigating fears and consequences. From a clinical perspective their goals for management were aimed at preventing the worsening of the lymphoedema, and reduced limb volume; and this offered reassurance for some participants. However, this was not the case for all participants, and a smaller number did not value, or even trust this measure as the most important indicator of their swelling. For most of the participants, maintaining a level of "normality" and function was what mattered, and this was how the "battle" was managed at home.

6.3.1 Pragmatic solutions: mobility, safety and independence

Maintaining function was an important goal and was described in relation to specific aspects of their life such as working (paid and volunteering), mobility and independence. This included individual goals, which were sought to enable taking control and gain confidence, particularly around decision making. This was not necessarily about maintaining the function they once had, however functionality represented some degree of normality. Maintaining function also represented an indicator of their lymphoedema status; if participants could undertake activities, or fulfil their role at home and work, life was perceived that life was “normal”. Many of the participants explained that the stiffness and thickness of the garments (garment and wraps), hindered mobility and physical movement, and that they were difficult to apply, even with aids that were meant to help. Furthermore, several participants chose not to wear their compression garments in certain circumstances, such as parties or weddings, or when on holiday. This was despite explaining that they wanted to wear them or feared that their swelling would worsen very quickly, if they did not wear them “all the time” (this usually meant every day, but not at night).

Being physically mobile and active, even for those with significant mobility issues, was important in terms of self-care, and in terms of the positive mental effect. Keith actively sought out situations to keep himself physically active around the house:

> *“I try not to have too much on hand, only what I’m absolutely using of course, I can’t get up and down all the time. But I just do it to try and make myself as mobile as I can” (Keith)*

A major, overarching narrative was mobility, and how it specifically related to shoes and footwear. This was not just in terms of walking but also what mobility represented. This was twofold; from a safety perspective and related to self-perception and identity. From a clinical perspective, the participants reported that they were educated on the importance of good quality, protective footwear when living with lymphoedema. However, the experience of these participants reflected the huge challenge of finding shoes which would fit well and offer the necessary protection. Hattie explained that even with appropriate, orthotic footwear mobility was impeded because of their bulkiness:

> *"They were very comfortable. I wore them for a couple of days and fell over twice … I'd never really fallen over for years as an adult" (Hattie)*

Many of the participants described that these restrictions made them feel childlike; in terms of the style of shoes on offer, their increased risk of trips and falls, and relying on others to help them mobilise. The role of footwear and feet issues was symbolic in terms of depriving individuals of social interaction and increasing feelings of isolation, threatening their identity and perception of themselves:

> *"So I decided well I'm not wearing these shoes no more and I found I could get in men's trainers, though they don't look very glamorous" (Hattie)*

For these participants the social meanings attached to wearing shoes were important, and particularly what wearing the "wrong shoes" represented. By "wrong shoes" these were either the large cumbersome specialist shoes made by orthotics; shoes they perceived were inappropriate for their gender and age; and or footwear worn for the wrong reason for example, slippers worn outside. Situations such as these increased the participants' feelings of embarrassment; an addition to their feelings of "otherness", and more reasons for others to stare. Moreover, the shoes they now "have" to wear are not like the shoes they "used" to wear.

Wearing shoes, was not just about how they looked, they also meant that participants were able to undertake “normal” activities successfully. This also included some of the personal goals that the participants wanted to achieve. Tina described that she was determined to walk down the aisle on her wedding day in “nice” shoes, and without her walker, if she could find the “right” shoes to wear. Tina highlighted the lack of choice, and that many were not aesthetically pleasing

> *“Well yeah yeah I mean you do have a choice but all of “em are horrible” (Mary)*

This issue of shoes also highlighted that choice was limited in terms of footwear, clothes and compression garments. This was complicated by their social circumstances, as the support available to them also led to feelings of restriction and dependence. The participants described negative feelings, in terms of how they perceived themselves, and the lack of control over how they were perceived by others. All of this was described within a context of making choices which prevented an increased risk of complications with their lymphoedema. Many participants believed there were also no realistic developments or choice in treatment options, which caused frustration and desperation:

> *“I said I will actually be a guinea pig and this lady whose symptoms were the same as mine and she had had something that likened liposuction “(June)*

This led to a willingness to try anything new that might be available or suggest hope for a cure. However, many participants described their misery and disappointment when a new treatment was not “successful”:

> *"I couldn't erm I had so much pain in the leg but that was because I have er dodgy knees so that all had to come off and that was abandoned" (Maeve)*

Or hoping that an innovative treatment would be developed and change their life.

This idea of choice was closely implicated with the operationalisation of care within the home, and the achievement of goals. It was often framed in terms of deciding what not to do: not to wear those shoes, not to work, not to go out, not to go on holiday. Many participants believed that despite shared-decision-making, a lack of choices in terms of treatment options, and restrictions to their life at home amounted to very little choice at all.

6.3.2 Restrictions to choice and control: allaying fears

The apparent lack of choice described was clearly frustrating for many participants, whether this was around treatments, activities, clothing and footwear. This was articulated in their fears, specifically in terms of whether they felt "safe". By "safe", they meant that any decisions they made would lead to a situation in which they had put themselves at greater risk such as increased swelling, infection or immobility. Whilst their lymphoedema was seen as "uncontrollable", having choice symbolised the opportunity to feel more "in control", through goals and decisions which were shared with the SHPs, and then implemented at home. Having choice, meant "feeling safe", and was a way of mitigating and suppressing their greatest fears.

The overarching fears of the participants in this study related to developing cellulitis (a serious skin infection), “losing control” or being “out of control”. Many participants described how they tried to cope, with their fears and worries, caused by the potential the negative consequences of having lymphoedema. Their fears became the driver for undertaking their care at home, and in some ways a strategy for coping.

Many of these fears were heightened because of previous experience of cellulitis, their knowledge of others living with lymphoedema, and in terms of the information given to them by the SHPs. A number described how they would wait at clinic and would reflect upon others, who looked “worse” and perceived this as evidence that those service-users were not “looking after themselves”, or worse, an example of what might happen to them if they did not care for themselves “properly”, or “take responsibility”. These concerns were compounded by the immediate fear, worry and shame of how they were also perceived by others, and the embarrassment this regularly caused; or fears around the disclose of information, which is deeply personal:

> *“It’s just an embarrassment I think [crying] so anyway we went to Dublin and erm I’d got to share with this girl I was working with and I thought I’ll have to tell her about me legs because she’s going to see it” (Jane)*

Their fears were expressed in terms of the known and unknown; fears of the known were specifically related to episodes of cellulitis/infection; and fears of the unknown were if and how this would affect in their future. Moreover, for many the main fear was this would lead to serious disability, the loss of a limb, or worse. Lloyd described numerous episodes of cellulitis, which had been occurring every 6 months, over the last few years. The last episode he suffered had made him life threateningly ill, with sepsis:

> *"I just collapsed on the bed when I woke up in was in 'ospital I was that bad That I felt ma body shutting down all ma body fluids just was coming out I could not control myself" (Lloyd)*

Many participants also described avoiding situations because of the risks they posed, for example, gardening and camping because of the risk of an insect bite, and subsequent cellulitis. Therefore, being active and carrying on a "normal" life was a strategy for counteracting this, and a way of dealing with the restrictions which have already been placed on their lives

> *"while ever these work I'll use "em as much as possible because I am that I am scared a little bit of losing em" because I've lost enough" (Derek)*

Many participants described how they feared for their future, and the future of their significant others. For Malcolm, this included the fear of undertaking activities that might risk the safety of others. He described his experience of a car accident, which he believed was his fault due to difficulty moving his legs quickly enough to depress the brake pedal. He believed that if he not been wearing his wraps, or if his feet were not so swollen that this would not have happened.

> *"Because I want to be safe I want everybody else to be safe" (Malcolm)*

Those who had developed lymphoedema as a result of cancer treatment, or had a diagnosis of primary lymphoedema, also feared the potential genetic component, which might be passed onto their children:

> *"Er so you know my ultimate fear is that my daughter might develop lymphoedema" (Cathy)*

In addition, there were also fears and feelings of guilt due to situations which occurred in the past. Guilt was the emotion often described, when participants had been seriously ill, or if their lymphoedema meant that they could not fulfil their role within the family. Nel spoke of her feelings of regret when an episode of cellulitis caused her to develop life threatening sepsis, a serious infection in the body. This led to the cancellation of a family holiday, and her teenage son took on the role of her carer during the summer, as she slowly recovered:

> *"And you know he ended up with an entire summer of all of well of sort of looking after me in effect being around and when he's 18 and shouldn't have had that worry" (Nel)*

Nel also shared that her son, now in his early thirties, had recently been diagnosed with the same genetic fault which causes her primary lymphoedema and those feelings of guilt re-emerged.

Other fears related to prospective relationships and how to approach sensitive and difficult conversations related to meeting new partners, body image and sexuality

> *"I'm nervous about sort of meeting people and getting into relationships really about how to talk to prospective partners" (Linda)*

Linda became very upset during her interview, as she explained she was waiting for a more definitive diagnosis, which she believed would enable her to:

> *"Move on with my life" (Linda)*

When I interviewed Linda six months later, she had a formal diagnosis. However, she explained that although this had not relieved her fears, she had accessed some counselling. This was helping her come to terms her long journey to a diagnosis of rare granulomatous lymphoedema, which was linked to her existing diagnosis of hidradenitis supparativa, an inflammatory skin condition.

These narratives demonstrated how the participants' fears framed their motivation, to prevent worsening of their lymphoedema and any subsequent effect this might have upon their social network. This was operationalised in the way they discussed concerns with the SHPs, about how they undertook their self-care and treatments, or what might happen if they omitted part of their care or put themselves in "risky" situations. Ironically, these fears often led to behaviours that did not always align with goals for management, for example, not exercising for fear of causing harm to themselves, when specific exercises are advocated for those with lymphoedema.

A significant aspect of these participants' experience of illness was mitigating between their goals and fears, within their domestic and social life. The perceived lack of choice and control, meant that sharing decisions with their SHPs, particularly the nursing staff, was imperative. This was often perceived by participants as a way in which they developed their expertise and efficacy in caring for themselves, and that alone was considered an overarching goal for management.

6.4 "Operant resources": skills and knowledge

Developing skills and knowledge was a factor which all the participants described as important to their understanding of lymphoedema. Whilst all recognised that this was "knowledge" was not "professional", they perceived their expertise from the perspective of learning to live with lymphoedema and their understanding of the care specific to their needs. Their narratives throughout the interviews returned to the constant threat of infection, and this characterised their goals for management and drivers for self-care; the articulation of their very real fears, that cellulitis is a shadow looming over their life; that lymphoedema can worsen as a result of this infection, which further increased susceptibility of infection, because of the effects of tissue damage on their lymphoedema. Participants described routines and rituals which were undertaken to mitigate this risk and keep them safe. This was guided by the information and knowledge they had about caring for lymphoedema, and the shared-decisions made in clinic.

However, many of the participants also described certain aspects of care which were undertaken because of superstition and worries about *"bad luck"* and *"keeping safe".* Moreover, it was apparent that this care hindered their aspiration and ability to remain as independent as possible, through a reliance and fixation upon fastidious routines of self-care. This included superstitious beliefs about looking after their body, for example being *"lucky"* if they managed to do undertake *"risky"* activities, for example gardening without getting bitten by insects (Malcolm, Nel, June); or *"tempting fate"* by not wearing their compression every day. Their efforts to remain independent were operationalised in the way that the participants mitigated their limited choices, and decision-making within the home.

6.4.1 Finding solutions: Routines and rituals

Mitigating goals and fears was often demonstrated by the participants' lengthy descriptions of the routine's they developed to prevent complications associated with lymphoedema, specifically cellulitis and infection. These fears were based upon the known risks associated with living with lymphoedema; their own experience of cellulitis; their interpretation of the experiences of other service-users whilst at the clinic, or with the support group; the concern of significant others; the service-user information available to them (Lymphoedema Support Network, NHS websites); and multiple sources of information and advice from their SHPs, all of which they had to process.

Many of the participants acknowledged that there are times they were obsessive and neurotic about their "routines"; even those participants who required assistance from family and carers explained that there were some aspects of their care that only they performed, for example applying moisturiser (Derek). Their skills, knowledge and expertise developed over time through trusting relationships with the SHPs, as they learned to live with their condition. In this study, the motivation of the participants to be accountable and responsible for undertaking their care was predominantly driven by a controlling fear; fear of *"getting worse",* fear of *"getting infections",* and cellulitis and death:

> *"Lymphoedema rules every aspect of my life*
> *from getting up in the mornings and bedtime*
> *rituals" (June)*

Moreover, it became apparent was that many of the participants described a perception of little real choice in terms of treatment, other than CDT, which functioned as a justification and reassurance for their actions. If there were less choices available, then the risk of making the "wrong decision" was reduced, and lessened their fears from becoming reality were:

> *"I'm absolutely terrified of getting cellulitis again"*
> *(June)*

Although these routines and rituals presented differed between the participants, it mostly related to washing and showering, which some participants reported doing two or three times a day. Many participants talked in detail about their morning routine of showering, and ritualised skin care which involved applying emollients and topical creams and ointments and included any massage techniques that participants had been taught. Furthermore, many of the behaviours focused on avoiding situations or activities, to reduce the risk, for example gardening, going outside on summer's evenings because of the risk of insect bites, swimming, or strenuous activity. Looking out for the "tell-tale signs" of infection was extremely important and this could be achieved when undertaking these care routines. This was in addition to recognising or *"waiting for"* that *"feeling"* of becoming unwell:

> *"… there was specific I mean it felt like erm I had a pain in my spine which was odd each time they each time it happened er a feeling of erm flu like [laughs](Nel)*

For many this was mitigated by always having a supply of antibiotics in the house *"just in case".* This was a source of frustration for many participants, who believed that they had to educate their GPs, to ensure a prescription was always available. In this situation participants perceived that they were the experts.

Exercising limbs was described as important to aid weight loss, and the perception that this would improve their circulation, and help them to remain mobile. This was in addition to wearing compression garments, bandages and wraps was generally accepted as something necessary:

> *"… obviously wear my stockings every day which I have done really just for 55 years" (Cathy)*

Undertaking routines and rituals was described in terms of maintaining normality, even when these became frustrating or exhausting. Being able to care for themselves, with differing levels of assistance from partners, family and carers (significant others) enabled the participants to feel that they were *"keeping safe".* It was a way to maintain some balance between treatment and personal goals, whilst also trying to manage the fear of what might happen in the future and/or the consequences of further infections. Within this study, these participants had insight into their behaviour, and tried to use their knowledge to make their own decisions (not shared), even when this was juxtaposed with feelings of guilt, worry and doubt.

6.4.2 Resisting help: maintaining normality

The aim of the routines and rituals that many of the participants described, was about *"keeping safe".* This also meant maintaining a semblance of normality and functionality, and many participants believed that this was a goal shared by the SHPs and significant others. It was clear from the participants' descriptions of daily life, the effort required, not only to undertake the skincare regimens and application of treatments (whether by themselves, a healthcare professional or family members) and to "keep going". The participants explained that this was something they discussed with their SHPs, especially in situations which deviated from the usual daily routines.

This enabled many of the participants to *"push myself",* despite the struggle, especially if this meant deviating from the usual plan of care. Many of the participants throughout the interviews stated that their lymphoedema *"doesn't restrict me", "doesn't stop me" or "I'm not bothered",* yet their narratives and the conversation often contradicted these statements. This included feelings of isolation because they were prevented from participating in activities which enabled exercise and socialising, such as running, playing golf:

> *"And yeah it does get upsetting it is maddening because you do yer best you do things I mean I do exercises and stuff and don't let it stop you doing yer day to day "(Graham)*

However, for most of the participants giving up was not an option; even though many of the participants described that this was a challenge because they also had a diagnosis of anxiety and/or depression (Lucy, Tina, Rod). Other participants described that the risk of "missing out" made them more tenacious in their attitude and approach; the physical and psychological challenges of daily life made them push themselves a bit harder. It was this aspect of the participants' narratives which really demonstrated their resilience. In addition, some participants described ways to cope with the daily routine of self-care at home, which also meant recognising when *"doing too much"* made their swelling worse:

> *"I'm not going to let it get me down too much*
> *it's just learning to cope with you know and*
> *learning how to like okay I've got to stop*
> *because I can feel it coming on more" (Lucy)*

Shirley had been told that her lymphoedema had developed as a result of having varicose veins and venous leg ulcers, with recurrent infections. Although her leg ulcers were now healed, Shirley believed that wearing compression garments every day helped to prevent further problems. For Shirley, going away for a week with friends was important, however at 85 she found putting on her compression garments difficult, and therefore she made the decision that when she was on holiday, she would only wear *"normal"* tights. This was because she wanted to *"look decent".*

A recurring theme, particularly related to the aesthetic appearance of bandages, wraps and garments; and when participants chose not to wear them, it was usually on the basis that they wanted to look "normal" or for special occasions. Lucy, at the time of the interviews, described at length how she was struggling to come to terms with her lymphoedema. She had a few personal issues which she described were a greater priority, and so she had made the decision not to wear her compression, despite knowing the risks

> *"I live in leggings erm I wear erm skinny jeans a lot as well because I find that they help instead of the compression legging" (Lucy)*

Being able to wear items which were, *"fashionable"* but also *"tight",* made her feel as if she was still looking after her legs, even if they were not ever going to provide the compression she required. Lucy discussed this with her SHPs and was aware of the advice they had given her. However, she was prepared to accept the responsibility for her decision. Whether it was adjusting medication, or wearing different compression in different situations, the decisions the participants made at home did not reflect a lack of commitment to their treatment. For some participants, it seemed to be the opposite, it was about using the information they had from the "experts" (SHPs) and then developing their own expertise about their lymphoedema. Their aim was to maintain their independence and mitigate feelings of constant fear and worry.

Navigating life with lymphoedema was a continuous process of complex decision making, which involved negotiating their own care within their domestic, social and work life. Many of the participants saw their SHPs only once every six months, being able to make confident decisions about their care at home was essential, even though it was constant source of worry. Therefore, many participants demonstrated to the SHPs that they were able to assess the risk and make the necessary decision:

> *"I try to go out in em you know like before if I was going down a nightclub or to a party or something I'd leave them off" (Jane)*

For many participants the skills, knowledge and expertise to implement care at home was highly valued, as the decisions discussed with the SHPs, could not be shared at the time of implementation at home. The battle was between everyday *"normality"* and the risk of actions which might worsen their lymphoedema.

6.5 Analysis and interpretation of "Developing Expertise".

Within this study, and this chapter of findings the development of expertise focused upon how the coproduction of care required collaboration, between service-user and SHP, with open channels of communication, recognition and appreciation of each other's operant resource, and move towards mutual goals (Bettencourt et al., 2002, Vargo and Lusch, 2004, Lusch and Vargo, 2006, Lovelock and Young, 1979, Morgan and Hunt, 1994). These findings also raised issues related to of identity, and a body which has transitioned from well to unwell, is confined, restricted and *"out of control"*; they demonstrated how living with lymphoedema affects their lives and in terms of how they attempted to coproduce their care within the home.

However, their commitment to treatment was often driven by the fear of negative consequences, and this reflected a more traditional definition of compliance (Brudney and England, 1983), which aligned to a bio-medical model of care. This demonstrated the need to empower service-users to be more accountable for their care (Ewert and Evers, 2014), by ensuring that they learned the relevant skills and knowledge, to address or counteract the rituals and routines. Furthermore, this required a significant shift away from a professional bio-medical model of care and to one which is also inclusive of those at most risk of health inequality (McMullin and Needham, 2018). Many of the participants in this study articulated well what was required in terms of the care they needed, however reverting to "default expertise" (Collins, 2014, p.15) by developing rituals and routines was a way of dealing with gaps in their knowledge, and a lack of trust, especially when they perceived that expert knowledge was not available. When the participants described this experience, it was interpreted as both a strategy for coping and to gain control within the home setting.

The plethora of definitions of coproduction recognised and promoted the assumption that service-users do have intangible, tacit skills knowledge and skills (Dolfsma, 2011) and act as responsible and accountable experts (Bettencourt et al., 2002), even if the knowledge they have is not "expert" in a professional sense, they may become "experts by experience" (Fenge et al., 2012, p.456).

Furthermore, the findings of this study support the proposition that lymphoedema is a "wicked problem" (Rittel and Webber, 1973, p.155); a "visible but hidden" LTC, which lacks scientific and social capital (Bourdieu, 2004, 2005) within the public sphere; a condition without an agreed definition, agreed outcome measures, and with a known impact upon quality of life (Morgan et al., 2005, Franks et al., 2006, Morgan et al., 2012, Douglass et al., 2016, Moffatt et al., 2017b, Nairn et al., 2019, Mercier et al., 2019b, Greene and Meskell, 2017, Moffatt et al., 2021b). This is especially in relation to conditions which are associated with assumptions about lifestyle behaviours, or LTCs which demonstrate greater social, cultural and scientific capital than those new and emerging conditions. This study demonstrates this specifically because of the social and cultural consequences of living with lymphoedema, and the factors which influence how these participants responded to their illness and interacted with health professionals to deliver their own health care (Olafsdottir, 2013, Voorberg et al., 2015, Palmer, 2006).

Moreover, a constant theme throughout the participants' narratives was the presentation of their lymphoedema or their diagnosis as "biographical disruption" and "disruptive event" (Bury, 1982, p.167), and how this threatened their identity. This was specifically relevant for this group of participants, because their trajectory of care was unknown and indefinite; the initial diagnosis often led to shock, a shift in identity and subsequently a sense of being let down by the perceived limitations of medical intervention (Bury, 1982). In addition, there was a conflict between the magnitude of the physical presentations, the health consequences of lymphoedema, and their social meaning. For these participants the physical presentation of lymphoedema was laden with stigma and assumptions due to a lack of public knowledge; and often led to a delay in access to appropriate healthcare, especially prior to diagnosis.

Many participants within this study believed that their experience of living with lymphoedema was incompatible with their previous credible self. This included dealing with the assumptions of family, friends, colleagues, service-providers and the general public held about their body. Several participants described how difficult it was to explain and justify their lymphoedema, when no one knew or understood the implications of the condition. These frustrations were more challenging because their SHPs were not able to predict or explain the how their lymphoedema might respond to treatment, and acknowledged that there were limits to the success or suitability of medical interventions (Bury, 1982).

The participants in this study described their bodies as paradoxically constraining and dictating their lives (Radley, 1989). The onset of

> *"shapelessness and lack of physical aesthetics"*
> *(Jäger et al., 2006, p.194)*

caused by the physical effects of lymphoedema challenged the expectations and norms, which denote good health and well-being (Bircher, 2005), particularly in terms of obesity and *"fatness".* This aligns to the literature which discusses the historical view of fatness, the history of *"sideshow freaks"* (Backstrom, 2012) and negative body identity. This is highly relevant, because many of the participants voiced feeling *"on show",* being stared at within the public domain, and fulfilling the cultural representation of groups who are stigmatised (Backstrom, 2012). Their narratives reflected that the stigma of being *"big"* (gross, fat, and lazy), was a distressing reminder of how they were *"before"* the lymphoedema progressed, and changed their body shape. This was frequently epitomised by their descriptions of struggling to maintain the required self-care at home, with a body "*too big* *to manage*". Moreover, the feelings the participants described supports the literature around perceptions of fatness/obesity (DeJong, 1980, Backstrom, 2012) and feeling *"discredited"* about themselves (Charmaz, 1983, p.172).

The stigmatisation of obesity perpetuated negative feelings which occurred because of the assumed responsibility that individuals should control how their body behaves (Vassilev et al., 2011, Backstrom, 2012). This was an example of a "naïve assumption" (DeJong, 1980, p.80), whereby there is little understanding and insight into why a person appears to be obese; therefore, blame is apportioned to the individual because of their perceived *"lack of control"* and this is interpreted as deviant behaviour (Sointu, 2017). This was particularly relevant given that obesity is regarded as contributing to the development of lymphoedema (Todd, 2009, O'Malley et al., 2015, Ching et al., 2015, Moffatt et al., 2017c, Todd, 2017, 2018, Newman, 2018, Green, 2020), and develops as a result of disease progression (Mehrara and Greene, 2014, Maclellan, Couto, Sullivan et al., 2015). Moreover, the existing lymphoedema literature suggests that a lack of service-user commitment to their management plan is the main hindrance to "successful treatment". This perspective places an outdated emphasis upon service-users to "comply" with treatment (Kerchner et al., 2008, p.330) without recognising the complexities they faced. This was even if the positive relationship participants described with their SHPs, seemed to go some way to mitigate these feelings.

Moreover, in this study, it was clear that the participants were self-aware and were able to articulate their understanding and insight into how they cared for themselves. Despite living within a geographical area considered to be socioeconomically deprived (Department for Communities and Local Government, 2015), and contrary to much of the existing coproduction literature (Alford, 2002, Etgar, 2008, Jacob and Rettinger, 2011, Thijssen and Van Dooren, 2016) the participants clearly articulated the care they needed. What became apparent as many of the interviews took place was the dichotomy between how the participants perceived they developed their expertise, and how they also relied upon "default expertise" (Collins, 2014).

Many of the participants believed there was only so much to be learned from the SHPS, the scientific papers, the advice sheets, and the internet. What mattered most was their experience of living with the condition and how this enabled them to learn about themselves, whilst attempting to allay their fears. Whilst decisions and goals were shared with their SHPs, the way that the participants (and their carers) interpreted and actioned these goals was diverse. Importantly, by undertaking these specific routines and rituals, it became apparent that this was how the participants attempted to be accountable and responsible for their own care. This was especially because they described moving between accepting and negating blame because of their *"uncontrollable"* body.

This also reflects the concepts described by Bettencourt et al. (2002) and the use of "operant resources" (Vargo and Lusch, 2004). In particular, the accountable and responsible role expected of the "customer" or the "service-user" in a successful, equitable, coproducing relationship. This is especially relevant within the frame of coproduction, and service-users as "co-implementer" (Voorberg et al., 2015, p.1347) at the point of delivery and consumption of healthcare. However, these participants did not overtly describe an equitable coproducing relationship; often it was described in terms of the traditional bio-medical model of care; whereby service-users assume a submissive role and do what is expected. Whilst this was interpreted as an unequal power dynamic between professionals and service-users in this setting, it also reflected a position which made several the participants feel safe and reassured. Furthermore, most of the participants, also recognised and reflected they lived a *"restricted life"* (Charmaz, 1983, p.172), relying upon rituals and routines which paradoxically relieved and perpetuated their fears.

Many of the participants described their relationship with the SHP as a positive and valuable even when they described feeling contradicted, about what do "for the best". The interpersonal relationships with the SHPS were important and often meant trusting the SHPs, even if the participants did not trust or believe that treatments and interventions were working. Moreover, the operationalisation of shared-decisions with their SHPs were not always defined in terms of specific clinical management, and it was often in terms of the adaptations made in day-to-day life. The key driver for implementation of care at home this was not articulated through recognised medical language such as "adherence", or "compliance", "concordance" or even "shared-decision making" (Stevenson and Scambler, 2005), as might be expected. If concordance involved exploring areas of difference, and negotiating a final decision (Stevenson and Scambler, 2005); whatever the final decision, this required implementation at home, and often depended upon what support was available from their social networks (family and significant others), social care or the primary healthcare services.

Furthermore, despite positive relationships and perceptions of shared-decision making, the drivers for implementing shared goals at home seemed to be their fears. This caused the participants to feel overwhelmed in the same way they felt overwhelmed by their body (Burian et al., 2021). It was evident, from many of the narratives, that separating the affected body from the non-affected body was a strategy for coping; navigating the complexity of accepting these changes, whilst trying to maintain control of a body which is not behaving as it should. Maintaining function was a compelling theme, and a goal which many participants aspired to achieve. Many of the participants recognised that they could not maintain the function they once had; however, functionality represented maintaining a level of normality, and represented a benchmark of their lymphoedema status. Whilst ever the participants could undertake activities, or fulfil roles which were important to them, their lymphoedema was perceived as stable, or not deteriorating. Maintaining function was described in relation to specific aspects of their life such as “working”, mobility and independence, including individual goals which sought to enable taking control, gaining confidence, and decision making.

This reflects a shift within healthcare in recognising that those living with LTCs should be perceived as resilient, rather than a focus upon language which emphasises normality, functionality and cure (Robertson, 2019). By reframing the language used Robertson (2019) suggests that this has the potential to enable service-users to re-examine how and what they, and their health care professionals, think about their bodies. This aligns to the way in which many of the participants described their “battle”; whilst they did not explicitly verbalise this, their narratives demonstrated examples of their personal resilience, even when they described feeling in the depths of despair.

Coproduction from this perspective suggested that the enablement of service-users to implement the care they need within the "home" setting was laden with the expectations of expert patient programmes, or traditional ideas around self-management (Lorig and Holman, 2003, Department of Health (DoH), 2001). Furthermore, their experience of long-term illness leads to the emergence of "rituals and routines" as the participants try to mitigate all the fears and issues they face daily. This was highly relevant, especially regarding the risk the *"vicious cycle"* (Al-Niaimi and Cox, 2009, p.38) of cellulitis, which is reported in much of the chronic oedema literature. Moreover, whilst the participants described being knowledgeable about lymphoedema, this knowledge was frequently based upon the superstitious beliefs; this created further tension and conflict (Palmer, 2006, Douglass et al., 2016, Jo and Nabatchi, 2016, Nabatchi et al., 2016, Nabatchi et al., 2017) and a return to their "default expertise". This was an issue for many participants, who only attended the clinic once every 6 months; despite a good relationship with the SHPs, and being able to contact the clinic in between appointments, the implementation of care was primarily undertaken at home.

In conclusion, for these participants living with lymphoedema was a *"visible but hidden"* LTC, which lacks scientific and social capital; it had a significant effect upon the opportunity of those with "unseen" LTCs to coproduce care. However, there was an aspiration for equality within relationship between the participants and SHPs, with open channels of communication, recognition and appreciation of each other’s “operant resources”; and a move towards mutual goals. The SHPs were a critical source of information and supported the participants to develop expertise. However, this relationship was frequently compromised, creating conflict and tension, especially the participants’ reliance upon “rituals and routines” and their “default expertise”(Collins, 2014, p.15). The Participants were perceived as having the “operant resources” to coproduce, however other factors, regarding the context of their care undermined opportunities for coproduction.

7 Interface with Health Professionals

7.1 Chapter overview

This empirical chapter explores the findings related to the interface between the participants and the SHPs and the non-specialist healthcare professionals (NSHP). Firstly, the challenge of “Finding a way when there is no path” explores the experience of participants in navigating the healthcare system from presentation and relationships with referring clinicians. The second sub-theme is the significance of “Relational Exchange”, which explores the importance of accessing specialist care, and if it is possible for participants to engage in a coproducing relationship; the context of shared-decisions, autonomy and patient-activation, when treatment choices are limited and where feelings of fear, mistrust and loss of control are paramount. The third relates to the interface with healthcare more widely; how care under other consultants and emergency admissions become a place of conflict and power struggles. This was due to the perceived power shift of “operant resources”. In this situation it was the NSHPs who are perceived to lack the “operant resources”, to engage fully in shared-decisions and coproduce care with the participants.

The empirical findings presented in this chapter focus upon interface with health professionals (Figure 15):

- Finding a way, when there is no path; “Lost in the system”; “Checking in”
- Relational Exchanges: What is the plan?:Mitigating risks: “Doing as I am told”; Acceptance and Adaptation:

- Context of the Healthcare system: Under the care of different consultant teams: Negotiating care?; Knowing my body: The nightmare of hospital admissions.

The final section introduces the proposed discussion, around the challenge of these findings to contemporary theories of coproduction, and new insights.

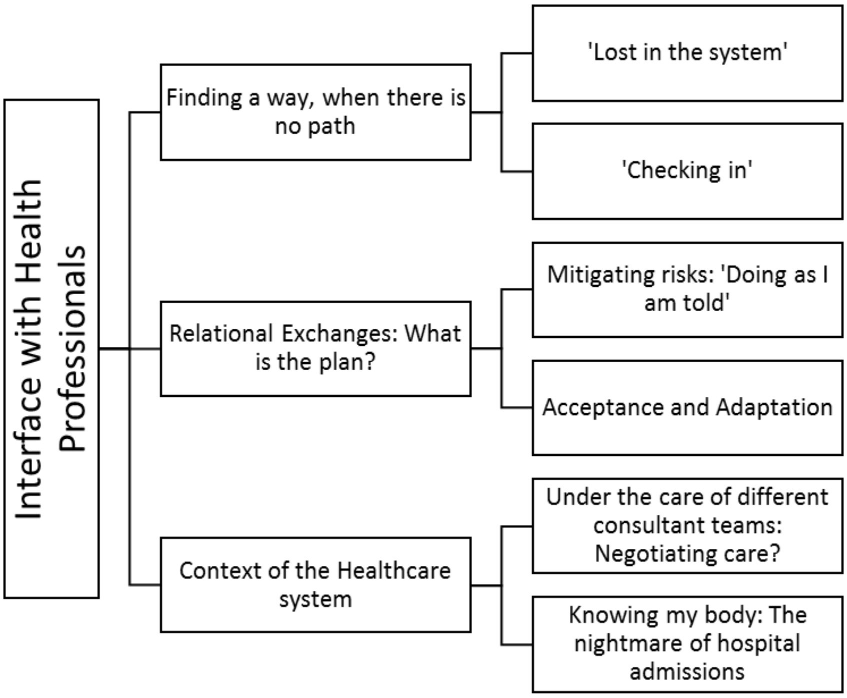


Figure 15: Theme 2; Interface with Healthcare Professionals

7.2 Finding a path when there is no way

A clear problem for many of the participants was how they navigated their way through their care; from pre-diagnosis and GP care; care with the SHPs; referrals to other consultant teams; and access to emergency care. The participants described their stress and anxiety as they tried to find a way to professionals who could provide the care they needed; many of the participants described these experiences of navigating healthcare as difficult and traumatic. The participants described that this was frequently due to assumptions they perceived NSHPs made about them. Once in the care of the SHPs, some of these feelings were mitigated because of the positive relationship they were able to develop; and the reassurance they gained from at last “being in the system”.

7.2.1 Lost in the System

A common experience for the participants, was of feeling completely *“lost in the system”* with no clear pathway, or sense of direction when navigating their journey to referral and diagnosis. In this study, participants described their GPs” lack of knowledge (“operant resources”) about lymphoedema, combined with assumptions about their identity and life circumstances, as the reasons for delayed referral to specialist services:

> *“He just he basically accused me of just wanting time off there were nothing wrong with me and I were like no I don’t have time off work” (Rod)*

This was even in situations when lymphoedema was suggested by the participant or was a known risk factor following previous treatment for cancer. In this study most participants were referred to the Lymphoedema Clinic via their GP (50%) (Table 11: Table of face-to-face interview participants), some of the participants were referred by other consultants, (dermatology, gastroenterology), or via an acute admission to hospital. A few participants articulated that being referred was down to *“luck”* or the fortuitous awareness of the clinician. Participants described rationalising or accepting their symptoms as an inherited family trait; or normalised their condition because of the perceived length of time they had experienced symptoms, due to their own lack of knowledge.

This resulted in very few participants who could recall exactly how long they had been experiencing symptoms, prior to either going to their GP or their eventual diagnosis.

Many of the participants described negative experiences, when GPs or nurses dismissed their symptoms, or advised them to:

> *"Carry on wi yer life" (Lucy)*

For some participants this reinforced the perceived lack of care and created an increased sense of mistrust and loss of faith in their GP's skills and knowledge. They perceived that the potential for any "relational exchange", or transfer of expertise was undermined. In addition, at the point of referral to the SHPs, many participants described how they had to use their own expertise, skills and knowledge to find where to be referred:

> *"Basically the doctor said no you can't go there and I said no I haven't I have the right to choose and book and go where I want to" (Penny)*

However, some participants, were seen by GPs who were aware and knowledgeable about lymphoedema. Jane and Cathy experienced very prompt referral to the local lymphoedema service, because both their GPs immediately recognised the symptoms:

> *"I went to the doctor for something else and it was a hot day I'd got no tights on sandals oh … he just looked at me legs and said you've got lymphoedema" (Jane)*

These excerpts exemplify the unwieldy trajectory of care, where appropriate referral from primary care was perceived as arbitrary and depended upon the knowledge of health professionals. The participants often viewed their GPs as gatekeepers, who lacked the “operant resources” to recognise their symptoms. For some this led to a complete disengagement with their GP, because consultations came to represent a struggle for justice.

Referral and access to the specialist lymphoedema service was described by many of the participants as a significant event, a “critical encounter” (Payne et al., 2008, p.90) during their care. This was the point at which they received their formal diagnosis and information, when they would learn about what was the *“matter with them”,* and the plan for *“making them better”.* However, the reality described by participants was that this was when they also learned that had a LTC, with no cure, and the expectation that they *“committed”* to prescribed care. Therefore, receiving their diagnosis was often revelatory and emotionally challenging:

> *“I could have been born with it so she told me things that nobody else had ever told me well I cried because all the years that I struggled” (Hattie)*

Moreover, any initial relief was replaced by further feelings of uncertainty that they were at the start of another indefinite journey. The awareness that some of their worst symptoms and experiences might have been prevented, led some of the participants to feel even greater resentment at being “let down” by their GP. A formal diagnosis represented affirmation that to those participants who had researched their symptoms and concluded that they had lymphoedema. Confirmation from their SHPs, further challenged the "operant resources" of their GP.

> *She looked and she was yeah you 'av actually got it so I was right to so it was me pushing the doctors now I had an explanation for the swelling and the pains that I was I want just going mad [laughs]" (Lucy)*

It confirmed that their symptoms and *"suffering"* was not a figment of their imagination, or because of stereotypes related to obesity and laziness.

7.2.2 "Checking in"

Most of the participants perceived that the purpose of attending the clinic was to "check-in" every six months, to assess if their symptoms were stable. Many perceived their interactions with the SHPs as a positive experience and therapeutic experience, both clinically and emotionally. The clinic SHPs, especially the nurses, were perceived as a critical source of information for the participants, offering reassurance and support to enable the participants to develop expertise about their condition. Moreover, participants described the value, and "relational exchange" of feeling able to speak openly and honestly about their lymphoedema; their fears and worries; the challenges they faced; and the strategies they used to cope with their symptoms, without feeling judged. This was especially important for participants who described being psychologically affected by their condition and life events.

Keith described how his life had completely changed since the death of his wife, a life-threatening episode of cellulitis, and the worsening of his lymphoedema. However, he described his complete trust in the care he received from the SHPs at his Lymphoedema Clinic. He explained that because of this trusting relationship, he felt able to be completely open about the aspects of his treatment:

> *"I don't keep anything from her that wouldn't be wise I don't do it (Keith)*

The way that Keith described his relationship with his SHP, was one of mutual respect and partnership. Keith acknowledged that his SHP did not always agree with his decisions, but this did not prevent them from reaching a compromise together about his care. Keith's experience demonstrated that whilst other aspects of his life were beyond his immediate control, the relationship with his SHP made him feel empowered:

> *"To look after myself" (Keith)*

Most of the participants perceived that everyone at the clinic was trying to do their best, even when attending the clinic represented a place of personal conflict related to their fears for the future. Many participants appreciated being able to contact the clinic outside of their appointment time. Especially if their symptoms were "out of control"; if they had received a previous diagnosis and treatment for cancer (Lucy, Betty, Jo, Peter, June), or had experienced cellulitis and/or sepsis (Nel, Keith, Lloyd, Graham, Taran).

Many participants described their overriding fear of developing an infection (cellulitis), and its consequences. Being able to contact the clinic in this way, led participants to feel that the SHPs recognised and valued their expertise and “operant resources”. Some participants attended more regularly, and if this was part of CDT, they would attend up to three times a week for a few weeks. Through the narratives of the interviews, this was interpreted as reassurance that they were “in the system”, even when the overall clinical improvement or prognosis, was not achievable. In addition, a small number of participants perceived that reduced limb volume measurements represented an overall improvement; a reward, and a sign that they were adhering to treatment, reflecting a paternalistic approach to their care.

For others limb volume was perceived as an arbitrary measure, independent or irrespective of how they are caring for themselves. For example, during the data collection phase (February-December 2018) the United Kingdom experienced a very hot summer (BBC News, 2020). Nearly all the participants stated that they had an increase in limb volume, even though they continued to wear their compression and follow their usual plan of care, which they discussed with the SHP. Several participants expressed that they believed it was due to the weather, and this made them suspicious of the value of measuring limb volume. This suggested that there were other reasons for increased swelling, which could not be fully explained.

The ways in which some participants described their treatment plan was often relaying a list of instructions they were expected to follow, rather than genuine opportunities to coproduce their care. Furthermore, there were times when the participants described that they were not entirely sure about the goal of their treatment. However, attending the clinic and interacting with their SHP was perceived as valuable and important, particularly in terms of the transfer of personal expertise and relational exchange.

7.3 Relational Exchanges: What is the plan?

Developing and having trust in the knowledge and skills of the specialist healthcare professionals (SHPs) emerged as a dominant theme within the findings. However, the findings suggest that not all the participants trusted in the choice of treatments available, or believed that they were effective. This became apparent through the collective narratives of the participants and enabled the exploration and insight into how decisions about care are made, within a context of trust, fear and control. The participants' experience of navigating their referral and diagnosis, and the development of their own expertise, all influenced their relationship with the SHPs, and their approach to implementing care.

7.3.1 Mitigating risks: "doing as I am told"

For several participants "doing as they are told" was perceived as a priority. These participants were so frightened by the risks associated with their lymphoedema that their aim was to comply with all prescribed treatment, rather than working in partnership and sharing decisions:

> *"Well that's right I tend I'm not sort of blowing my own trumpet here but if somebody says in the medical profession do this I do it" (Peter)*

These participants also fervently articulated their fears regarding developing cellulitis and hospitalisation; their perspective clearly derived from a time when they had been life-threateningly unwell because of their lymphoedema (diagnosed and undiagnosed):

> *"In 2013 I had erm an almost fully blocked er right coronary artery I could face that again any day but I do not want cellulitis" (Nel)*

In addition, 4 of the participants, who developed lymphoedema following treatment for cancer (Betty, Jo, Peter, June) perceived coping with lymphoedema as preferable to a far worse alternative. Therefore:

> *"Getting on and doing what needed to be done" (June)*

This was seen as part of the journey in surviving cancer.

Overall, these participants were clear; if they did not follow the prescribed treatment plan, then any "problems" would be their fault, because they had not followed medical advice. A number of these participants also commented on their perception of others at the clinic who looked "much worse", and that this was likely to be because they were not "doing as they were told". Their experience reflected the historical, bio-medical model of care and a lack of agency around their own care.

These participants greatly valued a positive relationship and often described their reverence towards the SHPs, stating that they were "fantastic", that they could not do enough to help, they were "always there". Moreover, they relied upon their SHPs to discuss their fears and concerns. A compelling theme throughout the findings was how some participants mitigated known risks. Whilst many participants articulated the same about the worsening of their condition, this was combined with responsibility for caring for themselves. They described their open and honest relationship with the SHPs, which enabled them to discuss the perceived limited treatment options, feel more empowered about managing their condition at home; and helped them to accept responsibility for the exceptions they made to their management plan. These participants believed that through their experience of referral and diagnosis that they had acquired the necessary "operant resources" about lymphoedema, with a motivation to learn more.

However, this was juxtaposed with a fatalistic attitude; that lymphoedema was for life, with little realistic chance of improvement. The value for participants was how they defined realistic and achievable goals with their SHPs, and how to attain them. Whilst this approach promoted a more equitable relationship with the SHPs, the participants also recognised that the driver for the clinical team was acting within their professional role. Ultimately, the driver for making exceptions was an emphasis on feeling in control, whilst being able to continue life with the new "normal"

> *"The day ma sister got married because I wanted to wear a dress and I wanted to feel like a normal lady" (Mary)*

These participants discussed the impact of the condition on all aspects of their life, and particularly spoke about the effect upon their psychological health, personal relationships, work and experience of illness. They too appreciated being able to speak to the SHPs at short notice, or bring clinic appointments forward, however this did not negate their responsibility for looking after themselves. For Keith, this was when his SHP (Site 2):

> "**** *always says if you've got a problem come down and I'll squeeze you in whatever" (Keith).*

Despite limited choices these participants perceived themselves as able to negotiate and make decisions with the SHP. Whilst treatment options were perceived as limited their focus was about feeling empowered to make the right choices, through adapting or making exceptions to their treatment plan. It was here that the potential for a coproducing relationship was most evident, given the value afforded to the partnership between the participants and SHPs. This was even when a truly equitable relationship was unlikely, due to the bio-medical model of care.

7.3.2 Acceptance and Adaptation

Whilst "doing as I'm told" and mitigating risks were themes throughout the findings; acceptance and adaptation were also prevailing factors for some participants. For a few, living with lymphoedema and accessing the SHPs was a source of immense conflict; Penny, Debbie and Lucy articulated that their experience, suggested that their condition overwhelmed every part of their lives. For these participants the therapeutic interventions on offer were not sufficient, whether in terms of treatment options or the relationships with the SHPs:

> *"But I think I've got to the point of beyond no return now I don't think it can be managed I don't think even if they bandaged me because it's gone up to my thighs now" (Debbie)*

Debbie described a humiliating episode when she had been “named and shamed”, by one of the SHPs. This had affected her relationship with the SHPs, which made her feel like a “second-class citizen”. This reiterated the challenges of living the “normal” life that she wanted due to the loss of control over her weight and lymphoedema. Penny believed that she had been completely let her down by her GPs, who she believed attributed all her symptoms to being morbidly obese. Therefore, by the time she was referred to the Lymphoedema Clinic, she was ready for another battle. Both Debbie and Penny stated that they only interfaced with the clinic when their lymphoedema reached a “crisis point” and was “really bad”. They would only see certain SHPs, who understood their specific issues, and would only undertake treatment on their terms:

> *“You know I have bandages boxes of dressings upstairs because I know how to dress my legs better than the hospitals” (Debbie)*

This was relevant within the context of the coproduction literature, as both Penny and Debbie described the “operant” resources, social status and level of education to coproduce their care. However, their descriptions indicated that both had actively disengaged with any opportunity to coproduce their care. Penny and Debbie perceived that there was no value in engaging with the SHPs, as there was no satisfactory treatment on offer.

For Lucy her acceptance and adaptation was more subtle, as she explained that giving up her job had led her to her feeling depressed and anxious. Lucy had missed a few appointments and justified why she had stopped wearing her compression.

Now aged 35, she explained that learning more about lymphoedema made it harder to “deal with”. Lucy was the only participant who did discuss her relationship with the SHPs. Although she appeared to possess the skills and knowledge to share-decisions with the SHPs, Lucy’s other issues were overwhelming, and she explained that focusing on her lymphoedema was not a priority.

For most of the participants, a positive relationship with the SHPs was essential for the participants, even though many approached their lymphoedema, with a range of acceptance or varying degrees of fatalism:

> *“they are non-repairable non-operational I’m like so this is a permanent feature of my life not…there was goals in life that I wanted to do that I don’t think I could do now I wouldn’t be able” (Matt)*

Throughout the interviews themes emerged around the participants understanding of aspects of self-care in terms of “looking after myself” or “doing what I need to do”, as this seemed to represent the only place of control:

> *“I go I try to get on wi’ me life as best I can I try my best to lead a good life despite of ma disabilities…doing what I need to do its life yeah just get on with it” (Lloyd)*

Throughout the narratives, all the participants described the diverse adaptations they needed to make to their daily life. For some this meant *“feeling in control”, “gaining control”*, or accepting that they had *“no control”* over their lymphoedema.

Fundamental to this was how the participants correlated this to their understanding of their relationship with the SHPs.

This represented affirmation for those who perceived themselves as complying or adhering with treatment, that what they were doing was *"right"*. Even if they could not control their swelling, this affirmation mitigated or reduced the perceived risks. This extended to feelings of control in other aspects of their life. Malcolm had recently been involved in a minor road traffic accident, which he believed to be his fault. This had made him consider whether to stop driving his car. He was reluctant to make the final decision, as he perceived it would stop him from maintaining his independence. He was absolute in his belief that he was not the best person to make the decision, and was keen to discuss this with his SHP, before he drove his car again:

> *"Until then I've got to make sure that I'm okay and er what erm what advice I can get the trouble is I don't want to make the decision myself I'd rather somebody in a better position could make that decision" (Malcolm)*

For others mitigating risks occurred in terms of their personal goals and navigating their fears. This was especially if participants did not feel that confident in their treatment regime. Mary explained that her husband had started to reapply her compression bandages when they loosened, following application by a new community nurse. They discovered this had a dramatic effect on their quality of life, because she was not beholden to the appointments with community nurses or practice nurses. More importantly for her, she felt able to keep her bandages on for longer, because they were tighter:

> *"so he does it right every time because he's not seeing lots of people so sometimes even **** who's done it for years sometimes she will do a bit looser than what I need on my legs" (Mary)*

Mary described how her SHP acknowledged this, and then taught her husband how to apply the bandages and educated him in the relevant aspects of her care. Mary explained how she requested that husband continued to apply her compression, because she trusted that he had developed the required expertise. Being clear about what she needed, enabled a shared-decision about her care, which made Mary feel empowered and autonomous. Being candid with the SHP facilitated trusting a relationship and created value for the participants.

Conversely, for other participants their personal issues or other health concerns were perceived as more important than with the management of their lymphoedema. Their appointments with their SHPs enabled the opportunity to discuss these with their SHP. For example, Keith explained that he slept in his reclining chair, and was not able to elevate his legs sufficiently. He explained that this was something his SHP asked him about each clinic visit (weekly). However, his response was always the same, he would continue using the chair, because he could not face sleeping in their marital bed, since the death of his wife:

> *"****'s always on about it, bless her. And I do take on board what she says but I cannot do it*

> *and I know and I appreciate she's right and I know all that" (Keith)*

Acceptance and adaption of their lymphoedema was different for each participant. For many in this study, the positive relationships with the SHPs helped them come to terms with the difficulties of accepting condition. For others, the fraught journey to the Lymphoedema Clinic, and the perceived limitations of the treatments affected their relationships with the SHPs less positively. Penny and Debbie described a conflicted, and paradoxical relationship with their SHPs, which manifested in terms of a power struggle around their perceived expertise and "operant" resources.

7.4 Context of the healthcare system

A major finding, related to "operant resources", was in terms of the acquired and tacit skills and knowledge of the participants and the SPHs, within the context of the wider health care system. For many participants their care was underpinned by a power struggle between themselves and NSHPs. They perceived a deficit in the "operant resources" of GPs, SHP and NSHPs within primary and secondary health settings.

7.4.1 Under the care of different consultant teams: Negotiating care?

Many of the participants had several comorbidities, some of which were directly associated with their lymphoedema. A few participants were also cared for by orthopaedic teams and referred for surgery and joint replacements. For most of the participants decision-making was fraught with worries of the pre-operative and post-operative risks, for and against surgery. Therefore, communication and decision-making with the NSHPs, and their SHP, was vitally important.

This was an extremely emotive subject for Richard, who perceived he was "denied" surgery to his severely damaged leg, from an accident he sustained a few years ago. He described how the orthopaedic consultant had informed him that due to his general health, his cardiac problems and his lymphoedema, as complicating factors, surgery was not an option. Richard believed that the surgeons used his lymphoedema as an excuse to exert their control. He stated:

> *"it's a risk that I would be willing to take because I can't see the difference between having a leg like this which is no good and not having a leg at all at least I wouldn't av lymphoedema in it but they don't listen to my argument about it"* (Richard)

Richard was aggrieved because he believed his worsening mobility problems prevented him from socialising, from feeling confident about driving and most of all prevented him from being a *"proper grandad"*. He explained that he noticed that since he had stopped drinking alcohol both his lymphoedema and episodes of cellulitis had improved. He explained that these changes to his life demonstrated he had taken responsibility, accountability and that he was knowledgeable, and committed to all aspects of managing his lymphoedema. Whilst he described himself as having a "happy disposition" and that others are "worse off", it was clear that he was devastated by the impact of this medical decision, especially because he believed no one was listening to his viewpoint.

Conversely, Mary, Lloyd and Rachel described how they were each extremely reluctant and sceptical about having orthopaedic surgery, because of their concerns about recovery. They each stated that the communication between the surgical and lymphoedema team instilled trust and confidence in their choice to consent to surgery. They perceived that they were fully engaged and partners in these consultations, with a clear plan of care which was agreed by all. These participants were relieved that the agreed plan of care occurred at the time of surgery, and none of these participants experience any post-operative complications.

This “success” represented regaining some control, especially undertaking activities, which they had reluctantly forgone, months and years prior to surgery. These experiences identified the importance of relational exchange and communication in representing opportunities for shared-decision making and personal agency. Even though the participants had initial concerns, trusting that the NSHPs also possessed expertise about lymphoedema, enabled them to feel that they were making informed choices.

7.4.2 Knowing my body: The nightmare of hospital admissions

These participants’ experience of an emergency admission to hospital emerged as the occasions where opportunities to coproduce care was most conflicted and eroded and represented by the culmination of all their fears. These interactions with the NSHPs were described as where any semblance of their control was completely lost; and where the power struggle, between participants and the NSHPs, was most evident. All the participants who stated they were admitted for emergency care (after their diagnosis of lymphoedema was confirmed by SHPs) believed that they possessed the relevant expertise about lymphoedema. Whereas they perceived the NSHPs to lack the relevant “operant resources” to care for them safely. All the participants described traumatic experiences of being life-threateningly ill, when cared for by junior and senior NSHPs, who had no experience of their condition. Lloyd was admitted to hospital due to numerous episodes of recurring cellulitis. He described developing sepsis, and when he was recovering, he explained that the Registrar was dismissive of his knowledge about primary lymphoedema, because he did not observe any redness of Lloyd’s skin:

> *“I got so annoyed with this er the ward round doctor he came round and he had a bunch of students with him and I says look mate I don’t I know ma body” (Lloyd)*

Lloyd clearly explained to the medical team that as he had experienced previous episodes cellulitis, and that as a person with black skin, redness was something they were not going to observe. Lloyd expressed his anger, frustration and mistrust of these NSHPs; he perceived that they lacked any cultural intelligence, or awareness of the presentation of cellulitis in highly pigmented skin, or black and minority ethnic (BAME) groups’ experiences of lymphoedema.

Feeling fearful, mistrustful, frustrated and dismissed, by the NSHPs, during emergency admissions was echoed by many of the other participants. This fear was twofold; because of the effects of the infection, which usually led to a worsening of their lymphoedema; and knowing how critically unwell they could become. Participants described this as genuinely terrifying experience, when there was a likelihood of being treated by an NSHP who:

> *"Didn't have a clue" (Graham)*

These experiences further exacerbated when they were moved onto an inpatient ward, as the participants perceived that the nurses lacked the "operant resources" in how to care for a patient with lymphoedema. Even when participants requested for the NSHPs to contact the Lymphoedema Clinic this was rarely organised. It was felt by many participants that their expertise was undermined, and therefore any opportunities to coproduce care were negated. Richard was so appalled by a perceived lack of care and indifference, that he contacted the lymphoedema service for help, during one admission. Although few participants were seen by their SHP as inpatients, those who were reported feelings of reassurance and credibility about their knowledge. Furthermore, Keith, June and Graham described the effect of being discharged too early from hospital, and "sent home" when their lower legs were still acutely infected. All three described how distressing this situation was, and all believed the situation could have been avoided if the NSHPs had more education and insight into their lymphoedema.

Whilst the participants acknowledged that they were constantly learning about their condition, they were steadfast in their opinions of admissions for emergency care; they were experts about their subjective experience, and knowledge of lymphoedema. This represented a challenge to the expertise of the NSHPs, and to the pre-existing, paternalistic hierarchical relationship recognised within the NHS.

7.5 Analysis and interpretation of “Interface with Health Professionals”.

A major finding within this study was how the participants navigated their way through and across the healthcare system. Many participants described navigating a system which appeared to have no clear professional route, and one where they perceived some NSHPs as having little awareness or ownership of the care they required. This demonstrated that aspects of the system of healthcare (both primary and secondary) lacked “organizational health literacy (Brach et al., 2014, p.274); in that the healthcare system was so difficult to navigate and access, to reach the services and information they needed. Many of the participants described their experiences as difficult and traumatic, because of the assumptions they perceived were made about them as individuals, or because a lack of knowledge from NSHPs.

It emerged that when participants reported the value of the relationships with their SHP, this was combined with an emphasis of upon the opportunities to exchange “operant resources” (Vargo and Lusch, 2004, Lusch and Vargo, 2006) and to learn more about their lymphoedema. Some of the participants expressed the value of their relationship, as the SHPs came to know more about their lives and their home circumstances, which demonstrated increasing social capital and reciprocity. Several participants described their life as a constant battle to gain control of their body. This was especially if the shared-decisions made with the SHPs could not be operationalised at home, and led to feeling lost and a loss of self (Charmaz, 1983). This reflected the participants’ fight against restrictions to life, feeling confident to *“take a* *risk"* or to *"do more"* to feel more in control, and recovering their self.

Therefore, for these participants, their engagement and motivation to develop realistic strategies with the support and advice of their SHPs, seemed most imperative. Although most of the participants only attended clinic once every 6 months, it was described as a pivotal part of their care and evidence of the social capital both perceived. This was most evident in how they described the care, kindness, negotiation and organisation of their care with their SHPs, especially in terms of in helping them to come to terms with their diagnosis of lymphoedema. This narrative accords with the original literature around the sensitivity of service-providers towards the needs of service-users (Lovelock and Young, 1979); and the individual operationalisation of autonomy and accountability of service-users (Bettencourt et al., 2002) to engage in coproducing relationships. It also reflects professional tolerance (Cooke et al., 2017) in understanding the individuals' perspective, sharing information, and reaching agreement on problems and future plans (Makoul, 2001).

The participants' narratives demonstrated that there were complex reasons and motivations for why, and how they implemented their care at home. Moreover, the socioeconomic context, described by some of these participants contributed to the imposition of living with lymphoedema. The participants gave many examples of activities which could be interpreted as "coproducing care", however the implementation and operationalisation of care at home was frequently motivated by their fears of complications, infection, and the impact it had upon their life in general. The ability of the SHPs to allay some of this fear led to the cocreation of value (Voorberg et al., 2013, Voorberg et al., 2015) and the relational exchange the participants perceived, in shared-decision making at the clinic.

Fundamentally, the emphasis was upon the personal relationships and social capital that the participants described with the SHPs, even if this did not involve a perceived transfer of “operant resources”. The concept of “operant resources” about their lymphoedema care, was clearly articulated by participants in this study; this this was predominantly in relation to their knowledge of what was required *to “look after myself”*. This was regardless of whether this enabled them to feel in control, or improve their condition, and the continuing assumption within the coproduction literature is that these participants were experts, about themselves (Brandsen and Honingh, 2016). Whilst these participants were empowered to make decisions, they wanted this within a context whereby the SHPs and NSHPs were also confidently knowledgeable about lymphoedema. For some participants this was not evident enough; especially when their questions were unanswered, or if there was a perceived lack of effective treatment or solutions for their lymphoedema, some reverted to their “default expertise” (Collins, 2014, p.15). This either manifested as disengaging with care and the transfer of “operant resources” (Debbie, Penny) or relying upon “routines and rituals”.

This was particularly relevant as many of the participants perceived their lymphoedema as a frightening, unpredictable illness; many initially accessed the service when their lymphoedema, whether diagnosed, or undiagnosed, had already seriously affected their morbidity and mortality (Moffatt et al., 2019c). Moreover, some of the participants, described the initial interactions with NSHPs in terms of “testimonial injustice” (Fricker, 2019, p.61); when their “operant resources” and “default expertise” was discredited or undermined (Richard, Debbie, Penny, Lucy). The experiences described by Debbie, Penny, Lucy and Richard were also examples of negative “critical encounters” (Payne et al., 2008, p.90); themes which reoccurred during each of their interviews, and reflected a “fatalistic” opinion, and low expectations of the efficacy of implementing any of their care at home.

Moreover many of the interactions with NSHPs represented “expectancy violations” (Burgoon, 1993, p.30); whereby the participants did not feel that the NSHPS listened to their concerned or facilitated share-decisions to meet the expectations of a therapeutic relationship. This was especially regarding their GPs and the consultant teams during admissions to their local emergency department. It was often the attitude of these NSHPs which distressed the participants. The NHSPs communication skills and tone of voice suggested blame, judgement and a position of superiority, especially if this was related to assumptions about their weight and being a “good” patient (DeJong, 1980, Backstrom, 2012, Sointu, 2017). Given that the participants described a predominantly a positive experience relational exchange, when interacting with their SHPs, the participants narratives also suggested that they expected the same when they interacted NSHPs.

Some of the participants’ descriptions of their relationships with the SHPs, demonstrated (Lloyd, Graham) that they also expected an “interactive exchange” (Shay and Lafata, 2014, p.296) with the NSHPS whereby they mutually exchanged information; were respectful and open-minded towards each other; where the participants could demonstrated “patient self-advocacy"; and the SHPs individualised recommendations for their care (Shay and Lafata, 2014, p.297). However, this was not the experience of several the participants and suggested where conflict arose; suggesting a marked lack of social capital, and where trust was eroded before it had the opportunity to become established. This again led some of the participants to reclaim their "default expertise" (Collins, 2014, p.15), and mitigate the negative experience with the NSHPs by reverting to their rituals and routines.

A small number of participants described that being visited by their SHP, when they were admitted to hospital for inpatient care was beneficial; they reported feeling confident to then impart the knowledge and skills of caring for their lymphoedema to the NSHPs together. However, there were a few participants who had been inpatients, and they reported that in all their experience, the NSHPs lacked the "operant resources" to even understand lymphoedema. This was a theme consistent within the chronic oedema literature, which identifies the paucity of knowledge, skills and understanding of NSHPs and the general public, further impeded by a lack of consistency regarding definitions of lymphoedema and chronic oedema and agreed outcome measures (Williams et al., 2004, Moffatt et al., 2019c, Moffatt et al., 2021b).

Within this context the exchanges with the NSHPs did not create, cultivate or sustain successful relational exchanges (Morgan and Hunt, 1994) or social capital, and this became a of point of conflict between the participants and the NSHPs. Moreover, in these situations the participants conveyed a sense of superior knowledge, which was neither recognised nor accepted by the NSHPs. This created further conflict during their interactions. Any opportunity for the coproduction of care was eroded and indicated the structural relationships which existed between the participants and the NSHPs, as a barrier to coproducing care. Despite the descriptions, from Rachel and Ginny, of a positive, coproducing relationship with their SHPs and the NSHPs, the other participants described their worry and concern when being cared for by NSHPs.

This demonstrates a fundamental challenge when exploring the context of the coproduction of care; how healthcare is organised. Despite evidence of positive relationships with their SHPs within this study, the positive relational exchange and the sharing of skills and knowledge (Batalden, 2018, Morgan and Hunt, 1994), it must be acknowledged that all of the care described by the participants was based upon a traditional, hierarchical and often biomedical model of care. Structural hierarchy and power remained with the service-providers, whether GPs, SHPs or NSHPs, in primary care, at the Lymphoedema Clinic or within the acute care setting.

This was even more apparent for those individuals accessing emergency care; their initial expectation was to be assessed and treated by health professionals (Timmons and Nairn, 2015), who diagnosed and prescribed the anticipated care, without argument or contradiction. In addition, at the time of the study, the position of the Lymphoedema Clinic at site 1, was within an acute hospital setting; a model which did not align to NHS policy (NHS, 2019) or CQUIN targets in relation to wound management (NHS England, 2018). The participants were receiving a service; however, this was not always perceived as responsive to their needs, and did not create opportunities for them to genuinely and equitably, coproduce their care. Moreover, this model of care was perceived by some participants (Richard, Penny, Debbie) as based upon the SHPs prescribing the only available treatments, amid fears regarding clinical accountability, policy and governance about the shared-decision making (Waring, 2009, Bevir et al., 2019). The emphasis was upon the participants to implement their prescribed treatment in the absence of any other choice. This created a tension whereby the professionalism, skills and knowledge of both SHPs and NSHPs were potentially challenged.

Contemporary healthcare coproduction literature suggests that for this inequitable power relationship to change there is an expectation that health professionals must relinquish control (McColl-Kennedy et al., 2017, Elwyn et al., 2019, Ocloo et al., 2021)., as service-users expect to be more involved in decisions about in their health (NHS Digital, 2021, NHS England & NHS Improvement, 2019, NHS, 2019, NHS England, 2018), even when the rhetoric suggests that choice is non-negotiable. This has implications for coproduction, and there are authors who have previously explored the disingenuous aspects of coproduction within healthcare such as scepticism about bias service-user representation; inclusivity and diversity; bias towards those with existing skills and knowledge; or whether service-users are even willing or motivated to coproduce (Etgar, 2008, Palumbo, 2015, Ocloo and Matthews, 2016, Palumbo, 2016, Palumbo and Manna, 2018).

Moreover, some of these participants' experiences were associated with feelings of distrust and trepidation, especially challenging the dominant position within healthcare and traditional power relationships (Trede and Higgs, 2003). Therefore, it is difficult to perceive how service-users, SHPs and NHSPs could share power (Batalden et al., 2016, Batalden,

2018) when a bureaucratic, paternalistic model of care challenges the fundamental principles of coproducing care, such as service-users' accountability, relational exchange, the exchange of "operant resources", equality, trust and commitment (Lovelock and Young, 1979, Morgan and Hunt, 1994, Bettencourt et al., 2002, Prahalad and Ramaswamy, 2004b, Vargo and Lusch, 2004). Few of these participants perceived a transfer of "operant resources" when interacting with GPs and the NSHPs (during emergency admissions), and they described negligible evidence of relational exchange. The participants perceived that these two groups of healthcare professionals completely lacked the appropriate knowledge and skills. The participants reliance upon their "default expertise" actually led them to perceive themselves as the "specialist experts" (Collins, 2014, p.15),

In conclusion, all of the participants possessed the "operant resources" to engage in the coproduction of their care. A significant finding from these findings, which challenges existing chronic oedema literature and coproduction literature, was the recognition of the real factors which made coproducing care genuinely problematic. For these participants, in addition to the challenges they described when interacting with GPs and NSHPS, many other challenges were beyond their immediate control; a lack of a clear pathway of care; delayed diagnosis or missed-diagnosis; a lack of evidence for the efficacy of treatments; a lack standardised measures for treatment outcomes and the symbolism of limb volume measurement; perceived limited treatment options; a perception that GPS and NSHPs lack the in addition to and the comorbidities associated with their lymphoedema, (Moffatt et al., 2019d).

The experience of these participants demonstrated service-users who had skills, knowledge, accountability and responsibility to coproduce their care, but for whom the structural hierarchy of the healthcare system did not facilitate the coproduction of care. This was despite evidence which demonstrated positive relationships with their SHPs. Throughout the narratives, the participants described how they operationalised their care, and coproduced with the SHPs and NSHPs as a complex process. These findings demonstrated that trust and confidence in all healthcare professionals was critical for building positive relationships, even when the opportunity to genuinely coproduce care was challenged. Coproduction was challenged when these participants were hospitalised, and when NSHPs did not recognise their "operant" resources regarding their condition. This challenged the power dynamic of the established model of care, and threatened the operationalisation of the coproduction of care, suggesting that it was an unachievable aim. Despite evidence of positive relationships with their SHPs within this study, and the positive relational exchange and the sharing of skills and knowledge, all the care described by the participants was based upon a traditional, hierarchical model of care.

8 “Operand resources”: socioeconomic impact

8.1 Chapter overview

The empirical findings presented in this chapter focus upon the financial and socioeconomic effect of living with lymphoedema. This was a major source of anxiety for the participants and extended to all areas of their life, affecting how they coproduced their care within the home. Moreover, the participants described how they felt about working, regardless of whether this was paid or unpaid, and how their daily activities were affected by the change in their physical mobility. For many the consequences of not working/retiring and the subsequently reduced finances led to a series of events, which negatively affected their financial and social status. This was specifically in terms in terms of social benefits and income, out of pocket costs, housing, and social networks. The participants often described these aspects of their life in relation to their perceived ability to undertake, and in terms of the “success” of implementation of their care within the home. Most of the participants explained that that having lymphoedema was a negative experience in terms of the financial effect in paid employment, time off work and sick pay. The themes explored in this section (Figure 16) are:

- “Operand resources”: socioeconomic impact:
- Working and not working: “Got to keep working”; “Giving up” work; “Being on Benefits”
- The hidden cost: Economic and Social Capital: Clothes and shoes; Travel and Transport; Prescriptions and Provision; Being Dependent; Medicalisation of home

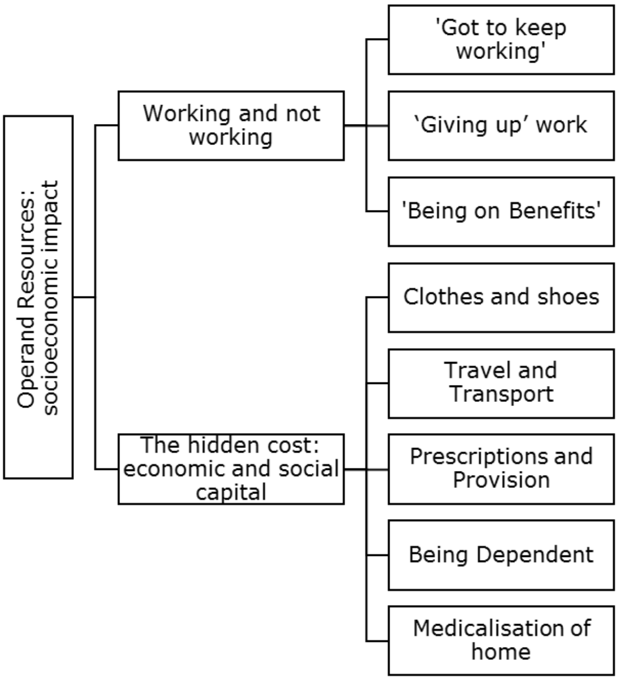


Figure 16: Theme 3: "Operand resources": Socioeconomic impact

8.2 Working and not working

For many participants one of their most worrying concerns was around the effect of lymphoedema on their role in terms of "work" (paid and unpaid employment). Several participants felt that they were left with no choice but to give up work or retire due to ill health because of their lymphoedema. In this study the majority of these participants (61%) were under 65, however, only 5 participants (35%) were in paid employment. 47% of the participants had retired due to ill health or felt forced to stop working due to complications related to their lymphoedema (Table 11, Figures 9-12).

8.2.1 "Got to keep working"

Those who had been forced to give up work or retire, with ill health due to their lymphoedema were often devastated by the effect:

> *"You know I just feel like I'm just gonna be chucked on the scrapheap" (Lloyd)*

Being able to continue to work was essential, especially because of the financial and psychosocial implications of being without paid employment, and the loss of purpose. Having time off work, or even knowing they needed time off work due to ill-health, affected the participants' opinion of themselves, apportioning blame upon their lymphoedema. Graham described being "off-sick" due to numerous infections:

> *"I've worked at the same place 26 years and I probably have been off five times with lymphoedema (Graham)*

Graham explained that he had a good job, and he was paid well, however, with a mortgage to pay, and a family to support, giving up work was not an option. His work involved working 12 hour shifts in a *"four days on, four days off"* pattern, driving a forklift truck at a warehouse. Although the work was not physically demanding, it meant that he spent most of his shift seated, without mobilising or any opportunity to elevate his leg. He explained that this had a detrimental effect on his lymphoedema; despite knowing the importance of self-care, he described that he did not always have time to undertake his care regime, before leaving for work in the morning. Graham knew that this put him at greater risk of developing cellulitis, which always led to being "off-sick", which was a constant source of worry, both in terms of his finances and his physical health. This was pertinent because Graham had previously received a verbal warning for being off work so frequently. He described that he had to continually find a balance between working and mitigating the risks of being off-work due to complications of his lymphoedema.

Graham described one of his worst episodes of cellulitis and how he felt obliged to show his boss the condition of his leg; He explained that his employer was visibly shocked by its appearance. Graham thought that his employer needed to know what he was living with, and why it was so important that he "looked-after" himself. Following his disclosure, Graham found that his employers were more sympathetic and understanding about the legitimacy of his reasons for being "signed-off" work. Graham explained that although he received sick-pay, it was only for 27 days, and after that he received statutory sick pay.

During the interview Graham explained that he was currently off "off-sick" again (6 weeks) and was worried that his skin was so fragile and delicate, that he did not want to risk going back to work too soon. Although this meant that Graham could concentrate on rigorous skin care and elevation of his leg, it also meant that the financial pressure to go back to work was ever present. Graham described life recently as a "domino effect"; not working, not being active, not exercising, putting on weight, increased risk of diabetes, increased risk of cellulitis and consequently worsening lymphoedema. Graham described that the risk of this happening was the motivator for him to "look after himself" as much as he could, but he knew that it was often not enough, and it was a source of constant anxiety.

For many participants, like Graham, feeling that they had to disclose their experience of living with lymphoedema, was paradoxically avoided, and unavoidable. The knowledge that at any time daily life could be interrupted by complications, meant that often participants were often reluctant to disclose exactly what they were living with to employers, as with June:

> *"Yeah and when I started the job I didn't tell em I ad erm not this one the one before I didn't tell em I had lymphoedema [crying]" (Jane)*

This was usually because many were worried that they would not be appointed or believed, if they stated that their condition was unpredictable, particularly those with lymphoedema affecting their legs. In a previous job, Jane felt obliged to disclose her lymphoedema on a work trip, when she shared a hotel room with another colleague. Given the complexity of her self-care regime, she believed that she had no choice but to tell her colleague what this involved. She explained her colleague was *"shocked"* by what Jane had to do and that she had *"hidden"* her lymphoedema so well. Jane explained that she was made redundant from a job earlier in the year and had recently started new employment as a catering assistant. She described the detrimental effects upon her lymphoedema and explained that she had not considered this when applying for the role. Jane explained that she felt like she was suffering more because of her new job, as she was not able to sit down during her shift:

> *"I don't know if it's the lymphoedema … when I've finished It's like five hours on me feet and it is taking its toll on me ankles and sometimes pains up me legs … but we'll see how I go" (Jane)*

It became clear, through their narratives, that the participants described not only worrying that a prospective employer would be concerned about how much time “off-sick” they required but would also be concerned about how capable they were of undertaking their job. This was especially if it meant long periods when sitting or standing or was physically demanding. It also meant that planning was required to pre-warn employers of appointments and necessary healthcare interventions.

Linda explained that she felt fortunate because her employers understand about her lymphoedema, and that she feels a valued member of the workforce. Linda was relieved that her employer was considerate, although she did not disclose the full extent to them, because it affects such an intimate part of her body. Linda believed it was paramount that she did all she could to prevent her complex lymphoedema from worsening. This was especially because she had experienced symptoms for 14 years and was still waiting for a definitive diagnosis. Many of the ongoing investigations and appointments have had a significant effect on her working life, and required extensive planning:

> *“I think I’ve had … you know over ten years I’ve had sort of ten operations under general anaesthetic which is quite a lot you know with time off work” (Linda)*

Linda made the point that this was not just time off from work for procedures, it included pre-operative assessments, follow-up appointments, infections and recovery time. For Linda, like many others, this often meant using a large amount of her “annual leave” to attend outpatient appointments; her clinics were in two locations across the UK, both a distance from each other, and where she lived. She explained that she was often left with no other option, as it was preferable to going "off-sick". Linda also acknowledged that some of this was because she felt so embarrassed, and at times shameful about her lymphoedema, and she did not have the emotional strength to explain this to her employers. She believed herself to be very competent at her job and did not want to make her employees think otherwise.

Participants also described the significance of only attending the clinics, once every six months. For some this meant that accessing their SHPs did not interrupt their working life. It suited their lifestyle, especially because of being able to contact their SHPs at any time in between; if there was any information they required, if they were experiencing problems or if they needed to bring an appointment forward. Being able to plan well ahead allowed time to organise their appointments around their work pattern. Aside from Linda and Penny, all other participants were thankful that their Lymphoedema Clinic was relatively near to where they lived, and easily accessible even if this meant swapping shifts or requesting time off work.

June was retired and described herself as financially "comfortable". Her role as an accountant enabled her to work flexibly around her lymphoedema care, and she was very "strict" about undertaking the "self-care" aspects (cleansing, moisturising, checking). Furthermore, as she had held a senior role, there were many tasks that she easily delegated to others. She made it clear that her lymphoedema did affect her whilst she was working, and that her work colleagues "never ever knew" about her lymphoedema, as:

> *"I hid it so well" (June)*

This was because she perceived that she was able to care for herself and adapt her care and prevent it interfering with her work.

Rachel was in a slightly different situation, prior to retiring she worked at a local pre-school nursery in her village, for 20 years. She explained that she “loved” her job, however she was often off-work for a considerable amount of time due to recurrent bouts of cellulitis, extensive lower leg lymphoedema and leg ulcers. In addition, her time off work was also due to the interventions she received at the Lymphoedema Clinic, which included twice weekly bandaging.

At the time of the interview Rachel had been retired for 11 years, and explained that during her working life she twice “retired” from her post as deputy assistant due to her lymphoedema. However, she explained that she loved her job because it was so fulfilling, and because it was rewarding, and made her feel even more a part of her community. This was not the case for many of the participants; the challenge of physically demanding roles, or those which meant sitting or standing for long periods, was at times insurmountable, and this was evident throughout the narratives. This was especially for those participants who were working prior to diagnosis, and as their lymphoedema worsened they could no longer continue working.

8.2.2 “Giving up” work

In this study many of the participants described retiring “early” due to their lymphoedema; for some this was in addition to comorbidities which were, and were not, directly associated with their condition. The notion of “early” suggested that this referred to retiring before they intended, rather than the official age of retirement within the UK. For many this was perceived as not only leaving paid employment; it meant "giving-up" work and represented an individual failure and loss of purpose. Continuing to work represented normality and a sense of value to the participants, by fulfilling their personal, family and societal role. Lloyd described what was happening to him with a sense of fatalism, as if retiring due to ill health was inevitable:

> *"So we're in talks on that and if that doesn't work out it'll probably be get retired on erm medical grounds" (Lloyd)*

This was a common theme, and all of those who had to retire, or "give-up" work did so with a sense of regret, and also a sense that it was no longer fair on their employer; the belief that circumstances beyond their control meant they were an unreliable member of the work force. Taran tried to continue working for as long as he was physically able, but with long periods of time standing, up to 15-16 hours a day, he had explained he had "no choice" but to go on sick leave, and then resign his position:

> *"……Yeah I was going you know back to work but I was in I couldn't stand I couldn't work I was in so much pain at the time so after I went on the sick" (Taran)*

For many making the decision to stop working was distressing and traumatic, compounding the financial implications and a risk to their socioeconomic status. However, trying to continue to work was equally stressful and untenable. The broader implications of not working were also related to a sense of purpose and credibility, being active and the social aspect of working, as Rod explained:

> *"So I'd carry on and then it just stopped like that it just ended and it was 'ard for me to cope with that at the time…I've got friends and family and that but when they're all at work and you're all alone you're at 'ome you know what I mean it took some getting' used to (Rod)*

Lucy also described how giving up her job had led her to her becoming more depressed and anxious, and she resented having to make this decision. It was a job she enjoyed, was very sociable, and she worked hard to achieve a position of responsibility as the manager of a pub. However, as Lucy's lymphoedema progressed, and her job became more physically demanding job, it became too difficult and painful. Lucy suspected that the long hours and late nights were accelerating her swelling, leading to further deterioration of her lymphoedema. This made her feel as if she was in a "lose-lose" situation, and compounded the other factors in her life, which she said were also causing her depression and anxiety. In addition, "giving-up" work posed a huge financial burden, and she felt embarrassed about now claiming state benefits.

Richard was made redundant in 2012, because the factory he worked at closed, and he also stopped looking for work because repeated episodes of cellulitis, and hospitalisation made him feel that it was futile to seek further employment. Subsequently, and due to other significant health conditions linked to his lymphoedema, he felt he had no choice but to retire due to ill-health. He too felt left in a position whereby he was financially vulnerable, and socially isolated.

Many participants described the emotional pain of leaving a job they enjoyed, and the fear of losing their income. For some participants, this was less of an immediate problem because they finished working near to retirement age and received a private pension. However, most of the participants relied upon state pensions, or were well below retirement age and this was a huge source of worry leaving them in a financially vulnerable position. The burden of "giving up" work was multifaceted; it represented a sense of failure, and an acceptance that this was the only option, because of the progression of their lymphoedema. This was made even more distressing when the participants described their experiences of accessing state welfare benefits.

8.2.3 "Being on benefits"

Many participants described being "out of work" as a major cause of stress, and financial vulnerability. The consequences were far-reaching for those participants who gave up work or retired, due to poor health before their state pension, or unable to use their private pension. Some of the participants had received what they described as an acceptable amount of sick pay before finishing work, however for most this led to either half-pay or less, and then statutory sick pay. Moreover, some of the participants described living day to day on their savings (Rod, Lloyd, Lucy), and applying for benefits such as DLA or PIP was described as a laborious and frustrating process, especially waiting for the payments to be made.

Rod, who had a rare, primary intestinal lymphoedema, which causes extensive swelling in all parts of his body, was "forced" to give up work due to ill health. He emotionally described his panic at that time:

> *"I've finished work I'm getting no benefits me sick pay's run out they've told me I can't claim sick pay they've told me there's nothing wrong with me they've told me that they don't recognise the illness I've got as an illness"* (Rod)

Rod explained that had separated from his wife when his adult children were young, and raised them on his own with the support of his ex-wife's parents. He worked long hours, and as Rod's lymphoedema progressed, he stopped working, and was *"forced"* to sell his large family home, and move into accessible local authority accommodation. Rod explained that he found the emotional upheaval difficult to come to terms with, despite knowing he was in a safer home and financial position:

> *"Because of the money I've got and stuff and then the that means that I aint got no worries if you know what I mean"* (Rod)

All the participants in this situation explained that whilst it was stressful when applying for benefits for the first time, it was even worse when reapplying. This was especially during the transfer from DLA to PIP which was underway during the period of data collection. For many, explaining their health and social situation, was a humiliating experience and made them feel perceived as a malingerer and/or a criminal; trying to justify why they needed the benefit, and communicate the challenges they faced living with lymphoedema was stressful and embarrassing. For many this brought back the anxieties of being perceived as "fat and lazy".

Lloyd was particularly upset when the report for his reapplication for PIP was refused on the basis that he longer “fulfilled the criteria”. He explained that the report did not reflect what he had put in his application form, or the discussion at the meeting with the assessor. He remarked that he was so frustrated at having to fight to explain his life with a condition, which no one understands:

> *“I know I should appeal but I’m I can’t be bothered now because … for me to sit down with three strangers asking how far you can walk what’s your toileting needs like what’s these things I said nah I’ve “ad enough yeah” (Lloyd)*

For those like Lloyd, who used the benefit for mobility car, no longer receiving the award represented meant much more than the cost of a vehicle. Whilst he knew that he should appeal, this meant going through the process of explaining and justifying his needs again and again. Lloyd explained that he found the whole experience deeply humiliating. Having a car enabled him to continue to work, and maintain a degree of normality, even if this was for the short term. The effect of being without this was significant, and he believed that it contributed to his depression and anxiety.

For many receiving the benefit was essential to help to alleviate the extra financial worries. Matt stated

> *“I do qualify for the low-rate mobility component which I mean it’s £90 a month erm it may not seem much but it helps it gets me out it gives me mah bus fare for where I ‘ave to goo so you know it’s all good otherwise I would probably be stuck in the house” (Matt)*

Receiving state benefits and a mobility badge (blue badge) was a paradoxical experience; for most participants it enabled the participants to feel less isolated. This support gave them the financial means to get out and be more active, and to park their car in a more accessible space. However, it also meant being labelled as "disabled" and many of the participants described that this made them feel less of a person. This led to feeling ashamed and embarrassed, especially when they had previously perceived their life to be good, or successful. Moreover, most of the benefits the participants received only just covered costs of rent, utilities bills and food, as Hattie explained:

> *"It wasn't easy at all but I persevered and I was lucky enough to get the full mobility allowance and everything and I'm just left now managing (Hattie).*

Throughout the interviews many participants described that receiving benefits did relieve some of the worry around the financial implications of their lymphoedema. However, as Taran described, PIP was only enough to cover the utilities and not enough to cover the expenses which were required to adapt his home and make it more accessible. Tina talked about the extra costs she believed were directly linked to her lymphoedema, and that she believed it was frustrating that even though she had PIP, she still worried about her financial situation. This had worsened recently because Tina's fiancé was now her registered carer, and since they started living together, they were worse off claiming their benefits as a couple:

> *"Because we now live together our monies are joint but they don't give you enough money to live on we're worse off claiming as a couple than we were as single people and it's all wrong you know" (Tina)*

Furthermore, the benefits rarely covered hidden "out-of-pocket" costs, which the participants spent to fully undertake those aspects of their management plan for which they felt accountable.

8.2.4 The hidden cost: economic and social capital

For many participants the financial implications of living with lymphoedema were compounded by the significant extra "out-of-pocket" costs which emerged as their lifestyle changed, such as clothes and shoes, travel and transport, prescriptions and aids/adaptations to their home.

Clothes and shoes

In this study shoes were a particularly provocative subject for the participants. Richard reflected on his experience of buying shoes, from a low-cost shoe shop called "Jonathan James". The store was infamous within the region, and was abbreviated to "JJ's":

> *"But it's an abuse of custom becus they're not there's nothing great about these I've bought better shoes from JJs [laughs]" (Richard)*

This was both in a practical sense, and the financial implications of more specialised footwear, which were often significantly more than most high street stores/online shops:

> *"You know so it's in a no-win situation … Yeah I've had to I've been known to go into town in me slippers" (Tina)*

In addition, many of the participants with lymphoedema in only one leg explained that they often had to buy two pairs of shoes in different sizes, as only one shoe was needed from each pair, due to the difference in foot size:

> *"Because I have spent a lifetime of buying two pairs of shoes [laughs] and then giving away the odd sizes to somebody you know er because the difference in my foot is a whole size" (Penny)*

This often meant buying cheaper shoes, because the cost of buying two pairs of specialised shoes was prohibitive. In addition, many of the participants described that the specialised shoes were no better, and often did not fit properly. Often many pairs of shoes were purchased online because accessing specialised shoe stores was difficult, especially when participants had no adequate footwear to wear. Furthermore, purchasing several pairs online also meant paying a large amount at once, or set payments over time, which incurred an interest charge. Derek explained he had bought numerous pairs of shoes and slippers, and his wife showed me an area in their dining room where there were many boxes of shoes along one wall, which were hardly worn.

Nel and June also explained that they had bought numerous pairs of shoes, some expensive and some cheaper. June had even been to a local shoemaker to see how much a bespoke pair of shoes would cost and was quoted £375. However, both described how they prefer to buy better quality brands, taking time to find a pair that fits well, and as the shoes begin to wear out, they have the shoes repaired or adapted:

> *"If I like the shoe and it's not quite enough Velcro I take it to a cobbler and he will extend it" (June)*

There were also significant issues with clothing. Many of the participants explained how they had difficulty trying to purchase clothes to fit well, that were fashionable and not "frumpy". The participants stated that it was relatively easy to buy clothing if their limb sizes were the same, even if larger. This included selective purchasing of clothes, to make their appearance as least conspicuous as possible. However, like buying shoes, purchasing clothing from specialist shops for "larger" men/women also tended to be more expensive. This was especially if the one limb was significantly larger than the other (Peter, June, Lloyd). Lloyd described that he could no longer buy appropriate clothes, for performing with his band:

> *"Yeah I actually found a tailor and he's started making me ma trousers but now it's costing me twice as much now yeah" (Lloyd)*

This was important for Lloyd, to feel that he looked the best he could, rather than wearing jogging bottoms or shorts, or trousers with elasticated waists.

Travel and transport

Paying for travel and transport costs also affected the financial position of participants quite dramatically, when they required more intervention and visits to their GP or SHPs. When Graham was discharged from hospital following a serious episode of cellulitis, he had to attend the outpatient's department for antibiotic therapy, for 16 days. This was a round trip of at 22 miles per day, incurring both petrol and parking costs of £3.50 each day. This was in addition to the stress of being off work for 6 weeks. Graham described feeling penalised for being ill, that travelling back and forth did not help him recover or rest. However, he stated that he knew had to attend to have the intravenous antibiotic therapy, or he would end up admitted again. The main inconvenience was waiting to be reviewed every three days, which made it difficult to plan, and waiting 3 or 4 hours to even have the antibiotics, which took 30 minutes to infuse. Graham believed that it would be easier if he was admitted to hospital and receive the care he needed, both physically and financially. For some participants the cost of travel prevented them for committing to potentially beneficial treatment regimens.

Derek's lymphoedema was getting progressively worse, and the increased swelling in his legs already significantly affected his mobility and levels of activity. He explained that his SHP suggested that he attend clinic 3 times a week to have a bandaging system applied, which might help reduce the swelling better than his current "wraps". Derek explained that he could not do this, despite knowing that this treatment might help; although he was not "poor poor", he could not afford the potential travel costs, or cope with hospital transport arriving either too early, or too late for his appointments.

Linda described that even though she has a good job and a good salary, the impact of travel was significant:

> *"The hardest thing about having this condition now really is erm the financial side is hard you*

> *know I've been on my own you know I'm paying to go to ****** you know" (Linda)*

Linda was travelling to the hospital in the south east regularly in recent months, which meant a significant time off work, using annual leave and paying for expensive rail fares and overnight stays. She was concerned about how long this would continue, whilst she was still seeking a definitive diagnosis.

Prescriptions and provision

Paying for prescriptions was a major cost for those who were not eligible for free prescriptions, even if the cost was part of an annual pre-payment plan. The cost of prescriptions could also be unpredictable, as all the participants needed a combination of emollients and topical treatments, prophylactic antibiotics, and any other medications due to their comorbidities:

> *"Erm so by the time I've 'ad all those in any one year it can be between 23 24 prescriptions then if you've got your antibiotics to have because oh I've got yet another infection here" (Penny)*

The annual prescription plan relieved some worry about additional prescription for those participants who used them; however, those who did not were frustrated because they had to ensure that they had a GP prescription for "emergency" antibiotics in case an episode of cellulitis developed. Due to the fear of cellulitis, they always had the prescription dispensed, so that the antibiotics were in their home if an episode developed suddenly:

> *"Sometimes I was paying out for prescriptions that I never ever I'd cash them because I needed them exactly in the drawer" (Cathy)*

Despite these extra costs, one benefit for all the participants in the study was that the regional service, which managed their Lymphoedema Clinics, had a contract with a supplier. This mitigated any financial cost for "made to measure" compression garments and specialist wraps. However, this did not apply to any other treatments or medications they required on prescription, unless the participant had a medical condition which meant prescription charges did not apply.

All the participants expressed relief that they did not have to pay for their compression garments or wraps. However, the participants did perceive a significant reduction in choice, particularly related to the colour or design of fabrics of the garments, which were only available in block colour, mainly dark and neutral. Moreover, some of the participants described previous experiences, when garments were prescribed by other SHPs prior to attending their current clinic and administered at community pharmacies. Often the garment prescribed was replaced by a cheaper version, with a lesser classification. This meant that they not only paid for their prescription but paid for an item that was not adequate to deliver the required compression.

In addition to the garments, wraps and bandages there were treatments, which were part of recommended "CDT". This included scrupulous skin and nail care, manual lymphatic drainage, compression bandages, and exercises, aimed at reducing swelling. In this study, very few participants described having accessed all these interventions through the

NHS, especially MLD. This could only be performed by trained practitioners, and the participants within this study stated they were not always able to access this, especially if they had to pay for it.

Being dependent: Medicalisation of home

Many of the participants described that as their lymphoedema progressed and their mobility worsened, adaptations within their home were required to help them to optimise their mobility, independence and self-care. For those living in local authority properties adaptations, equipment and furniture within the property were often funded, or part funded. However, for other participants this was another "out-of-pocket" cost.

Taran described that his "profiling bed" was part funded, and his adapted bathroom had been fitted with a "wash and dry toilet". His toilet was beginning to come away from the wall and the reclining chair he had self-funded, were both out of warranty, and required servicing:

> *"So I had to buy myself the chair Yeah reclining chair yeah unfortunately I'm onto a point I weren't able to afford to pay it so it came out of the warranty period" (Taran)*

For many participants the initial relief at funded or part-funded adaptations was replaced by worry and anxiety, because they could not afford to renew the warranty or pay for service costs.

Furthermore, Taran felt penalised because they had two bedrooms room, and the local authority was beginning to threaten to apply the "under-occupancy charge" (Citizens Citizens Advice, 2021). For Taran, the importance of having the profiling bed was much more than just being able to undertake his self-care. It also meant that he was able to continue to sleep in the same bed as his wife, whereas the local authority had suggested that they sleep in separate rooms. Taran felt very aggrieved about this, stating he worked for many years, making his tax contributions. Furthermore, he stated that because of their combined health needs, only their bed could fit in their bedroom. Their other bedroom was not a "spare room", as it was full of medical equipment and other furniture from their bedroom. This was important to Taran and his wife as their bedroom represented a place of care and intimacy, rather than being full of all their medical aids and equipment.

Other out of pocket costs were "aids" which helped the participants to keep as mobile and independent as possible. Approximately half of the participants, in this study, stated they had purchased a mobility scooter. In most cases these cost between £2,000 and £6,000, and participants were often only able to pay in instalments or pay less for pre-used scooters. The latter meant that these were often out of warranty:

> *"And I got a mobility scooter. Well thank goodness we've paid the loan off … we pay the loan off this month [laughs] so it's two years we've struggled to pay it" (Hattie)*

For many participants this was a cost which had to be managed, because the alternative meant that their ability to mobilise independently outside of the home was significantly compromised. Purchasing a stair lift was considered essential for those participants who wanted to remain living in their own home but found using the stairs physically impossible or impassable. For a small number of the participants using a stair lift was problematic because their weight exceeded the recommended weight limit, or they could not physically sit in the chair safely. Along with the financial implications, many participants believed that the combination of needing these adaptions and aids, and the associated social stigma increased their feelings of being constantly judged as a discredited member of society.

Many of the participants described that since developing lymphoedema, their home was no longer a place of comfort and safety. This was especially the case for those whose socioeconomic position meant they did not fulfil the criteria for housing benefit, and were struggling with rising costs. Debbie explained that her situation meant that she had to consider moving:

> *I’m going to have to sell this cottage next year I was thinking about it this year I had it valued this year but I’ve very reluctant I don’t want to leave it because I love it and I’ve got a lot of support (Debbie)*

Moving house was not only about the trying to make life more financially bearable. Moving house was about realisation that their home was no longer a suitable environment; that their living conditions were not conducive to a body which was too big, cumbersome and clumsy to move around. Remaining in their current home prevented them from caring for themselves, and increased the risks associated with their lymphoedema. This was in addition to an acceptance that the rising out of pocket costs, no longer working and reduced income, meant that these participants believed they were “forced” to move house. This was described by those participants as an upsetting and distressing situation, especially when moving to a completely different locality, or feelings of loss and guilt when moving away from friends and their community, but moving nearer to family, so that they would have more caring support.

Many of these participants described that they were currently in the worst financial position they had ever experienced. This not only had implications for day to day living, but also in terms of socialising with family and friends, in the way they had previously. Matt explained that he was feeling “very low” because he had to miss a family get together with his cousins; he could not afford to save the money for a hotel and spending money over the planned weekend:

> *“It’s pushing it the only way I could manage it is if I save up for three or four months and go up but then I wouldn’t have any money really to go out with of an evening with em” (Matt)*

It was evident that the diagnosis of lymphoedema coincided with, and contributed to, several financial challenges. This was exacerbated by subsequent “hidden” out of pocket costs, which were only realised as their lymphoedema and swelling worsened. This was then compounded further for those participants with worsening mobility and increased risks of infection, leading to a descending spiral of worsening social deprivation and social capital.

8.3 Analysis and interpretation of “operand resources”: socioeconomic impact”

These participants’ narratives demonstrated that they were actively and consciously engaged in implementing their care (Brudney and England, 1983, Prahalad and Ramaswamy, 2004b, a). They had capacity to coproduce (Alvarez et al., 2017) which also demonstrated their responsibility, with the support of their significant others. However, the issue of accountability was challenged by their self-perceptions of living with a body which cannot be “managed” (Bettencourt et al., 2002, Chan et al., 2010), and this led to feelings of frustration, disappointment, and fear. It was clear that many of the participants felt conflicted about the limited choices available; they described having to make impossible choices, in terms of working and not working, when they perceived that there really was no choice at all.

The idea of shared-decisions was more about agreeing to undertake the “best” option available, in terms of navigating and mitigating the perceived limited treatment choices. It was apparent from the narratives of the participants in this study that they understood what was required in terms of implementing their care at home. Despite describing the negative socioeconomic and financial effects of living within chronic oedema, these participants appeared to possess the “operant resources “(Vargo and Lusch, 2004, Lusch and Vargo, 2006, Etgar, 2008, McColl-Kennedy et al., 2012, McColl-Kennedy et al., 2017). These were the skills, knowledge, insight and health literacy (Palumbo, 2015, Mackey et al., 2016, Palumbo et al., 2016) to coproduce and implement their care within the home.

Any difficulties or resistance to implementing agreed care was not reflective of the shared-decisions made within the clinic. It was due to their reality, that some of the agreed care could not be effectively implemented at home, due to a lack of "operand resources", rather than whether the participants were compliant, concordant or adhered to treatment. This reflected the dilemma of what can be realistically achieved when there was a lack of "operand resources" and recognised the conflicted position of these participants. This finding also demonstrated the importance of exploring conflict and contextual barriers which limit the operationalisation of coproduction (Evers et al., 2014, Ewert and Evers, 2014, Jo and Nabatchi, 2016, Osborne et al., 2016, Nahi, 2016, Osborne, 2018), at the point of consumption, as the "co-implementer" of care (Voorberg et al., 2013, Voorberg et al., 2015, Adinolfi et al., 2016).

The issue of conflict was explored, in terms of why these participants were so challenged when trying to implement interventions within the home. The argument, that those who are less likely to coproduce are those with less formal education, and in a lower socioeconomic position had some relevance (Etgar, 2008, Thijssen and Van Dooren, 2016). This is not in terms of the participants' health literacy, or their ability to understand, comprehend or appreciate what needed to be implemented. It was their lack of "operand resources" which prevented an absolute commitment to agreed care (Franks and Jarrett, 1997). The conflict which arose within the coproducing relationships was most apparent, for some participants, within their domestic setting; not in terms of the interpersonal relationship with their SHPs, but in terms of feeling conflicted about what care to implement.

Despite this conflict many of the participants described during the interviews how their relationship with their SHP cocreated value. This was interpreted as developing positive relational exchange and social capital through “knowledge transfer” (Bettencourt et al., 2002, p.101), and sharing skills and knowledge (Batalden, 2018). They described that discussions with their SHPs helped to seek solutions to problems the participants were experiencing with implementing their care. However, their narratives suggested that value was not always created beyond the confines of the consultation, especially when the participants tried to implement their care at home. The participants also described situations at home which induced stress and conflict (Jo and Nabatchi, 2016, Nahi, 2016, Osborne et al., 2016, Osborne, 2018); these participants were not passive in their attempts to coproduce care (Ostrom, 1996, Bovaird, 2007, Cova and Dalli, 2009), and this was apparent from the way they described trying to navigate what care to undertake.

For some, the lack of “operand resources” meant that shared-decisions, which occurred within the clinic consultation were often an unachievable aim within the home (Stevenson and Scambler, 2005); and this led to feelings of frustration, resentment and distress. The participants demonstrated through their narratives, especially during the observations, how they often appeared to agree to care which they were not confident they could implement at home.

For those in paid employment, it was clear that they struggled to manage their “self-care” (Sezgin Ozcan et al., 2018) whilst at work, especially when their work was physically demanding (Graham, Lucy, Richard, Taran, Rachel). Whilst there is evidence to suggest intensive therapy can help with returning to work (Stanisić et al., 2012), it also required a significant time away from work, and could accrue further hidden costs. However, the fear of not working; the fear of losing their job; or being off-sick, and not being financially stable seemed to override their sense of responsibility for managing their care.

These experiences challenged the concept of self-management (van Houtum et al., 2015, Douglass et al., 2016). This was especially in terms of and how socioeconomic factors led many of the participants to feel that their lymphoedema was “unmanageable”, as they were not able undertake every aspect of agreed care. A significant amount of each day was needed to complete the regimens and routines, including rest and elevation, exercise and massage. This meant that decisions had to be made, about time management and financial resources. Those participants who worked in paid employment, were forced to organise their care around their work, which often meant they had to be selective about what they could realistically achieve.

In addition, many of the working participants was questioned their ability to undertake their role and were fearful of if their employer would also ask this too. This was not limited to how they cared for themselves but extended to responsibilities they had for caring for their own spouse (Taran, June); or the caring responsibilities they imposed upon their significant others, who often also had their own health issues.

There is some evidence to support that there are significant costs associated with living with lymphoedema which are hidden (Morgan et al., 2005, Keast et al., 2015, Mercier et al., 2016a, Mercier et al., 2016b, Humphreys et al., 2017, Nairn et al., 2019). For the participants in this study, these were the costs described in terms of medical equipment, furniture, prescriptions, travel costs, shoes and clothing. This was particularly regarding footwear, and the difficulties in buying affordable footwear which enabled them to work, mobilise and exercise safely (Taran, Derek, Penny, Hattie).

This was a repeating theme in the findings, and supported by existing evidence which suggested that inadequate footwear is known to affect well-being and health negatively, and exacerbate existing health conditions (Farrelly, 2008). There was an emotional element for these participants, as they described once being able to wear certain shoes, which they can no longer wear, and how this negatively affected their identity. Their descriptions of shoes worn previously aligned to what Hockey et al., (2014) refer to as "memory objects" (Hockey et al., 2014, p.256) reminding the participants of a time before lymphoedema. This represented another "vicious cycle" in terms of ongoing risks of complications, and "out-of-pocket" costs and further challenged these participants' coproduction of care at the point of consumption and implementation (Voorberg et al., 2013, Voorberg et al., 2015).

In this study, the participants were recruited from region of England recognised as significantly socioeconomically deprived, and many of the participants lived within locations considered to be highly deprived (NCC, 2015, Ministry of Housing, Communities & Local Government, 2015). In much of the chronic oedema literature access to specialist services is recognised as an important factor for service-users, whether in terms of geographical location or available treatments (Watts and Davies, 2016, Wang and Keast, 2016). In this study, all but two of the participants in this study had reasonable geographical access to their nearest clinic. In addition, given that physical access to the clinic was once every 6 months, being able to call the clinic for advice was described by the participants as important and reassuring. However, for most of these participants the implementation of care was within their domestic setting, either by themselves or by their significant others. Very few of these participants accessed care from either a community nursing team, or their GP practice nurse.

Whilst the implementation of care was based upon their agreed, shared-decisions with the SHPs, ultimately the participants made complex decisions about how implemented care within the home. Furthermore, even those participants who described that they were in a "secure" financial position (Linda, June), also described the significant "hidden costs". All the participants also described the "hidden costs" in their "hidden day" of implementing care, which no-one really knows about. Much of the coproduction literature proposes that those in a higher socioeconomic position are more likely to undertake coproduction activity, in terms of both "operand" and "operant" resources relationship (Etgar, 2008, Thijssen and Van Dooren, 2016), however some of these participants described their experience as if they are "denied" treatment because of their socioeconomic status. This was not described in terms of the SHPs denying them treatment, but in terms of their perception of lymphoedema awareness and care in general. Some of the participants described that they were fully aware that they did not implement the exact care they needed, but they had very little control of this due to the socioeconomic factors previously described.

In addition to the financial implications of living with lymphoedema number of participants described the effect upon their social networks (social capital). Those who described “good” social networks and gave the impression that these went some way to mitigating their feelings of social isolation, and in a literal sense “social deprivation”. The psychological impact of lymphoedema and LTCs is well documented and reflected in the descriptions of the significant support these participants required from their SHPs, NSHPs and significant others (de Valois et al., 2016, Dudek et al., 2016, Douglass et al., 2016, Stolldorf et al., 2016, Tsuchiya and Takahashi, 2016, van de Pas et al., 2016, Greene and Meskell, 2017, Joachim and Acorn, 2000, Williams et al., 2004, Moffatt et al., 2017b). However, lymphoedema is also a condition which is perceived to lack economic, social and scientific capital (Nairn et al., 2019, Ferlander, 2007), and this is reflected in a lack of UK health policy and care provision (Stout et al., 2013, Moffatt et al., 2017c, Moffatt et al., 2018, Moffatt et al., 2019c).

Furthermore, within areas of social deprivation, it is suggested that those with less social capital are significantly more vulnerable and at risk of exclusion (Cockerham et al., 2017). Although the participants in this study demonstrated individual agency regarding their specific needs, they also relied on upon their support and networks of care. For these participants, even when financial resources were lacking, they described that belonging to social groups, networks and communities helped to mitigate their circumstances, and feelings of isolation. The unequal distribution of social capital, is not always fully reflected in the health literature due to a focus on health outcomes, not specific health conditions (Ferlander, 2007, Nairn et al., 2019). However, a lack of social capital may impact negatively upon these participants health outcomes, given that LTCs can increases the risk of social isolation and reduced social capital (Keeley et al., 2010, Moffatt et al., 2017c). Furthermore, most of these participants were not passive actors in the coproduction of their care and were motivated to undertake their care.

Many of the participants relied upon family members for help with implementing their care, as they reported that they rarely accessed the care of community or GP practice nurses, preferring to just go to their SHPs, even if it was only every six months. During the interviews, it became apparent that several of the participants reported a significant shift in their intimate relationships, and their family dynamics, especially when spouses/partners became their carer (Matt, Tina, Debbie, Hattie, Shirley, Derek). Being dependent upon others caused many of the participants to discredit themselves, and perceived themselves as a useless burden (Charmaz, 1983). The extent to which the participants believed themselves to be a burden was on a continuum; from those who depended upon the help and support of a loved one, to those who undertook caring roles themselves (Taran, June, Matt).

In this study social capital functioned at an individual level and a collective level (with carers and SHPs, and other service-users) (Song, 2013). The information and treatment described by the participants, when attending the Lymphoedema Clinic was an example of “circumstantial support” (Vanleene et al., 2017, p.116). The other aspect of social capital, described by the participants, was that between the SHP and the significant other. This was an example of “linking social capital” (Ferlander, 2007, p.120) because of the evident hierarchical relationship within the SHPs, even if the participant and their significant other did not perceive this to be the case. This was of particular importance regarding the relationship between the significant others and the SHPs, for several reasons.

For a few the participants their significant other was the person who implemented the care at home. The significant others also demonstrated the drive and motivation to implement the treatment plans; this emotional investment in the care of the participants, demonstrated a “strong bonding” social capital (Ferlander, 2007, p.120). This was in terms of the role that the carer assumed within the home, which at times was described as a similar role to that of the SHP. Participants frequently expressed deep gratitude and faith in their significant other to know, and to be skilled regarding the level of care required. This was reflected in the way they perceived a special relationship with the SHP, and how the significant other fulfilled this role within the home. The SHPs relationship with their significant other was equally important, as their relationship with the participant. There was recognition that they shared a common goal; a sense of understanding and being understood; a means of sharing and developing knowledge together which is implicit in much of the literature on coproduction (Lovelock and Young, 1979, Morgan and Hunt, 1994, Bettencourt et al., 2002, Prahalad and Ramaswamy, 2004b, Vargo and Lusch, 2004).

The care delivered by the significant other supported the operationalisation of care, both from an emotionally supportive (bonding) perspective and in a practical sense. This was specifically in terms of the assumed role of the significant other, as the SHP, within the home. In addition, this was perceived that both the participants and the significant others became “experts by experience” (Fenge et al., 2012, Mayer and McKenzie, 2017). The negative aspect of this was that the “home” became medicalised; it was no longer described as a place of relaxation; it had become a place of care delivery, which challenged the idea that the participants could ever “self-manage” (Knowles et al., 2016), whilst ever they required the support of their significant other, or any health professional. However, the social capital within the home and with their significant others, and their SHPs emerged as an “operand” resource, and a factor which contributed to those instances when participants were coproducing care (Hattie, Derek, Mary).

One of the greatest challenges for these participants was the perpetual risk of health inequality, because of the strain upon financial “operand resources” and economic capital (Scambler, 2013). The loss of their work, homes, friendships, and social networks meant that for some of the participants, the SHP became their significant other; especially those who had to attend more regularly than every six months. These relationships were important because the SHPs were people who understood lymphoedema, in the light of friends, employers and GPs who had little or no awareness. Paradoxically these participants also lacked social capital. Existing literature suggests that many individuals living with Lymphoedema experience social isolation and marginalisation, and lack social capital (Papadopoulou et al., 2012, Nairn et al., 2019), not only because of the physical manifestation of the condition which can restrict their activities, but also due to their socioeconomic and/or geographical position (Moffatt et al., 2018). Furthermore, some of these participants described a profound sense of not fulfilling their social role (Radley and Green, 1987), and that both they and their significant others were “missing out on life”; having only each other, led to the loss of social capital in all other spheres of life.

Many of the participants needed the emotional and physical support of family and friends, due to the lack of “operand resources” and economic capital (money). Some of the participants expressed feeling even more stigmatised because of the loss their employment status; this led to a loss of role, purpose and status, and a new set of labels which fulfilled the social stereotypes of “fat”, “lazy”, “out of work” and “on benefits”. These labels diminished social capital even further, causing the participants to feel as if they were living “between a rock and a hard place”, with the potential to worsening health outcomes (Keeley et al., 2010, Moffatt et al., 2017c).

In conclusion, despite the positive relationships between the participants, their significant others and the SHPs, it emerged that to genuinely benefit from value creation and relational exchange through a coproducing relationship, there should be minimal hierarchy, and an equitable power dynamic. However, this is a significant challenge due to the bio-medical model of care, and therefore it imperative to explore what structural barriers there may be to a coproducing relationship, which are further hindered by a lack of “operand resources”.

Moreover, these participants were not able undertake every aspect of agreed care due to working, financial reasons and or the economic impact of not working, and many of the participants reported trying to manage an “unmanageable” condition. Their coproduction of care was framed in terms of the social capital available to the participants, as an example of an operand resource, and this was evident within the confines of the relationships with SHP. Conflict within the coproducing relationships was most apparent for participants within their domestic setting; the conflict was not on a personal level with those whom they are coproducing, or about the interpersonal relationship with their SHPs, but in terms of the participants feeling conflicted the care they needed to implement.

9 Final Discussion of the thesis

9.1 Chapter overview

This is the final discussion of the thesis, and the whole study; this includes overview of the main findings in terms of revisiting the definitions of coproduction, and the discussion in terms of scientific capital, structural position, social capital, and economic capital; how this relates to power, status and capital and coproduction, and finally the conclusion.

9.2 Overview of main findings

It is important to return to the original objectives of this study, and reflect upon all the findings, and the how these are interpreted through the contemporary coproduction literature and a social constructivist lens of service-user and SHP experience. These were in terms of how coproduction is operationalised within this context of ongoing care, across hospital and home settings, for individuals living with a LTC (chronic oedema); and how is care coproduced, at the point of implementation within the "hospital" and "home". This also included, if and how socioeconomic position and social capital influences coproduction between service-users and service-providers in this context; whether the SDH and socioeconomic factors influence the decision-making strategies and coproduction of care, for service-users living with chronic oedema; recommendations for policy makers in relation to access to chronic oedema care, and an exploration of the socioeconomic context and geographical location of the setting, in terms of the distribution of service-users.

The key contribution of this study extends the scope of the healthcare setting to include the home setting and the activities of service-users, when not directly engaged with SHPs. A notable research gap exists in the coproduction of health which takes place across multiple sites, and in particular the home. The importance of the home, in addition to healthcare organisations, as a site for the coproduction of healthcare delivery is perhaps most obvious with respect to LTCs.

It is also important to recognise that this study contributes to contemporary Improvement Science and Implementation Science literature. The integration of theory, rigorous research methods, data collection, and analysis, enables high quality evaluation to facilitate sustainable quality improvement within healthcare (Marshall et al., 2013). Moreover, Improvement and Implementation Science emphasise the importance of context and setting in the design, development, and implementation of health innovations. The findings of this study suggest that the Coproduction of Care (Figure 17) can be discussed in terms of:

- Scientific capital:
- Social Capital & Economic Capital
- Structural position

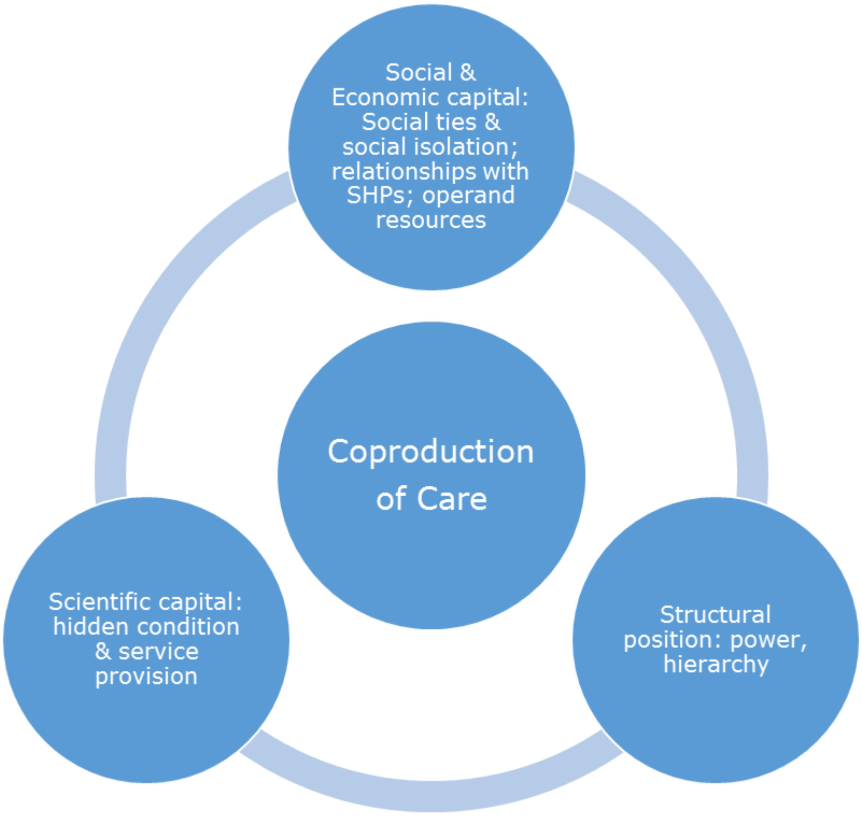


Figure 17: Findings from the empirical study

In this study, the exchange of operant and "operand resources" were pivotal for these participants; the value of the exchange of "operant resources", and the relationship was based on deep gratitude for the care, and also bound by expectations of reciprocity and trust (Putnam, 2004, Ferlander, 2007, Song, 2013, Salisbury, 2020). Despite the challenges these participants experienced in implementing their care at home, they tried to maintain a sense of hope (Alford, 2002, Van Eijk and Steen, 2014, Vanleene et al., 2017) through the encouragement, and the promotion of care and behaviour. This contributed to their perceptions of "managing" their lymphoedema, even if they believed their condition was uncontrollable with no tangible improvement.

During the observations and the interviews, most of the participants exhibited the willingness and motivation to coproduce, in addition to the acquisition of health literacy, and the skills and knowledge regarding their lymphoedema. However, this was contradicted by the participants' consistent reports of a lack of "operand resources", which they identified as preventing the complete operationalisation care at home. Moreover, this was often also challenging for the SHPs, given the recognised lack of "operant" and "operand" resources, and scientific capital regarding chronic oedema.

Furthermore, it was relevant to consider the dynamics of social relationships and interactions between service-users and service-providers, and this study reflected the significance of the socially constructed realities for service-users and service-providers, and how these may or may not be commensurable (Denzin and Lincoln, 2005). This study uncovered this problem, and emphasised the economic burden of coproducing care for service-users with chronic oedema, (Etgar, 2008, Nahi, 2016), which is recognised as an under researched phenomenon. It examined the factors which influenced individual choice and needs, and whether social capital mitigated, or exacerbated this experience.

The findings of this study demonstrated how it was difficult to sustain the ownership and autonomy which coproduction proposes. For the SHPs this was in terms of scientific capital and service provision; and for the service-users, this was reflected the in their perceived lack of choice and control over their lymphoedema progression, and their lives in general. Moreover, the concept of self-management was often seen as unrealistic and unfeasible, and lacked clarification by the SHPs, who were delivering care to these participants.

On reflection the repetitive and lengthy descriptions of coproduction, which were discussed in the NR, were inadequate when describing the experience of these participants. This was due to the revelation that they had the "operant resources", in terms of their health literacy personal motivation, and lacked the "operand resources" to implement care. Moreover, to label service-users as non-concordant, non-compliant or non-adherent is inappropriate, and perpetuates a paternalistic perspective of care, which coproduction attempts to reconcile. However, the relationship between the participants and SHPs in this study was suggestive of a coproducing relationship, especially in terms of the original definition by Ostrom (1996), where

> *"Coproduction implies that citizens can play an active role in producing public goods and services of consequence to them "(Ostrom, 1996, p.1073)*

The findings of this study demonstrate many aspects of the relationship between the participants and the SHPs, which point to key elements of coproduction theory: the exchange of "operant resources", positive relational exchange, responsibility, accountability and nurturing, trust and commitment suggested by Lovelock and Young (1979), Morgan and Hunt (1994), Bettencourt et al. (2002), Vargo and Lusch (2004), Lusch and Vargo (2006), Bovaird (2007) Jacob and Rettinger (2011), Bovaird and Loeffler (2012) and Voorberg et al. (2015).

Furthermore, the findings of this study align more to those coproduction theories which focus upon the importance of the experience and rather than the outcome (Payne et al., 2008, Wu et al., 2013). This is perhaps a naïve proposal given that the outcome for these participants is unpredictable and uncertain due to a lack of standardised outcome measures for chronic oedema. Therefore, it may be argued that there is a "dark side" of coproduction (Palumbo, 2015), and that the SHPs used "hidden strategic actions" (Outhwaite, 2009, p.470) to encourage participants towards a line of treatment. However, in this study it was not to suppress or control the participants. These SHPs were observed as being open and transparent with the participants, about the complexity of the condition, and the complexities of living with the condition. It must be acknowledged that at no point during the non-participant observations did the SHPs make any predictions or promises about the participants' positive clinical outcomes. The SHPs recognised the anxiety these participants felt because of their condition, and this study demonstrates that a new interpretation of coproduction is required. This is due to factors such as the:

- shared experience of the SHPS working within a field of care without scientific capital
- participants, who perceived they experienced good care despite limited treatment choices or control of their condition
- limited of social and economic capital due to living with an underrepresented LTC

Moreover, this study demonstrated that to accept the structural position of their relationship, does not preclude coproduction activity; it depends upon what is expected in terms of "outcome". In the absence of any real hope of cure and/or improvement, the maintenance of a supportive relationship, enabled the service-users to exchange "operant resources”, despite their lack of “operand resources” and difficulties in implementing care at home. From the findings of this study there are three aspects which suggest an opportunity for rethinking coproduction, as demonstrated in Figure 17: Findings from the Empirical Study; these acknowledge the usefulness of the contemporary literature, but also suggest where limitations can hinder how coproduction is genuinely operationalised.

9.2.1 Scientific Capital

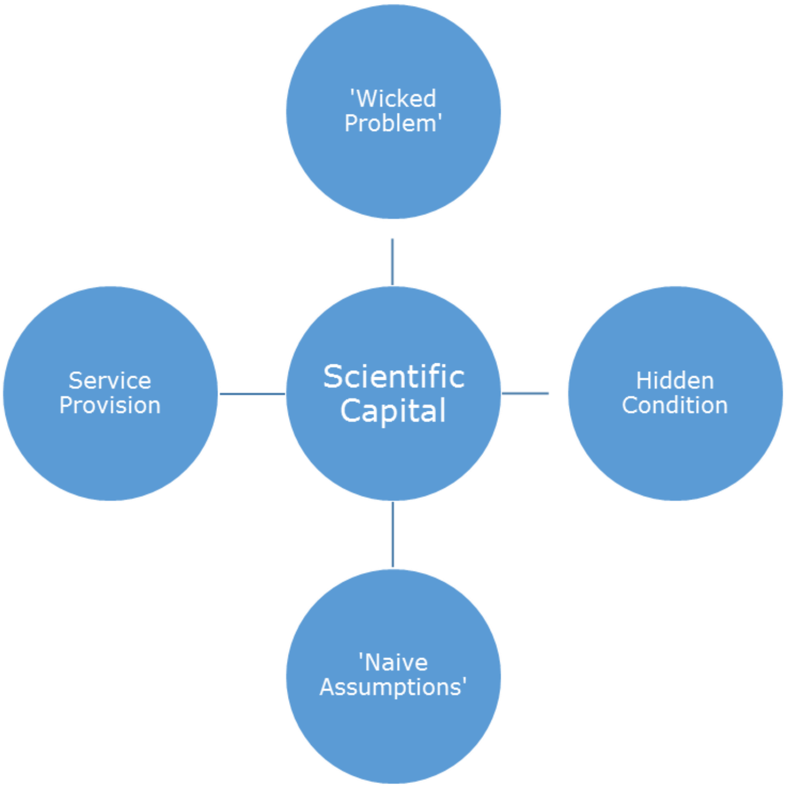


Figure 18: Scientific capital

The extent to which this study also revealed the “wicked Problem” (Rittel and Webber, 1973, p.155) of chronic oedema is worthy of further discussion. This is in terms of the overarching understanding of the term, and the interchangeable use of the term lymphoedema, by health professionals and service-users. For these participants the lack of scientific capital (Figure 18) attributed to lymphoedema

(Nairn et al., 2019) perpetuated socially constructed stigmas and stereotypes. Service-users attended from a wide geographical area which aligns with other studies (Morgan et al., 2011, Morgan et al., 2012) and demonstrated and supported the inequity of access across England.

Moreover, the lack of scientific capital (Abel and Frohlich, 2012, Morgan et al., 2012, Nairn et al., 2019), identifies a lack of recognition at policy level (Cooper and Bagnall, 2016, Williams et al., 2005, Williams and Mortimer, 2007, Morgan et al., 2012, Moffatt et al., 2017c, Moffatt et al., 2018, Nairn et al., 2019, Moffatt et al., 2019c) for a condition which is perpetually misunderstood, and which risks a lack of economic capital. This is in terms of investment in service provision, and perpetuating low "operand resources" and lack of economic support for service-users. Many participants expressed feeling completely "lost in the system" with no clear pathway, and no "organizational health literacy" (Brach et al., 2014, p.274) available for navigating their journey to referral and diagnosis. This was further exacerbated as the findings, from the clinic setting, also suggested that they were navigating a system with no clear professional route and little ownership, in terms of where the service is located. This supported the recurring theme in this study, that chronic oedema (lymphoedema) is a hidden condition; the lack of scientific and social capital associated with this condition; the awareness and treatment options; and how this affects those living with this LTC (Morgan et al., 2005, Keast et al., 2015, Mercier et al., 2016a, Mercier et al., 2016b, Humphreys et al., 2017, Nairn et al., 2019).

The lack of scientific capital perpetuates chronic oedema as a hidden healthcare problem, both organisationally and individually. This was demonstrated in terms of where the clinics were positioned and situated; the problem of diagnosis and recognition in primary care and secondary care; and how the participants attempted to coproduce care with NSHPs who did not recognise their condition. In particular, this reflected the participants' experience of care, in terms of feeling judged by their size, when contemporary evidence indicates that obesity is a significant co-morbidity associated with chronic oedema (Mehrara and Greene, 2014, Ching et al., 2015, O'Malley et al., 2015, Moffatt et al., 2017c, Conolly and Davies, 2018, Hooper et al., 2018). These participants perceived that many NSHPs held "naïve assumptions" (Dejong, 1980, p.75) about the reasons for their size and body mass. Furthermore, obesity is known to be disproportionately related to social deprivation, and increase the risk of cancer and subsequent cancer treatments, which also increases the risks of developing chronic oedema (Cockerham et al., 2017, Newman, 2018, Hooper et al., 2018, Conolly and Davies, 2018). For these reasons, chronic oedema can also be considered complex, ambiguous, and controversial, and therefore a "wicked Problem" (Rittel and Webber, 1973, p.155). Therefore, the coproduction of care needs to occur over their lifetime, and even more so when many of these participants accessed the clinic only two, or three times a year.

In conclusion, a significant finding in this study was the recognition of the factors which made coproducing care genuinely problematic for these participants were those beyond their immediate control; a lack of a pathway of care; delayed diagnosis or missed-diagnosis; lack of evidence for the efficacy of treatments; a lack standardised measures for treatment outcomes and the symbolism of limb volume measurement; perceived limited treatment options; and the comorbidities associated with their lymphoedema (Moffatt et al., 2019d). The lack of scientific capital led to minimal “organisational health literacy”, (Brach et al., 2014, p.274), which left many participants floundering, and unable to navigate the health system, and reliant upon their “default expertise” (Collins, 2014, p.15), through “routines and rituals”. All the participants in this study possessed the “operant resources” to engage in the coproduction of their care. The factors which made coproducing care genuinely problematic for these participants were those beyond their immediate control, all of which were underpinned by a lack of scientific capital.

9.2.2 Structural position

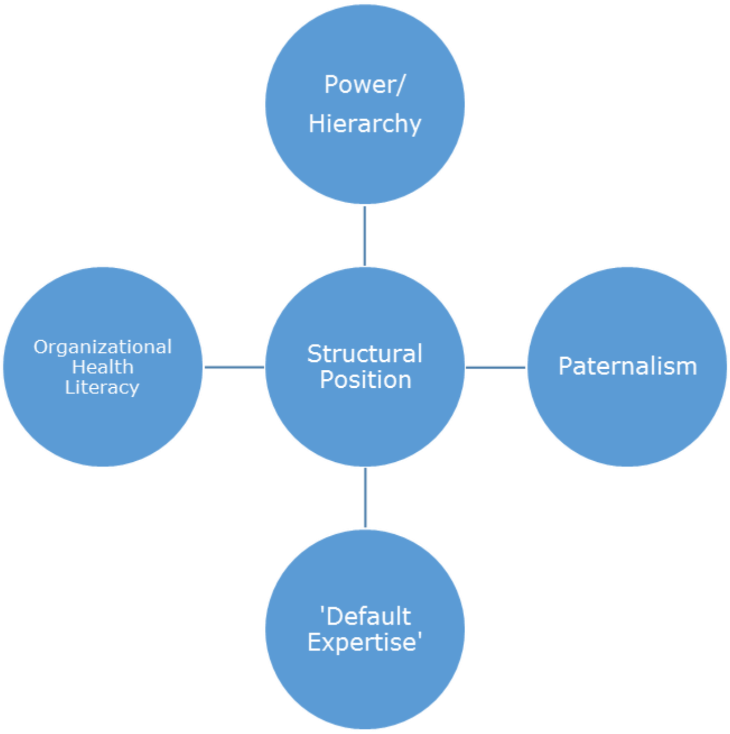


Figure 19: Structural Position

The findings of this study also demonstrated a dichotomy between a bio-medical, hierarchical model of care and one which related to structural position (Figure 19) centred upon paternalistic, relationship-centred care. The evidence of coproduction of care within this study, did not align to the usual definitions of coproduction. This was specifically related those studies which suggested that coproduction requires a shift in balance and power that leads the service-provider and the service-users to be equal partners. This finding challenged the traditional definition and concept of self-management, adherence, concordance, and self-care; the expectation that service-users conform to the norms and tacit rules of being a “patient” (service-user). Furthermore, the idea that a lack of individual and “organizational health literacy” (Brach et al., 2014, p.274) increased the inequitable power dynamic, for some participants, and was a barrier to an equitable coproducing relationship (Palumbo et al., 2016).

In this study, whilst most of the participants sustained a positive relationship with SHPs, it remained hierarchical. Despite there being evidence of “relationship-centred care” (Tresolini, 1994), care was delivered in paternalistic manner. For some participants this was important because it was, and remains, difficult for them to navigate their way easily through the healthcare system. Furthermore, the behaviour of a small number of participants was perceived as actively avoiding a contemporary coproducing relationship; either because they had disengaged entirely (Penny/Debbie); or because the paternalistic relationship made them feel safer (Dennis, Hattie, Peter) if they were “doing as they were told” or being a “good” patient. This was highly relevant to the structural power dynamic with their SHPs; for some of the participants it also seemed to be strategy which enabled them to negate their agency and responsibility for implementing the required care, which might not work anyway.

A further reflection of the hierarchical power dynamic was the idea that service-users can only become expert, if they have confidence in the specialist knowledge and expertise of the SHPs. However, in this study coproducing care was most challenging when the participants perceived that the NSHPs lacked the "operant resources" and expertise to meet their care needs. This represented a shift in the perceived power dynamic between service-user and professional, and challenged the idea of expertise amongst healthcare professionals. This was especially related to trust, relational exchange and social capital, which was not acknowledged by NSHPs.

The findings of this study recognised coproduction as a concept, in terms of a complex process of decision-making, partnership, trust, relational exchange, autonomy and value-creation, between the participants and the SHP. In this study, these factors emerged as the cornerstones of contemporary coproduction theory. However, there was some conflict in the relationship between the participants and the SHPs, and it is relevant to recognise the impact of the structural barriers upon a coproducing relationship. These were related to the difficulties in the implementation of care at home, due to limited "operand resources", and fluctuating social capital. In this study the participants' feelings of isolation and marginalisation were made worse by the distance (whether physical or metaphorical) from family, friends (Rod, Malcolm, Keith) and their SHPs.

In terms of the principals of coproduction outlined in this study, the relationship between the SHPs and the participants was paradoxically aligned to the historical, paternalistic, bio-medical model of care; in the absence of adequate outcome measures (Morgan et al., 2012, Keast et al., 2015, Moffatt et al., 2021b). The participants had to focus upon aspects of their lymphoedema care that they defined as important, given the contextual and structural barriers to their care. This combined with the lack historical lack of consistent definitions (Herpertz, 2001, Moffatt et al., 2003, Williams et al., 2004, Morgan et al., 2012, Keast et al., 2015, Moffatt et al., 2017c, Quéré et al., 2019, Moffatt et al., 2019c) made chronic oedema/lymphoedema a relevant example, for service-users inconsistently navigating the health care system.

This study demonstrates that coproduction can occur despite the unequal power dynamic within the relationship between the SHPs and the participants (Batalden et al., 2016). The common tenet, throughout the coproduction literature reviewed, was that to genuinely benefit from value creation and relational exchange through a coproducing relationship, there should be minimal hierarchy (Bovaird, 2007, Palumbo, 2015, Palumbo, 2016, Palumbo et al., 2016, Palumbo and Manna, 2018), or that there should lower “power distance” (Chan et al., 2010, p.52). Moreover, the hierarchical distance between these participants and their SHPs, could be perceived as contrary to the principles of coproduction (Bovaird, 2007, Palumbo, 2015, Palumbo, 2016, Palumbo et al., 2016, Palumbo and Manna, 2018). However, this opposition did not prevent coproduction from taking place. In this study, the cocreation of value, through the relationship between the SHPs and participants, was what determined successful coproducing activity. Furthermore, the majority of these participants described a positive, pro-active, valuable, accountable relationship, as defined by Bettencourt et al. (2002).

The interpersonal interactions, and relational exchange observed within the observations, and described in the interviews, mitigated and deflected some of the structural issues regarding hierarchy, power, social capital and choice. Moreover, the notion of power and hierarchy, was most challenged in terms of the NSHPs, and their perceived lack of “operant resources”. Coproducing care was challenging when NSHPs were perceived as lacking “operant resources”, and fear led to the participants’ reliance upon “default expertise”. Default expertise was the strategy participants described and assumed, to cope with the fear, operationalised in terms of their routines and rituals. Whilst some, were based on appropriate skills and knowledge, others were based on superstition and lay belief. These were the drivers which led the participants to coproduce care, and where findings from both the observations and the interviews gave critical insight into the perpetuation of the hierarchical dynamic.

Implementing coproduction within public services will always be a significant challenge, if there has to a complete absence of a power imbalance due to the system of care within the NHS. This study demonstrated that even when this power distance and dynamic is unavoidable, the potential for coproducing relationships; and the generation of social capital between the participants and the SHPs, is possible.

9.2.3 Social Capital and Economic Capital

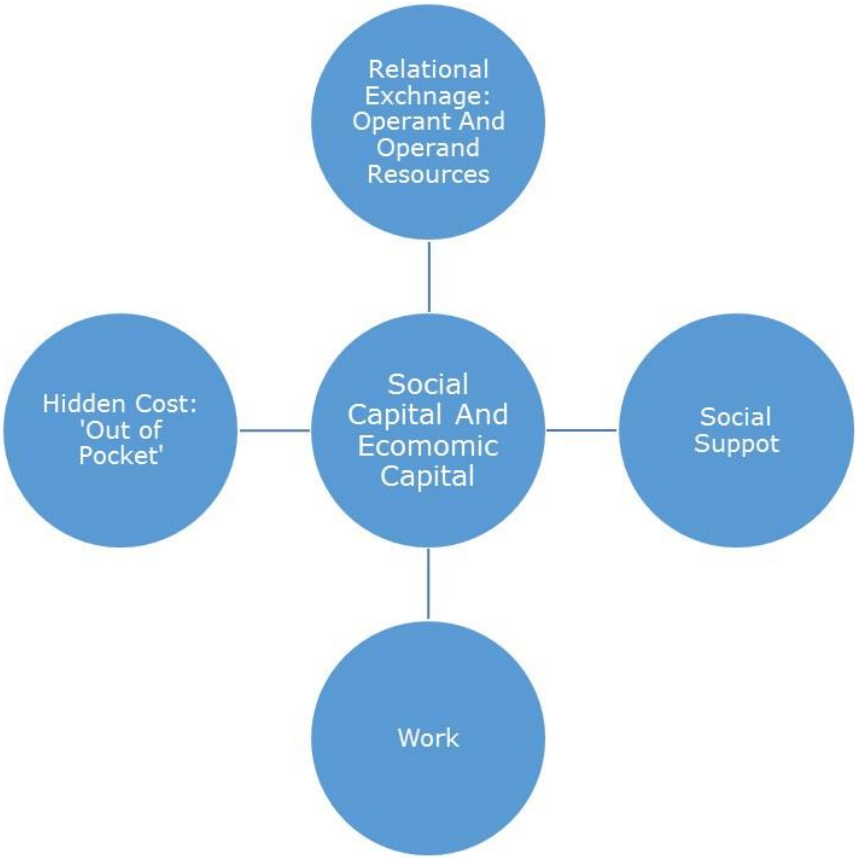


Figure 20: Social Capital and Economic Capital

Social capital (Figure 20), within the context of this study was related to relationships with the clinical team delivering care and the relationships which exist at the domestic level (home). These often nurtured positive relational exchange, and demonstrated how the SHPS influenced and negotiated the implementation of treatment and care. The participants described and demonstrated that they owned the “operant resources” (knowledge and skills) to coproduce care, however it was their “operand resources” (socioeconomic context) which prevented full implementation of care at home. Despite this challenge, many of the participants were innovating their own care, through adapting elements of their daily life to mitigate these challenges. Many of the participants expressed their frustration at the limited opportunity for significant improvement, reflected in the limited treatment outcomes (reduced risk of infection, reduced swelling). Many of the participants also reported that the "relational exchange" and the exchange of "operant resources" and "expertise" was what created value.

This revealed a relevant finding in this study, which was that through the long-term relationships the participants established with the SHPs. Their interactions created value and social capital for the participants, despite the recognition of a hierarchical structure. This is less considered in terms of the existing coproduction definitions and it is an important aspect when discussing the cocreation of value between the SHPS and the participants. This was especially important as most of the participants hoped for a cure and control, which they knew was not be possible when faced uncertainty with the uncertainty of an LTC.

The cocreation of value within their relationship was critically important, especially regarding trust and satisfaction with the care they received; even loyalty in terms of "sticking with treatments" (Dwyer et al., 1987, Bettencourt et al., 2002, Wu et al., 2013, Fledderus et al., 2014). Furthermore, a positive relational exchange was critical in terms of influencing the lay health beliefs, routines and rituals and "default expertise" (Collins, 2014, p.15) of the participants. This is especially when they felt they had no locus of control or their anxieties regarding complications increased. It is therefore important to recognise what service-users define as meaningful, and how they perceived the absence of real choice in treatment, and their reliance upon significant others for support. The experience of isolation described by many of the participants demonstrated their feelings of marginalisation. This deepened their sense of being misunderstood by others, and the social stigma they experienced because of the appearance of their lymphoedema, and dependence upon significant others. The complexity, at the interface of implementation of care at home, cannot be underestimated; many of the participants valued the a “supportive social atmosphere” (Song, 2013, p.9) of the clinics, the yoga and swimming, which supports existing research (Wei et al., 2019, Wanchai and Armer, 2020, Sneddon and Lewis, 2007). This was both in the sense of being with others who understood their experience, and time away from feeling dependent upon significant others, and the SHPs

Whilst the participants viewed the SHP as an authority on lymphoedema, the coproduction of care was challenged when access to treatment options and choice was perceived as limited. This was in terms of a perception that the healthcare provision “outside” of the SHPs care, did not meet their needs for example, requiring antibiotics as an outpatient, or attending for treatment when they could not afford transport. However, many of the participants perceived these as circumstances beyond the control of the SHPs, because of the trusting and reciprocal relationship they described.

Despite these challenges, it was interpreted that socioeconomic status, as described by these participants, did not prevent them from coproducing their care, in terms of “operant resources”, skills and knowledge. All the participants described the appropriate skills, knowledge and health literacy to coproduce care, and engage in shared-decision making. However, there were more complex factors which affected whether they chose to coproduce their care; for some participants it was a choice, to engage with implementing care which made it very difficult to remain financially secure (work and "out-of-pocket" costs".

The most prevalent issue for all the participants, regardless of where they perceived their socioeconomic position, were the hidden costs. This was predominantly described as the constant financial burden of the condition, whether the cost of essential items (shoes/clothing) or the costs incurred by being out of work, "off sick" or retired. The other hidden costs were to self, identity, biographical disruption and stress and anxiety, and these were not mitigated by the positive relational exchange with the SHPs. The findings from this study demonstrated how the participants learned to live with their lymphoedema, and how they implemented care at home, when lacking financial "operand resources".

The limited findings of the postcodes and the GP surgeries demonstrated that these participants all lived within areas of the city and the rural setting considered to be significantly socially deprived, and this is well documented in much of the SDH health literature. Moreover, the findings of the in-depth, face-to-face interviews suggested that the participants' experience of socioeconomic deprivation was not only their geographical location. It was related more to the impact this hidden condition has on their living circumstances, the strain and pressure it puts upon the participants, because of the "domino effect" many described. The combination of not being able to work or retiring due to ill-health placed an inordinate amount of emotional strain upon many of the participants and their significant others. This was exacerbated as their lymphoedema remained static or worsened, leading to an increased risk of comorbidities, which led to further "out-of-pocket" or unforeseen expenses. This effect of this was most clearly when the participants described they were not able to fully operationalise the agreed care at home because the constraints of their "operand resources".

Moreover, a further consideration was if it is possible for SHPs and participants to genuinely coproduce care if they are attending clinic twice in 12 months, and as Lehrer et al. (2012) suggest, this may not lead to a positive experience of co-implementing care. However, for these participants the relational exchange was the most important factor in the coproduction of care, for these participants the social capital, which was created with the SHP, became the predominant "operand resource"; for some participants this positive experience mitigated the difficulty of implementation of care at home.

9.3 Conclusion of the thesis: A Framework for Coproduction

The findings of this study support the NR, in suggesting that the concept of coproduction is difficult to define and conceptualise. The 'wicked problems' presented by definitions of coproduction and chronic oedema exemplify conflict, as the experiences of participants interacting with healthcare professionals in this study extend beyond the usual definitions of coproduction. This justifies why we might consider both 'wicked problems' (Rittel and Webber, 1973, p.155), in terms of their unique difficulties with definition, and as symptom of larger societal issues, in particular health inequality.

A key finding in this study, which explored the coproduction of care, reflected through relational exchange, trust, development of skills and knowledge, and shared-decisions, as a model of coproduction across the context of LTC care between “hospital” and “home”. Although the participants engaged in self-care within the home setting, much of their interaction with SHPs was based upon a traditional, hierarchical and biomedical model of care. Structural hierarchy and power remained with the service-providers, whether GPs, NSHPs within the acute care setting, or SHPs, at the Lymphoedema Clinic.

This approach was not always well aligned with the day-to-day work of participants, which involved balancing the unpredictability of their lymphoedema with and self-management. This was all against the desire to maintain normality, and achieve the goals that were important to them in their everyday life. Furthermore, it must be recognised that the absence of “operant” amongst health professionals, or “operand” resources amongst the participants limited the full implementation of the coproduction of care. The findings suggested that the skills and knowledge used to make discreet decisions, about aspects of care which could and could not be implemented at home, was significantly dependent upon the participants’ socioeconomic circumstances. Socioeconomic position was described as significant barrier for implementing care at home, especially regarding being out of work, retired and the “out-of-pocket” costs incurred.

The mitigating factor for many of the participants was the social capital and network of support they had through the SHPs and their significant others; this evolved as their operand resource, in terms of trust and reciprocity and the tangible effect of co-implementing and co-delivering care. The context of this study demonstrated that the participants depended greatly upon the social capital and networks of support, from their significant others and their SHPs. Furthermore, the SDHs and socioeconomic factors did influence the decision-making strategies and coproduction of care, for service-users living with chronic oedema, in terms of the adaptations they must make to deliver their care at home.

Exploring the experiences of service-users within healthcare through the conceptual lens of coproduction was a relevant study to undertake. A number of these participants described that their long-term relationship with their SHP, and their interaction was perceived as a place of value co-creation and reciprocity within their relationship. Moreover, these inferred that the participants also perceived the SHP with a sense of reverence; their hierarchical relationship represented the part of their existing belief system, in terms of the expected relationship between SHPs and service-users. This was evident throughout the observations, and the participants demonstrated and described genuine value from their interactions, which a number confirmed during their interviews.

This is a complex issue and does not align to traditional definitions of compliance, concordance, adherence or self-management, which imply a value-judgement by the SHPs, as demonstrated in the findings from the non-participant observations. This is where the concept of coproduction is problematised in terms of what this means in practice, and this study questions whether ‘concordance’ is realistically achievable. This is not least when the treatment options available are perceived by service-users as limited, restrictive, time consuming with outcomes that demonstrate little meaningful opportunity for improvement.

This is even more pertinent when considering the discourse around LTCS, "cure" and the reality that some service-users perceived the implementation of care, as a futile effort despite, a positive relationship with the SHPs. Moreover, this relationship only partly mitigated very challenging circumstances for some service-users; it cannot be assumed that even when shared-decisions are made, that service-users can or will implement prescribed care.

Therefore, it is important to recognise that shifting power to the service-users, individually and collectively, and by increasing the levels of service customisation and control (within the home) may lead to better outcomes; whether clinically or experientially (Chan et al., 2010, p.52). This study demonstrated that many of the reasons for this are external to the "life" within the clinic, due to practical challenges and limitations, or the conflicting goals or beliefs service-users and the socioeconomic burden. This is where social capital, social networks and support to implement care at home is important, and whilst ever chronic oedema is unrepresented or marginalised as an LTC, this issue will remain a "wicked problem".

This study has demonstrated, through the social constructivist perspective, the methods used, and the analysis of the data that a valuable and genuinely rewarding relationship can exist between service-users and SHPs. Whilst this PhD was positioned within an Implementation and Improvement Science, it has also highlighted the challenges for service-providers, within the context of care in which the existing chronic oedema service is delivered. The study identified the need to eliminate organisational barriers, to increase quality and value. Therefore, coproducing activities with service-users and service-providers can identify how "organisational health literacy", (Brach et al., 2014, p.274) can be improved, and develop and "explicit consumer strategy" (Etgar, 2008, p.105). These will underpin how pathways of care can be developed, and how patients can influence service-design, as a "co-creator", "co-initiator", "co-designer" and a "co-implementer" (Voorberg et al., 2015, p.1347), using principles and methodology promoted within Implementation and Improvement Science. The conclusions of this study demonstrate that a model of coproduction is also relevant to facilitate how service-providers need to evaluate services; to put research findings, which are not only randomised-control trials and observational studies, into practice; and to measure success and sustainability (Damschroder et al., 2009, Tansella and Thornicroft, 2009, Bergman et al., 2015).

This will only happen by confronting the disingenuous perceptions of coproduction and patient involvement (Ocloo and Matthews, 2016, Ocloo et al., 2021), which perpetuates; the perceived lack of equality, diversity and inequitable power dynamic. The findings of the NR suggested that many contemporary studies of coproduction, within healthcare, focus largely upon planning and design of services. The findings of this study indicate that by exploring coproduction at the point of implementation, key factors such as the impact of service-users' economic status and the implementation of treatment at home, rather than a focus upon disease. Uncovering this new knowledge, through the use of the research methods applied in this study, have identified factors that suggest coproducing with service-users is a sound way in which they can inform service-design.

In this thesis I have set out to discuss if and how coproduction is operationalised in the context of ongoing care across “hospital” and “home”; how socioeconomic position and social capital impact upon coproduction in this setting; and how social capital, trust, accountability, responsibility, social networks and reciprocity are essential between service-user and SHP to operationalise the coproduction of care, despite the hierarchical power dynamic. This study emphasises the relevance of Implementation and Improvement Science, and the MRC’s perspective on new or complex interventions (Craig et al., 2013); the importance of identification and consideration of the relationship between services; the context in which they are planned and implemented; and the needs of service-users who will access them (Tarrant et al., 2014). Therefore, any recommendations for practice and future service development must recognise these. The conclusions of this study suggest that this can be genuinely achieved through a model of coproduction and relationship centred-care.

In conclusion, whilst this study is not the first to translate coproduction to a health context, it is a novel exploration of coproduction at the interface between healthcare and the community for people living with LTCs. The contribution of this study presents a challenge to contemporary coproduction literature, which suggests that those most likely to be involved with successful coproduction are more educated, higher socioeconomic status and affluent. Whilst these factors need to be acknowledged, in terms of how service-users described their socioeconomic status, they did not define service-user engagement, or the value within the coproduction of care. This research reveals the specific factors which need to be present for the coproduction of care, to be operationalised. Therefore, rethinking coproduction, within healthcare settings, will go some way to preventing the hierarchical dynamic from being a barrier to the implementation of care.

10 Strengths, Limitations and Recommendations for Clinical practice and service re-design, and suggestions for further research

10.1 Chapter overview

Here I discuss the strengths and imitations of the study, the recommendations for practice, in terms of PPI, Service re-design, policy making and Training and education, and for healthcare professionals; suggestions for further research, both in terms of chronic oedema, and more generically; and the strategy for dissemination of findings

10.2 Strengths

The strengths of this study are reflected in the way that this PhD was positioned within Implementation and Improvement science, the constructivist perspective and the methods of data collection chosen. In the introduction, I stated the need to identify the interplay between healthcare and the context of the environment/organisation in which they are planned and implemented (Greenhalgh et al., 2008), and the service-users who will access them. A strength of this study is that I achieved this, using a mixed methods approach, which is recognised as relevant and appropriate within healthcare research (Craig et al., 2013). The overt non-participant observations enabled me to observe the interactions, both verbal and non-verbal, between the SHPs and the participants, and explore the dynamics of their relationship, which would not have been apparent if I had only undertaken interviews. In addition, I was able to observe this interaction within the clinic environment, in terms of how this impacted upon care delivery, specifically within the space they occupied.

By using in-depth interviews, I was able to appreciate and reflect the reality of the participants' experiences, as they talked me through the story and journey of their care. This included how they described their experience of the socioeconomic impact of living with chronic oedema. This study demonstrated how the non-participant observations and the in-depth face-to-face interviews, led to the emergence of rich data, which would not have been realised if using one or other on their own. Despite the limitations of the postcode data, which are discussed later, the decision to include this aspect of the study was justified; it confirmed that at the time of the study the service-users attending clinic and living within the postcode areas of the city (Site 1), resided in a geographical location which was within the top 10% of the most socially deprived cities of the UK. In addition, the findings of the study demonstrated the rigorous process undertaken during the analysis of the data, including the iterative and reflexive process I adopted, and the separate analysis of transcripts by two of my academic supervisors.

The recording of participants' demographics supports the themes which emerged from the participants' narratives. Together, these offer important insights regarding the effect of chronic oedema upon the lives of these service-users. Furthermore, the diversity of the sample demonstrated the heterogeneity and complexity of this group of service-users living with chronic oedema. This included participants from BAME background; of working age and retired; those with cancer and non-cancer related lymphoedema; those with complex primary lymphoedema; and participants who were living in specific parts of the region, known to be significantly disadvantaged. Whilst these findings may not be generalisable, a strength of the study’s methods and findings, is that it provides insights which could be translated across to those living with under-researched LTCs and underrepresented groups engaged in the coproduction of care.

10.3 Limitations

There are also limitations to take into consideration regarding this study. Firstly, it is important to consider the limitations of constructivist, mixed methods perspective where the combination of qualitative and quantitative data collection methods aimed at representing service-users’ individual reality and experience. This was acknowledged and addressed in Chapter 3. However, there remains a criticism that a constructivist perspective is incommensurable with a quantitative approach, which seeks to generalise about the social world. This is in terms of how data was integrated, and that observation and interviews are incommensurable, and that my presence as a researcher may alter the interpretation of reality by being present.

The data collection methods for the postcodes and GP surgeries were significantly limited as the REC only gave permission to use the partial postcode. This affected the analysis of the postcode data in terms of identifying the exact geographical location of participants. This is a significant factor, which made analysing the data challenging, even when using GeoPunk, the LADs, and the ISD. Although the findings of the postcodes and GP Surgeries, indicated grouping of service-users within geographical areas considered as socially deprived on the ISD, no assumptions can be made about whether the service-users were individually socially deprived. I was not able to identify the GP surgeries, who were referring the most service-users, due to the absence of the last two letters of the postcode, as potentially some of the service-users attending the clinic were recurrent attendees.

It must also be acknowledged that the sample of service-users' postcodes was small in comparison to the numbers of potential attendees at the clinic. The clinic staff completed the documentation and they reported that there were frequent times when this could not be completed because of their time constraints and busy clinical workload. This was also because they had to access the paper notes or the hospital electronic system to find the GPs. Furthermore, the participants were only recruited from one geographical area, and from only two of the three lymphoedema clinics in this region.

The recruitment of the participants to observation and interview also depended upon the SHPs, and therefore participants were only recruited if the SHPs made an initial approach. Whilst my intention was for purposive sampling and extreme-case sampling, this is also an example of "gatekeeping". The sample of participants recruited was skewed to the more challenging extreme; there were few if any participants who demonstrated that they believed to have "control"; and a very minimal number who had a diagnosis of primary lymphoedema. I was also prevented from observing any participants who were attending their first appointment. In addition, I did not attend any home visits with the SHPS; although 2 participants were identified, they were both later admitted to hospital for emergency care.

During the non-participant observations I was not able to attend any of the service-users first appointments interviews due to these being described as "too busy". Further exploration of this may have been worthy, however I explained in Chapter 4.2 why I chose not to address this at the time. Although many of the participants reflected upon their experience of their first appointment during the non-participant observations and the face-to-face interviews, there were other insights to observe at first diagnosis, including the dynamic between the SHP and the service-users. Whilst the recruitment did fulfil the extreme case sampling I hoped to achieve, it did not reflect the known heterogeneity and diversity of individuals living with chronic oedema, who are reflected in contemporary chronic oedema literature.

Posters were taken to some GP surgeries, however this did not lead to the recruitment of any self-selected participants. Individuals who were diagnosed with lymphoedema and not accessing the Care at the Lymphoedema Clinic; or were accessing care via community and practice nurses; or not accessing care from any health professionals may have offered a different perspective, of implementing care at "home" and the challenges this might highlight when not receiving the care of SHPs.

Only one participant was recruited via the support group, and only one participant agreed to take part in a follow-up interview; and none of the participants recruited resided in residential or nursing homes. I recognise that some of these limitations could be addressed in further study, whereby participants self-recruit, for example it the study was advertised more widely on social media platforms (Twitter). In addition, these specific methods meant that it was not possible to make any assumptions about the specific or individual socioeconomic status of these participants other than what they disclosed during the interviews.

10.4 Recommendations for Clinical practice and service re-design

These findings of the study provide innovative and valuable insights, which translate across to other service-users with chronic oedema and those with underrepresented LTCs, in similar settings. In addition, there are opportunities for service development which include, PPI, Service re-design, policy making and Training and education, and for healthcare professionals

10.4.1 Coproducing: Patient and Public Involvement for Service re-design

This study identifies the need for designing effective service delivery for those with underrepresented LTCs, and chronic oedema was explored as one example, within an area of socioeconomic deprivation. The findings of this study recognise the "wicked problem" (Rittel and Webber, 1973, p.155) of coproduction, and this enables a number of recommendations to be made in terms of addressing the issues for service-users. This includes PPI events, which use a model of coproduction to enable service-users and their significant others to be genuinely involved in designing pathways of care, which will meet their needs. These could include consultation events, whereby service-users, specialist service providers and primary care work together to identify key priorities for service delivery.

This would lead to the formalisation of a coproduction framework which integrates the principles of coproduction, suggested in the thesis, into an assessment framework for health professionals and service-users. This would be appropriate when developing service-provision, across the integrated care system (Primary, Secondary, Tertiary and Social Care). This would be influenced by findings from the thesis, which suggest that many issues for service-users occur at the point of referral, the knowledge and understanding of NSHPs, and the implementation of care at 'home'.

These coproduction events would lead to a process of service-redesign. An example of this could be a patient conference, which uses the principles of the James Lind Alliance (JLA) Priority Setting Partnership (PSP) (James Lind Alliance, 2021) to focus upon chronic oedema. These principles are usually directed at research priorities; however, I suggest that they are useful as a framework for service re-design. This would enable service-users, significant others, carers and health professionals to work together on an equal basis; to explore challenges around service provision which are important to all members. They would coproduce and prioritise known challenges, with the consensus of all and produce a ranked list of service priorities. This would enable service users to directly influence the decisions made regarding their care needs. Furthermore this reflects "co-creation" in terms of the planning, design and delivery of service innovation, as a "co-initiator" or "co-designer" (Voorberg et al., 2015, p.1347).

It is key to recognise that this approach is adaptable to all LTCs, not only chronic oedema, and particularly those which are underrepresented within the public sphere. This will generate sound evidence, which demonstrates the value of coproducing programmes, which are designed with robust measurable outcomes to ensure their success and sustainability. It also enables the genuine opportunity (Ocloo and Matthews, 2016) for the development of professional skills amongst non-experts, which contributes to addressing structural barriers and the culture change required, as suggested by Bovaird and Loeffler (2012), and which aligns to an improvement/implementation science approach.

10.4.2 Recommendations for clinical practice

The recommendations for clinical practice should demonstrate how care can be implemented using coproduction frameworks, which recognise the cogent aspects of coproduction theory identified in this study, social capital, trust, accountability, responsibility, social networks and reciprocity. This includes operationalising a model of care for chronic oedema and other LTCs, which also reflects service-users' psychosocial and socioeconomic needs, in addition to clinical needs. This may also include business plans to economically evaluate the cost-effectiveness of "outreach" or mobile chronic oedema services, which are aimed at the implementation of "clinics" within service-users' homes.

It is also relevant to consider greater development of multi-disciplinary "combined" clinics whereby NSHPs and SHPs coproduce care with service-users with chronic oedema, and other LTCs. This may mean "combined" in terms of multiple service-users who describe similar experiences, or "combined" in terms of health professionals, across several clinical specialties, such as mental health services, physiotherapy and occupational therapy.

The study identified, through the narratives of the participants, the benefits of "social prescribing" and "affective resources", such as yoga and swimming. Therefore, these should form an embedded part of care provision, including gym memberships, weight loss programmes, and online forums, as an intrinsic part of pathways of care (primary, secondary and tertiary) for those living with LTCs. This is especially for service-users recognised as at risk of health inequality, and those living within geographical locations identified as high on the UK Indices of social deprivation, and who may require financial support to access these initiatives.

This also includes coproducing with service-users and their significant others, social media groups, online forums, or café style meetings, to provide support to those diagnosed with under-represented LTCs. Embedding practical support into all aspects of care for those with chronic oedema or underrepresented LTCs is one of the main findings within the study in terms of a lack of socioeconomic resources. This is where formal "advocates" support service-users, who may be eligible to apply for PIP, financial benefits, and bursaries and grants; reductions in social payments, for example Council Tax; and applications for the disability "Blue badge". This includes the opportunity to discuss and action practical solutions related to remaining in employment, and/or planning for retirement.

10.4.3 Recommendations for policy makers

There is a need for programmes of work using PPI and coproduction principles, to work with service-users and SHPs to influence and educate policy makers regarding the physical, psychosocial and socioeconomic impact of living with chronic oedema. This would specifically look to outline the financial cost to service-users when implementing care, in addition to the financial burden to the UK health service, and not only the cost of service provision. This could include a review of health authorities and commissioning groups to ensure that services are strategically positioned within locations service-users can access. This would enable opportunities for implementing services within those affected communities could be optimised. Examples of this are services re-located within community centres, or non-healthcare settings.

Furthermore, this includes using the principles of Improvement and Implementation Science to support programmes of work which also use PPI and coproduction to improve "organizational health literacy" (Brach et al., 2014, p.274) and to formally recognise chronic oedema/lymphoedema as a LTC (Department of Health, 2012). This is to work with service-users and SHPs, to influence and educate pathways of care which fully scope the physical, psychosocial and socioeconomic impact of living with chronic oedema. This also includes identifying key measurable, clinical outcomes, which are important to individuals and their significant others. This includes creating opportunities to coproduce care provision with the National Wound Care Strategy Programme, the Department of Health which could influence, the NHS Long Term Plan, The NHS Outcomes Framework Indicators and (NHS Digital, 2021, NHS, 2019, Department of Health, 2012)

10.4.4 Training and Education for healthcare professionals

This study demonstrated a lack of overall "organisational health literacy", (Brach et al., 2014, p.274) for the participants living with chronic oedema in this geographical location, despite there being a service considered a centre of excellence for chronic oedema care. This also aligns to the finding regarding a lack of “scientific capital” (Bourdieu, 2004, p.55) in terms of knowledge and awareness regarding chronic oedema, and concerns regarding the development of “expertise”. Therefore, there are several issues which should be addressed. The first is in terms of overall awareness regarding chronic oedema. One way to promote this within the public sphere would be to ensure that there is standardised training and education for health professionals, which is developed using a coproduction framework and uses the principles identified by the James Lind Alliance (2021). This would ensure that service-users and SHPs jointly identify the topics to be covered, which involve the principles of evidence-based care; patient preference and acceptability, clinical expertise and well conducted research findings (Bath-Hextall, 2010)

This approach also means addressing the deficit in the knowledge of health professionals regarding the use of coproduction principles to work with service-users and their significant others. This seeks to define the cogent principles of coproduction within health care; and describe how to use the principles of coproduction, in the design and delivery of care for service users with chronic oedema, and other LTCs. This includes an overview of the barriers and enablers to coproduction, and practical guidance in terms of how these might be addressed, particularly for those living with underrepresented LTCs, within a context of social deprivation. This could be used across the integrated care system, especially for those living newly diagnosed with LTCs and the NSHPs, with whom they may access care.

10.5 Suggestions for further research

Recommendations from the MRC suggest that it is important to understand existing evidence, existing theoretical perspectives and a modelling approach for complex evaluations (Craig et al., 2013). Further inquiry is necessary to explore fluctuation in the engagement and motivation of service-users, to ensure that the provision of future healthcare services meet their actual needs.

10.5.1 Priority research for chronic oedema:

These research recommendations may also include formal opportunities for service-users living with a diagnosis of chronic oedema, and their significant others, to be involved in identifying research priorities, with health professionals regarding chronic oedema, such as the activity of the James Lind Alliance Priority Setting Partnership (Thomas et al., 2017, James Lind Alliance, 2021). The research topics may include:

- The development and evaluation of a validated coproduction model of care for chronic oedema using the principles of improvement science
- The development and validation of service-user outcomes of care for chronic oedema, this includes factors such as the subjective experience of swelling
- Design of research to identifies and evaluates the socioeconomic impact of chronic oedema on service-users and their families (economic evaluation) using interviews and focus groups.
- Coproduction Research exploring underrepresented groups living with chronic oedema, including BAME groups; non-English speakers; those in residential carer; prisons. This would involve working with these groups

and their advocates to decide the methods of data collection.

- Mixed methods research into the further exploration of lay-beliefs, and symbolism for those living with chronic oedema, which includes interviews and focus groups, across a number of regional services; and a larger survey, based upon the findings which would be publicized nationally and internationally.
- Using Participatory Action research (Cawston, Mercer and Barbour, 2007), to involve service-users living with chronic oedema/underrepresented LTCs, to design and development, and implement of priority studies, including further studies regarding social capital
- Research into the experience of service-providers and SHPs coproducing care with service-users, which includes qualitative interviews and focus groups

10.5.2 Broader research priorities

There are several research priorities the findings from this study identifies. These include further empirical research which explores how significant others (partners, spouses, family, friends, carers) influence coproduction within healthcare settings; studies into social capital and the use of social media and the use of internet support groups for those living with marginalised, LTCs. Further research is imperative to understand the social and cultural contexts of service-users (Bovaird, 2007, Bovaird and Loeffler, 2012, Bovaird et al., 2015, Eriksson, 2019); why coproduction is a place of conflict; and to explore fluctuation in the engagement and motivation of service-users (Lehrer et al., 2012), to understand how the provision of future healthcare services meets their actual needs.

A significant issues which arose at the time this thesis was being written (2020-2021)during the Covid-19 pandemic, is regarding the priority for research into coproduction within healthcare, and the exploration of service-users with LTCs, who may be accessing care more remotely (Steen and Brandsen, 2020, Everett et al., 2021). A greater understanding of the challenges faced by SHPs caring for service-users with underrepresented LTCs. This may include a Delphi study approach, with experts in coproduction theory or health professionals caring for service-users with underrepresented LTCs.

10.6 Dissemination strategy

A dissemination strategy is designed to ensure that the findings from this study are effectively communicated to those living with chronic oedema and the healthcare community. The dissemination strategy includes:

- The presentation of findings during a plenary session at the International Lymphoedema Conference (ILF) (2022)
- Commissioned publications on the “wicked problem” of the coproduction of care (Lymphatic Research and Biology, 2022)
- Lay summary of findings to the participants living with chronic oedema
- Presentation at national conferences (UK)
- Present the findings to a dedicated patient conference for individuals living with chronic oedema (ILF)
- Sharing the findings with the medical devices industry to promote the importance of the aesthetics of compression therapy and improved choice

- Posting the recommendations from this research on appropriate organisations social media pages, for example NHS Trusts and relevant charitable organisations (with appropriate permissions).

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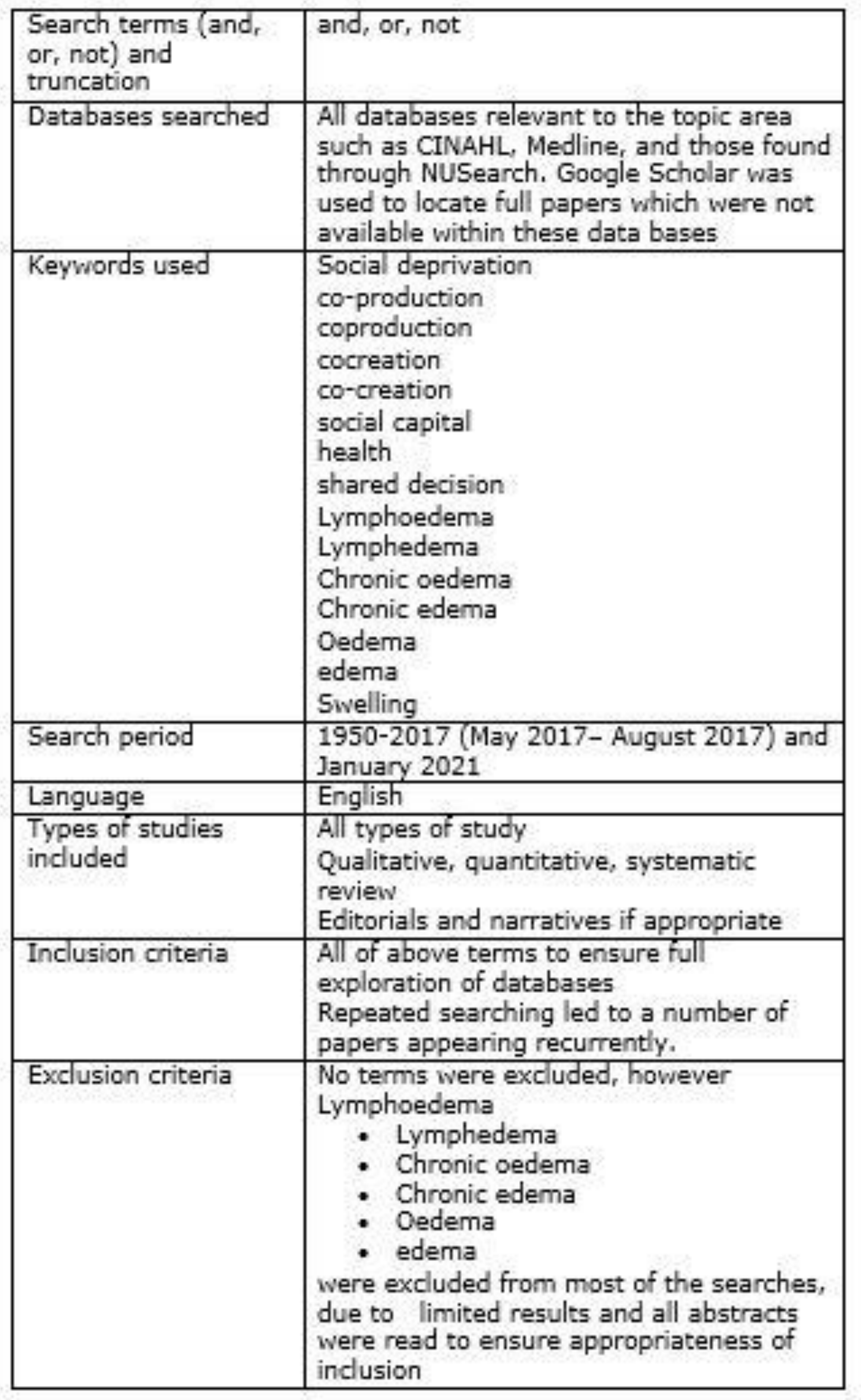
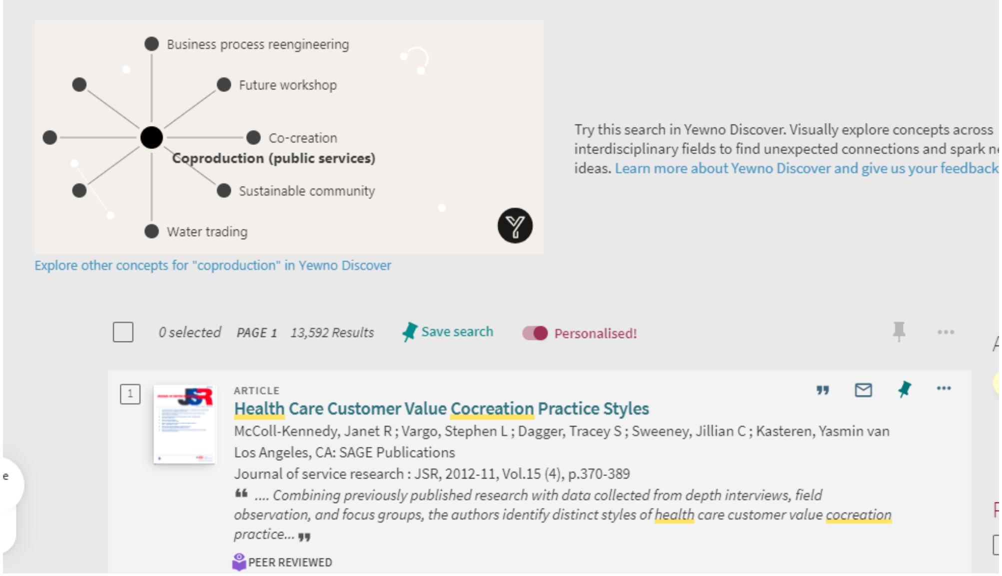
Appendices

Appendix 1: Search Strategy



Search terms (and, or, not) and truncation	and, or, not
Databases searched	All databases relevant to the topic area such as CINAHL, Medline, and those found through NUSearch. Google Scholar was used to locate full papers which were not available within these data bases
Keywords used	Social deprivation co-production coproduction cocreation co-creation social capital health shared decision Lymphoedema Lymphedema Chronic oedema Chronic edema Oedema edema Swelling
Search period	1950-2017 (May 2017– August 2017) and January 2021
Language	English
Types of studies included	All types of study Qualitative, quantitative, systematic review Editorials and narratives if appropriate
Inclusion criteria	All of above terms to ensure full exploration of databases Repeated searching led to a number of papers appearing recurrently.
Exclusion criteria	No terms were excluded, however Lymphoedema • Lymphedema • Chronic oedema • Chronic edema • Oedema • edema were excluded from most of the searches, due to limited results and all abstracts were read to ensure appropriateness of inclusion

Appendix 2: examples of searches with NUsearch



Try this search in Yewno Discover. Visually explore concepts across interdisciplinary fields to find unexpected connections and spark n ideas. Learn more about Yewno Discover and give us your feedback

Explore other concepts for "coproduction" in Yewno Discover

☐ 0 selected PAGE 1 13,592 Results

1 ARTICLE

Health Care Customer Value Cocreation Practice Styles

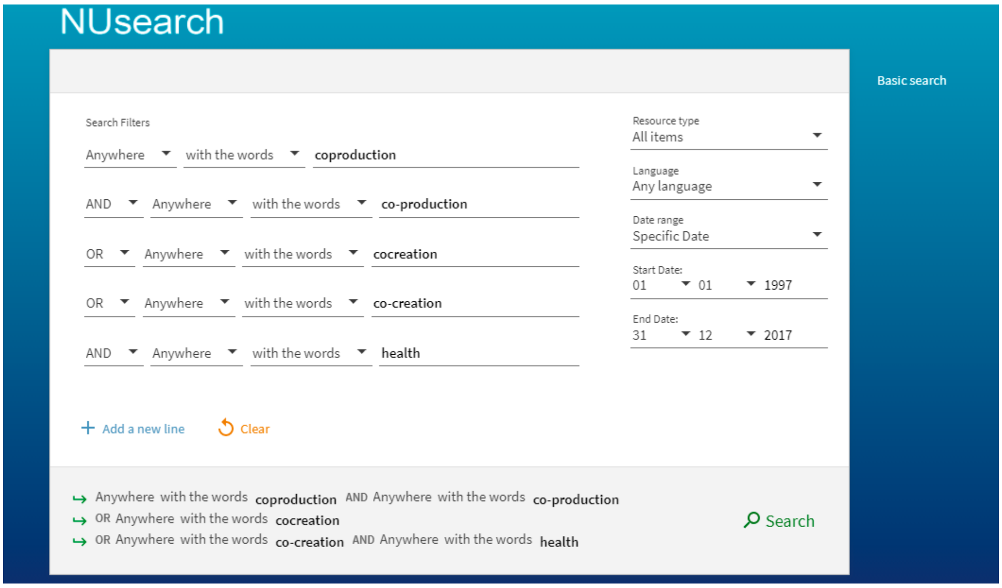
McColl-Kennedy, Janet R ; Vargo, Stephen L ; Dagger, Tracey S ; Sweeney, Jillian C ; Kasteren, Yasmin van

Los Angeles, CA: SAGE Publications

Journal of service research : JSR, 2012-11, Vol.15 (4), p.370-389

❝ .... *Combining previously published research with data collected from depth interviews, field observation, and focus groups, the authors identify distinct styles of health care customer value cocreation practice...* ❞

PEER REVIEWED



Search Filters

	Anywhere	with the words	coproduction
AND	Anywhere	with the words	co-production
OR	Anywhere	with the words	cocreation
OR	Anywhere	with the words	co-creation
AND	Anywhere	with the words	health

Resource type: All items

Language: Any language

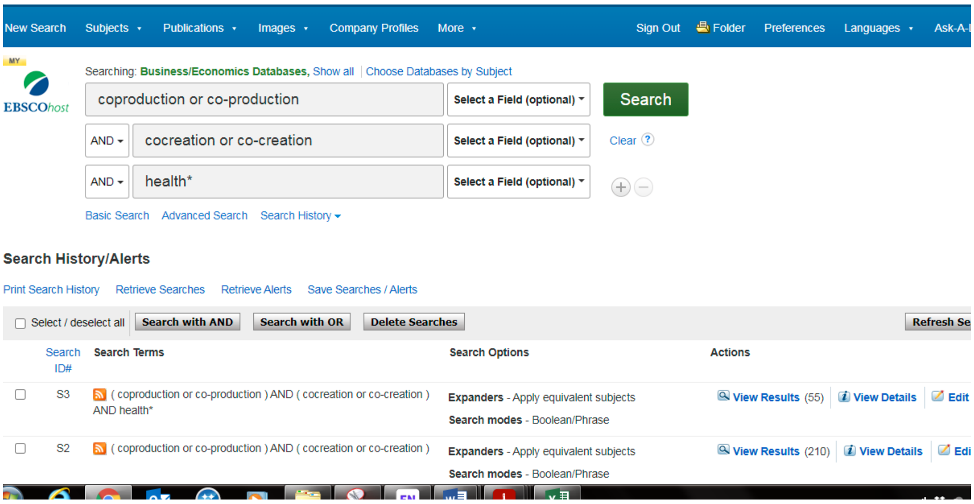
Date range: Specific Date

Start Date: 01 01 1997

End Date: 31 12 2017

Anywhere with the words coproduction AND Anywhere with the words co-production
OR Anywhere with the words cocreation
OR Anywhere with the words co-creation AND Anywhere with the words health

Appendix 3: Example of searches with EBSCOhost

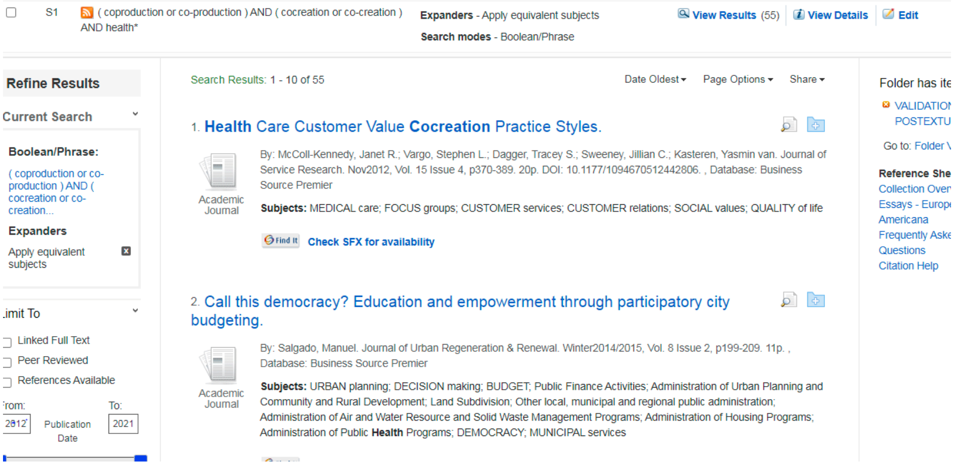


Searching: **Business/Economics Databases,** Show all | Choose Databases by Subject

	coproduction or co-production	Select a Field (optional)
AND	cocreation or co-creation	Select a Field (optional)
AND	health*	Select a Field (optional)

Search History/Alerts

	Search ID#	Search Terms	Search Options	Actions
☐	S3	(coproduction or co-production) AND (cocreation or co-creation) AND health*	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (55) View Details Edit
☐	S2	(coproduction or co-production) AND (cocreation or co-creation)	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (210) View Details Edi



	Search ID#	Search Terms	Search Options	Actions
☐	S1	(coproduction or co-production) AND (cocreation or co-creation) AND health*	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase	View Results (55) View Details Edit

Boolean/Phrase: (coproduction or co-production) AND (cocreation or co-creation...

Expanders: Apply equivalent subjects

From: 2012 To: 2021

Search Results: 1 - 10 of 55

1. **Health** Care Customer Value **Cocreation** Practice Styles.

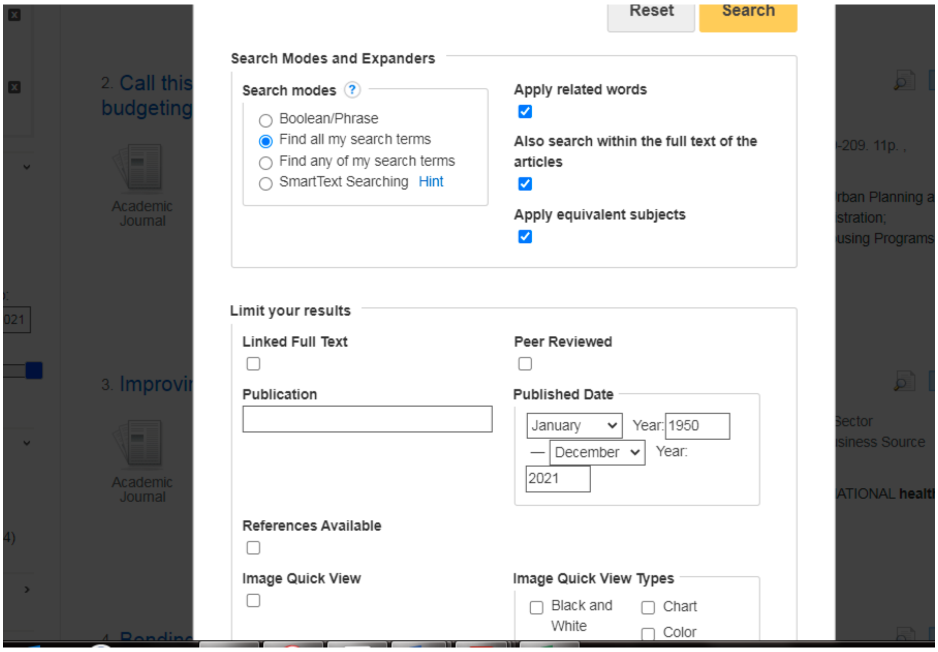
By: McColl-Kennedy, Janet R.; Vargo, Stephen L.; Dagger, Tracey S.; Sweeney, Jillian C.; Kasteren, Yasmin van. Journal of Service Research. Nov2012, Vol. 15 Issue 4, p370-389. 20p. DOI: 10.1177/1094670512442806. , Database: Business Source Premier

Subjects: MEDICAL care; FOCUS groups; CUSTOMER services; CUSTOMER relations; SOCIAL values; QUALITY of life

2. Call this democracy? Education and empowerment through participatory city budgeting.

By: Salgado, Manuel. Journal of Urban Regeneration & Renewal. Winter2014/2015, Vol. 8 Issue 2, p199-209. 11p. , Database: Business Source Premier

Subjects: URBAN planning; DECISION making; BUDGET; Public Finance Activities; Administration of Urban Planning and Community and Rural Development; Land Subdivision; Other local, municipal and regional public administration; Administration of Air and Water Resource and Solid Waste Management Programs; Administration of Housing Programs; Administration of Public **Health** Programs; DEMOCRACY; MUNICIPAL services



Search Modes and Expanders

Search modes ?

○ Boolean/Phrase
● Find all my search terms
○ Find any of my search terms
○ SmartText Searching Hint

Apply related words
☑

Also search within the full text of the articles
☑

Apply equivalent subjects
☑

Limit your results

Linked Full Text
☐

Peer Reviewed
☐

Publication

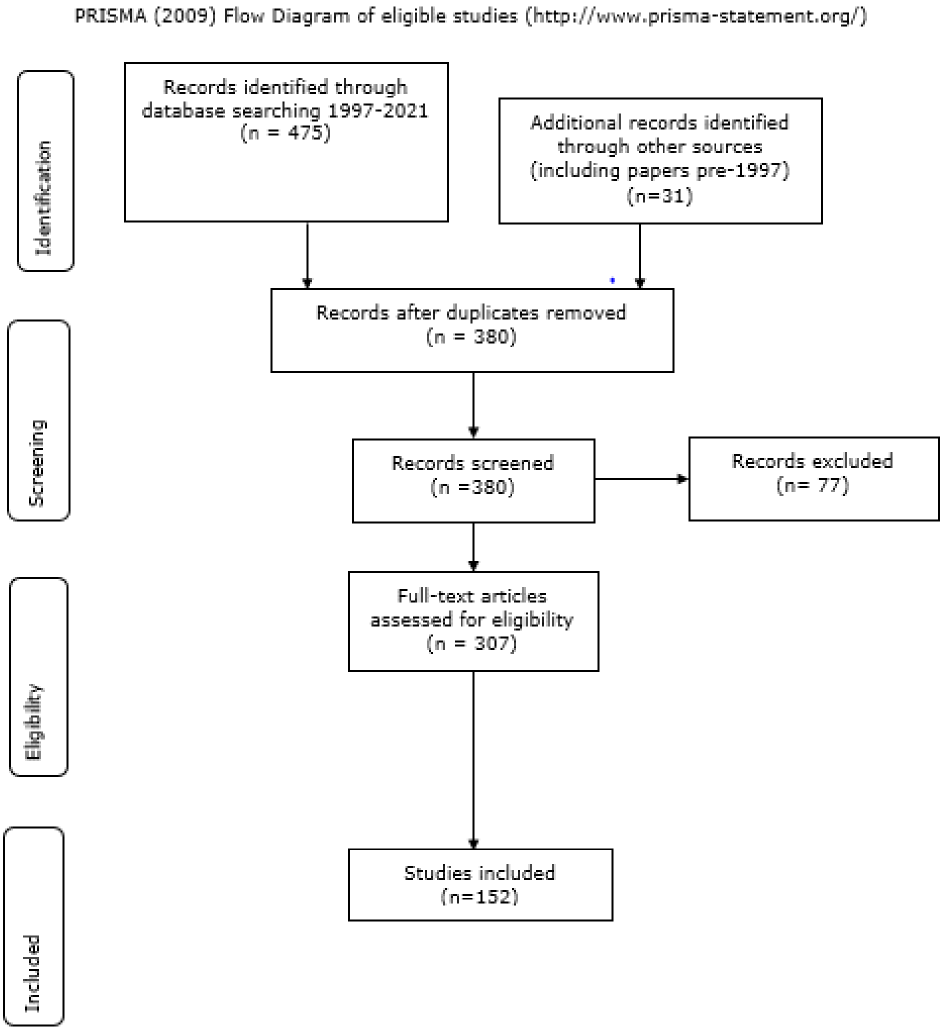
Published Date
January Year: 1950
— December Year: 2021

References Available
☐

Image Quick View
☐

Image Quick View Types
☐ Black and White
☐ Chart
☐ Color

Appendix 4: PRISMA (Moher et al., 2009) flow diagram of eligible studies



PRISMA (Moher et al., 2009, p.3)

Appendix 5: Selected Papers from the Narrative Review (Chronological)

	Date	**Authors**	**Study**	**Content**	**Theme**
1.	1973	Rittel & Webber	Original Paper	Original definition of “wicked problem” in planning and policy (Rittel and Webber, 1973, p.155).	Relevant Theory
2.	1979	Lovelock & Young	Theory Paper	Improving in service industries: 7 ways of how to counteract this by being sensitive to customer needs.	Coproduction/Marketing
3.	1979	Haynes	Book	Introduction to the book, defining the meaning of compliance in healthcare	Health/Theory
4.	1982	Holbrook & Hirschman	Theory Paper	Experience of consumption as a phenomenon directed toward the pursuit of pleasure, with a framework based upon typical consumer behaviour	Coproduction/Marketing
5.	1983	Brudney & England	Discussion Paper	An early proposed definition and concept of coproduction	Coproduction/Public Administration
6.	1984	Habermas	Book	The Theory of Communicative Action, Volume 1: Reason and the Rationalization of Society	Relevant Theory
7.	1984	Bourdieu	Book	Outline of social capital, habitus and the field	Social Capital/Theory

8.	1985	Porter	Book	“Value Chain” describes the chain of activities as product gains some value. (Porter, 1985 p.33)	Coproduction/Value
9.	1987	Dwyer, Schurr & Oh	Theory	Framework for developing buyer-seller relationships, which offers a viewpoint for developing marketing strategy and direction for subsequent research	Coproduction/Marketing
10.	1991	Fournier	Theory Paper	Typology/framework of consumer consumption	Coproduction/Marketing
11.	1991	Bandura	Theory Paper	Social cognitive theory of self-regulation.	Relevant Theory
12.	1993	Burgoon	Theory Paper	Key concepts and discussion of emotional communications and expectations within interpersonal relationships	Relevant Theory
13.	1994	Constantin & Lusch	Book	Guidelines for identifying internal and external resources and maximizing these resources for the overall benefit of the firm.	Coproduction/Business
14.	1994	Tresolini,	Report	Report of the Pew-Fetzer Task Force on Relationship-Centered Care (Tresolini, 1994, p.13).	Coproduction/Health
15.	1994	Morgan & Hunt,	Theory Paper	Effective cooperation that is required for relationship marketing success.	Coproduction/Marketing
16.	1996	Ostrom	Theory Paper	Original definition of coproduction	Coproduction/Business

17.	1999	Department of Health	Government Paper	Outlines the Patient and Public Involvement policy in the NHS.	Coproduction/Health
18.	1999	Ramirez	Discussion Paper	Framework for value co-production associated with industrial production.	Coproduction/Value
19.	2000	Prahalad & Ramaswamy	Discussion Paper	Engagement of customers for cocreation of value	Coproduction/Marketing
20.	2000	Summers & Tudor	Theory Paper	social constructivism, therapeutic relationships and the reality of narrative	Relevant Theory
21.	2001	Department of Health	Government Paper	Outline of the "Expert Patient Programme" (Department of Health (DoH), 2001) improve the length and quality of lives	Coproduction/Health
22.	2001	Makoul	Consensus Report	Report of the Bayer–Fetzer Conference on Physician and Patient Communication in Medical Education.	Health
23.	2001	Baxter	Discussion Paper	Habermas's theory of law, critique of Habermas "system" and "system/lifeworld" (Baxter, 2001, p.473)	Relevant Theory
24.	2002	Bettencourt, Ostrom, Brown & Roundtree	Primary Research	Co-production management model	Coproduction/Business
25.	2002	Alford	Discussion Paper	How governments can use positive coproduction	Coproduction/Public Administration

26.	2002	Amorim Lopes & Alves	Systematic Review	How antecedents of coproduction and organisational capability	Coproduction/Public Services
27.	2002	Gibbert, Leibold & Probst	Theory Paper	Five styles of Customer Knowledge Management (CKM) with examples (Gibbert, Leibold & Probst, 2002, p.459)	Coproduction/Value
28.	2002	Woods	Clinical Review	Using philosophy, knowledge and theory to assess a patient with lymphoedema	Theory/Lymphoedema
29.	2003	Orem	Electronic Book	Self-care theory in nursing selected papers of Dorothea Orem	Health
30.	2003	Moffatt, Franks & Doherty	Original Paper	Seminal work of definition of chronic oedema and determine the scale of chronic oedema in the community, and on use of health resources, employment and patients' quality of life with a Questionnaire-based survey.	Health/LTC
31.	2003	Trede & Higgs	Theory Paper	How practice knowledge, cultural and political influences clinician and patient relationships	Theory/Shared-Decisions
32.	2004	Vargo & Lusch	Theory Paper	The authors explore shift from goods to service as fundamental to economic exchange	Coproduction/Marketing
33.	2004	Prahalad & Ramaswamy	Discussion Paper	The interaction between the firm and the consumer as place of value creation and value extraction.	Coproduction/Marketing
34.	2004	Prahalad & Ramaswamy	Discussion Paper	The authors offer a DART model for managing co-creation of value processes (Prahalad &	Coproduction/Value

				Ramaswamy, 2004, p.6).	
35.	2004	Bourdieu	Book	Outline of scientific capital and reflexivity	Relevant Theory
36.	2005	Shepperd & Iliffe	Systematic Review	To assess the effects of hospital at home compared with in-patient hospital care. Twenty-two trials are included in this review, which concluded insufficient evidence of economic benefit	Health
37.	2005	Zarcadoolas, Pleasant, & Greer	Analysis Paper	An expanded model of health literacy characterized by four domains: fundamental literacy (reading, writing, speaking and numeracy), science literacy, civic literacy and cultural literacy	Health/Theory
38.	2005	Bourdieu	Book	The need to study the economy and society, in addition to cultural aspects of society with a multi-methods approach to the discussion of relevant economic phenomena	Relevant Theory
39.	2006	Lusch & Vargo	Discussion Paper	Attempt to understand service-dominant logic, greater understanding of value and exchange, within marketing. This includes a distinguishing between cocreation of value and coproduction and the new dominant logic of marketing	Coproduction/Marketing
40.	2006	Korkman	Thesis	Introduces a new approach to customer value creation, in service marketing, through an ethnographic study, of families on cruises.	Coproduction/Value

41.	2006	Chatterjee	Discussion Paper	Clinical ethics paper applying an understanding of compliance and concordance in diabetes care.	Health/Theory
42.	2006	Greenhalgh, Robb & Scambler,	Primary Research	Qualitative study of 69 individual interviews and two focus groups, between clinician, interpreter and patient within UK primary care. Exploration of Habermasian concepts which suggest that interpreted consultation rarely meet the preconditions for communicative action	Health/Theory
43.	2007	Bovaird	Review	Co-production offers potential improvements in outcomes, and cost savings but cannot produce value without money.	Coproduction/Public Services
44.	2007	Hogg	Discussion Paper	Historical effectiveness of PPI and argues issues from patient involvement in the 1970s are not resolved	PPI
45.	2008	Department of Health	Government Paper	Vision for the NHS, patient's involvement to reflect their needs and ensure equitable access to care; focus on quality and prevention of ill health.	Coproduction/Health
46.	2008	Etgar	Methodological Paper	A five-stage model of model of consumer engagement in co-production	Coproduction/Marketing

47.	2008	Needham	Primary Research	Reports a workshop case study involving social housing users and providers, to for genuine coproduction.	Coproduction/Public Services
48.	2008	Payne, Storbacka, & Frow,	Theoretical Paper	The authors explored value co-creation in the context of service-dominant logic; they developed a conceptual framework for understanding and managing value co-creation;	Coproduction/Value
49.	2009	Boyle & Harris	Discussion Paper	Argues for better understanding and foundation of coproduction theory, for reform of public services	Coproduction/Business
50.	2009	Dunston, Lee, Boud, Brodie & Chiarella	Discussion Paper	The application of coproduction healthcare	Coproduction/Health
51.	2009	Kaminsky, Rosenqvist and Holmström	Primary Research	A qualitative interview study of telenurses, with an understanding of their role as educators and detectives, delivering care to patients remotely.	Coproduction/Health
52.	2009	Cova & Dalli	Discussion Paper	Consumers active in the value creation socioeconomic and cultural factors suggest they contribute to economic value but that they do not benefit from this	Coproduction/Marketing
53.	2009	World Health Organization (WHO)	Report	WHO guidelines on hand hygiene in health care: first global patient safety challenge clean care is safer care,	Health

54.	2009	Petticrew, Tugwell & Welch	Discussion Paper	Better evidence about “wicked issues” (Petticrew, Tugwell, Welch et al., 2009, p.453) in tackling health inequities.	Health/Theory
55.	2009	Greenhalgh	Analysis Paper	Discussion of PPI from four perspectives regarding LTCs	PPI
56.	2009	Outhwaite	Book	Detailed critical analysis of Habermas, in particular lifeworld and communicative action	Relevant Theory
57.	2010	Chien & Chen	Primary Research	Taiwan Customer involvement.	Coproduction/Business
58.	2010	Department of Health	Government Paper	NHS Policy outlining the plan for patient-centred care, focus upon clinical outcomes and empowering frontline staff	Coproduction/Health
59.	2010	Freire & Sangiorgi	Conference Paper	Four case studies of healthcare with clients as consumers and a focus upon cocreation of value and coproduction	Coproduction/Health
60.	2010	Realpe & Wallace,	Discussion Paper	A working definition of co-production of health based on shared decision making between the service users and providers as they contribute knowledge	Coproduction/Health
61.	2010	Piller, Ihl & Vossen	Theoretical Paper	evolution and typology of customer co-creation and related forms of customer participation	Coproduction/Innovation

62.	2010	Chan, Yim, & Lam	Primary Research	Questionnaires to 349 pairs of customers and service employees of the Hong Kong and U.S. multinational bank suggests matching customers and employees by their cultural value orientations	Coproduction/Marketing
63.	2010	Ostrom, Bitner & Brown	Discussion Paper	a set of global, interdisciplinary research priorities and a discussion of co-creation and co-production	Coproduction/Public Services
64.	2011	Dolfsma	Theory Paper	Conceptual paper with insight into how a firm's reputation helps to establish value from innovation.	Coproduction/Business
65.	2011	Jacob & Rettinger	Primary Research	Qualitative interviews. Six factors may influence participation in co-production and value-in-use created: distinctive preferences, age, situational factors, customer role clarity and ability to co-produce, customer willingness to co-produce, and perceived "importance" of service (Jacob & Rettinger, 2011, p.II)	Coproduction/Value
66.	2011	Renedo & Marston,	Primary Research	Ethnographic study: in-depth interviews with public participants and healthcare professionals involved in PPI, and observation of PPI activities in London.	PPI

67.	2011	Vassilev, Rogers & Sanders et al.	Realist Literature Review	Exploration of the theoretical and empirical links between social networks, social capital and the self-care practices associated with LTC, work and management in people's everyday lives.	Social Capital/Health
68.	2012	Hibbert, Winklhofer & Temerak	Theory Paper	Presents the idea of "dysfunctional consumer participation". A framework enables managers with and consideration of strategies to restore relationships. (Hibbert, Winklhofer & Temerak, 2012 p.329)	Coproduction/Business
69.	2012	McColl-Kennedy, Vargo, & Dagger et al.	Primary Research	In depth interviews, field observation, and focus groups, identify distinct styles of health care customer value cocreation practice.	Coproduction/Health
70.	2012	Vadiee	Discussion Paper	Critique of the Expert Patients Program	Coproduction/Health/LTC
71.	2012	Bovaird & Loeffler	Discussion Paper	Coproduction in the context of multipurpose, multi-stakeholder networks implications for reform of public services.	Coproduction/Public Administration
72.	2012	Fenge, Fannin, & Hicks	Discussion Paper	Co-production and social capital of lay people and volunteers. Two volunteers were asked to reflect on their experiences of becoming researchers, as "experts by experience" (Fenge, Fannin and Hicks, 2012, p.456)	Coproduction/Social Capital
73.	2012	Lehrer, Ordanini & DeFillippi et al.	Primary Research	This interview-based study of three design-oriented knowledge intensive firms the study suggests how to improve quality of outcomes	Coproduction/Value

74.	2012	Grenfell	Book	Outlines Bourdieu's key concepts	Social Capital/Theory
75.	2013	Ngo & O'cass,	Primary Research	A survey of services firms in Australia. This study proposes that customer participation may account for the effects of service firm innovation capabilities on service quality.	Coproduction/Business
76.	2013	Wu, Huang, & Tsai et al.	Primary Research	This study examines the relationship quality in a coproduction context and suggest trust is the key determinant of loyalty outcomes	Coproduction/Business
77.	2013	Voorberg, Bekkers & Tummers	Systematic Review	122 articles and books (1987–2013) of the objectives of co-creation and co-production, with citizens in public innovation influential factors and the outcomes of cocreation and co-production processes.	Coproduction/Public Services
78.	2013	Lupton	Primary Research	60 qualitative interviews with mothers of who care for their children with illness.	Health
79.	2013	Meiklejohn, Heesch, Janda & Hayes	Primary Research	Qualitative study of lymphoedema, through a social constructivist theoretical lens using focus groups and telephone interviews	Theory/Lymphoedema
80.	2014	Brach, Dreyer, & Schillinger	Discussion Paper	Identifies ten attributes which organizations need to be health literate, so people can navigate, understand, and use information and services to take care of their health more easily	Coproduction/Health

81.	2014	Ewert & Evers	Primary Research	Coproduction is an ambiguous concept 22 expert interviews, undertaken in Germany, with consultants working in patient organizations, self-help groups, and customer services. Mutual trust has the potential to lead to successful co-production relationships.	Coproduction/Health
82.	2014	Van Eijk & Steen	Primary Research	The article describes theoretical insights and Q-methodology is used to distinguish different perspectives citizen have on their engagement in co-production.	Coproduction/Health
83.	2014	Fledderus, Brandsen, & Honingh	Theory Paper	Insufficient research evidence to suggest that coproduction fosters trust, through involving clients in public service delivery.	Coproduction/Public Services
84.	2014	Evers, Ewert, & Brandsen, T	E-Book	The main objective of this part of the research project was to "describe instruments and approaches that are used by innovatory social projects and networks to fight social inequality and stimulate social cohesion" (Evers, Ewert, & Brandsen, 2014, p.9).	Coproduction/Social Capital
85.	2014	Shay & Lafata	Primary Research	23 Qualitative interviews with primary care patients following a recent appointment. Patients were asked about the meaning of shared-decisions and about specific decisions	Health

				that they labelled as shared. Interviews were coded using qualitative content analysis.	
86.	2014	Snowden, Martin, Mathers & Donnell	Discursive Paper	Argues that prioritising adherence is flawed with current health rhetoric. Different health behaviours should be incorporated into a concordance framework, negating the need for adherence	Health
87.	2014	Collins	Book	A discussion of the extent to which scientific methods are pre-eminent, and why we should to continue to have confidence in scientific expertise	Relevant Theory
88.	2014	Vassilev, Rogers & Sanders et al.	Primary Research	300 participants in a cross-sectional survey with nested qualitative interviews regarding experiences of social status of those living with an LTC with reference to employment status.	Social Capital/Health
89.	2015	Batalden, Batalden & Margolis	Discussion Paper	Partial history of the coproduction concept, present a model of healthcare service coproduction and explore its application in delivery of innovations.	Coproduction/Health
90.	2015	Hardyman, Daunt, & Kitchener	Discussion Paper	Reflecting on marketing and public management literature and paucity of evidence regarding value-cocreation.	Coproduction/Health
91.	2015	Palumbo	Discussion Paper	Discussion paper: health literacy perspective to	Coproduction/Health

				explore the concept of health services co-production.	
92.	2015	Voorberg, Bekkers & Tummers	Systematic Review	Systematic Review: Citizen's involvement in public service delivery and current gaps in the research	Coproduction/Innovation
93.	2015	Kendall-Raynor	Analysis Paper	Using the principles of coproduction to address rising costs and increasing demand while still wanting to improve patient care.	Coproduction/Lymph
94.	2015	Bovaird, Van Ryzin, Loeffler, & Parrado,	Primary Research	Quantitative large-sample survey on citizen co-production behaviours in five European countries, exploring the gap between levels of collective co-production and individual co-production, and implications for policy.	Coproduction/Public Services
95.	2015	van Houtum, Rijken & Groenewegen	Primary Research	Cross-sectional linear regression analyses of data from 1731 patients with chronic disease(s) One third of people with LTC encounter financial and social problems in their daily life. Younger people, people with poor health and people with physical limitations are more likely to have everyday problems.	Health/LTC
96.	2015	Scambler	Book Chapter	Philosophical sociology and "theory of communicative action" the relevance of this extensive body of work to issues of health and healing (Scambler, 2015, p.355)	Health/Theory

97.	2015	Timmons & Nairn	Critical Review	Critical review of the literature, of emergency medicine, as a new medical specialism in the UK, and the cultural and symbolic context	Health/Theory
98.	2016	Nahi	Systematic Review	“Base of Pyramid” (Nahi, 2016, p.416) research on cocreation and proposes a framework for organizing the diverse conceptualizations	Coproduction/Cocreation
99.	2016	Adinolfi, Starace & Palumbo	Primary Research	A case study of pilot project in Italy, which involved empowering patients, comparing this with similar initiatives European and non-European countries, coproduction and outcomes of health interventions.	Coproduction/Health
100.	2016	Palumbo	Literature Review	Descriptive literature review discussing the relation between health literacy and patient involvement.	Coproduction/Health
101.	2016	Palumbo, Annarumma & Manna et al	Primary Research	Primary research: A survey measuring health literacy-related skills with a random sample of 600 Italian patients.	Coproduction/Health
102.	2016	von Thiele Schwarz	Primary Research	Concept of “co-care”, (von Thiele Schwarz, 2016, p.10) where the role of healthcare providers is to complement people’s own resources for managing their health, linking	Coproduction/Health

				needs and knowledge for the best health outcome	
103.	2016	Vinall-Collier, K., Madill, A. & Firth	Primary Research	A multi-centre mixed methods approach to interaction between patients in physician-led and nurse-led Rheumatology clinics.	Coproduction/Health/LTC
104.	2016	Brandsen, & Honingh	Theory Paper	Review of the coproduction literature, with suggested typology which recognises different types of coproduction	Coproduction/Public Administration
105.	2016	Jo & Nabatchi	Discussion Paper	Understanding the Diversity of Coproduction: Introduction to the IJPA Special Issue	Coproduction/Public Administration
106.	2016	Loeffler & Bovaird	Commentary	Critique of Brandsen and Honingh's typology of coproduction	Coproduction/Public Administration
107.	2016	Nabatchi, Steen, Sicilia	Commentary	Introduction to IJPA special issue	Coproduction/Public Administration
108.	2016	Tuurnas	Primary Research	Case study which examines effective coproduction in the neighbourhood community development context.	Coproduction/Public Administration
109.	2016	Meijer	Theory Paper	Builds upon coproduction literature of public services, to identify the nature, drivers and implications of the transformation, healthcare is one example	Coproduction/Public Services

110.	2016	Osborne, Radnor & Strokosch,	Theory Paper	Conceptualization of a co-production typology in both public management and service management theory using Bovaird's (2007) definition.	Coproduction/Public Services
111.	2016	Thijssen & Van Dooren	Primary Research	Quantitative analysis neighbourhood characteristics which explain co-production, in terms of social capital not social status	Coproduction/Social Capital
112.	2016	Leclercq, Hammedi & Poncin	Integrative Review	Clarification of concepts related to cocreation, knowledge and provides a foundation for further empirical investigations	Coproduction/Value
113.	2016	Mackey, Doody, Werner & Fullen	Literature Review	Assess the association between health literacy, patient characteristics and self-management behaviours. Low health literacy may affect behaviours necessary for the development of self-management skills	Health
114.	2016	Ocloo, J. & Matthews	Narrative Literature Review	Selective narrative literature search of systematic literature reviews. Current models of PPI are limited, and few address equality and diversity in their involvement strategies.	PPI
115.	2017	Cooke, Langley, Wolstenholme & Hampshaw	Discussion Paper	Designs in health projects which seek to address power issues through coproduction and make contributions visible	Coproduction/Health

116.	2017	Lwembe, Green, Chigwende, Ojwang & Dennis,	Primary Research	Evaluation of a pilot initiative semi-structured interviews and focus groups, using co-production approaches to deliver a mental health service to meet the needs of the black and minority ethnic communities.	Coproduction/Health
117.	2017	Mayer & McKenzie	Primary Research	Phenomenological study: Semi-structured interviews explored the psychological impact of co-production for young people who were "experts by experience"	Coproduction/Health
118.	2017	McColl-Kennedy, Hogan, Witell & Snyder	Theory Paper	Review of 3 studies discussing the effects of health care customer value cocreation practices on well-being.	Coproduction/Health
119.	2017	NHS, England, Public, Participation & Team	NHS Document	Framework for patient and public participation in public health commissioning	Coproduction/Health
120.	2017	Thomas & Morgan	Service Development Report	Describes the creation of the network and the importance of capturing performance data on the three programmes of work; service development; education and research; and innovations and technology for lymphoedema care in Wales	Coproduction/Lymph

121.	2017	Dong & Sivakumar	Theory Paper	The authors suggest using "customer participation" to reduce confusion regarding definitions of coproduction and cocreation	Coproduction/Marketing
122.	2017	Durose, Needham, Mangan, & Rees	Debate	Theory-based and knowledge-based routes to evidencing co-production in public services	Coproduction/Public Services
123.	2017	Nabatchi, Sancino, A. & Sicilia	Theory Paper	The article aims to clarify the concept of coproduction in public administration concludes with a discussion of implications for research and practice.	Coproduction/Public Services
124.	2017	Vanleene, Voets & Verschuere	Primary Research	Study the different citizens' motivations discussed in the coproduction literature. Used a Survey to collect data on different motivations in a Belgian case in a community development setting	Coproduction/Social Capital
125.	2017	Sointu	Primary Research	Longitudinal study of student experiences of clinical learning in 72 qualitative in-depth interviews with 27 medical students from US medical schools. A sociological understanding of inequality in medicine and ideas of the "good" and "bad" patient	Health/Theory
126.	2017	Alvarez, Kawachi & Romani,	Systematic Review	Examination of the family and social capital and how this affects health outcomes. More research required to understand the relationship between social capital and health	Social Capital/Health

127.	2018	Batalden	Discussion Paper	Modelling healthcare as either a product or a service neglects essential aspect of coproduction between doctors and patients	Coproduction/Health
128.	2018	Palumbo & Manna	Primary Research	Primary research: A random sample of 591 Italian patients screening tool to measure individual health literacy skills	Coproduction/Health
129.	2018	Voorberg, Jilke, & Tummers, et al.	Primary Research	Two Studies to determine if financial rewards stimulate coproduction. The authors concluded that financial incentive could be a form of external support that strengthens intrinsic motivation, but does not effectively increase people's willingness to coproduce	Coproduction/Public Administration
130.	2018	Oertzen, Odekerken-Schröder & Brax,	Literature Review	Screened the articles published in five major service research journals to determine relevant contributions on the concept of co-creation of services.	Coproduction/Public Services
131.	2018	Osborne	Editorial	argues for a revised conceptualization of co-production and value (co-)creation and roles of public services and citizens	Coproduction/Public Services
132.	2019	Beresford	Discussion Paper	Identifies four key stages in the development of public participation in health and social care.	Coproduction/Health
133.	2019	Eriksson	Primary Research	Relevance of social context when evaluating, designing, and delivering services. Data from a collaborative and longitudinal research project	Coproduction/Health

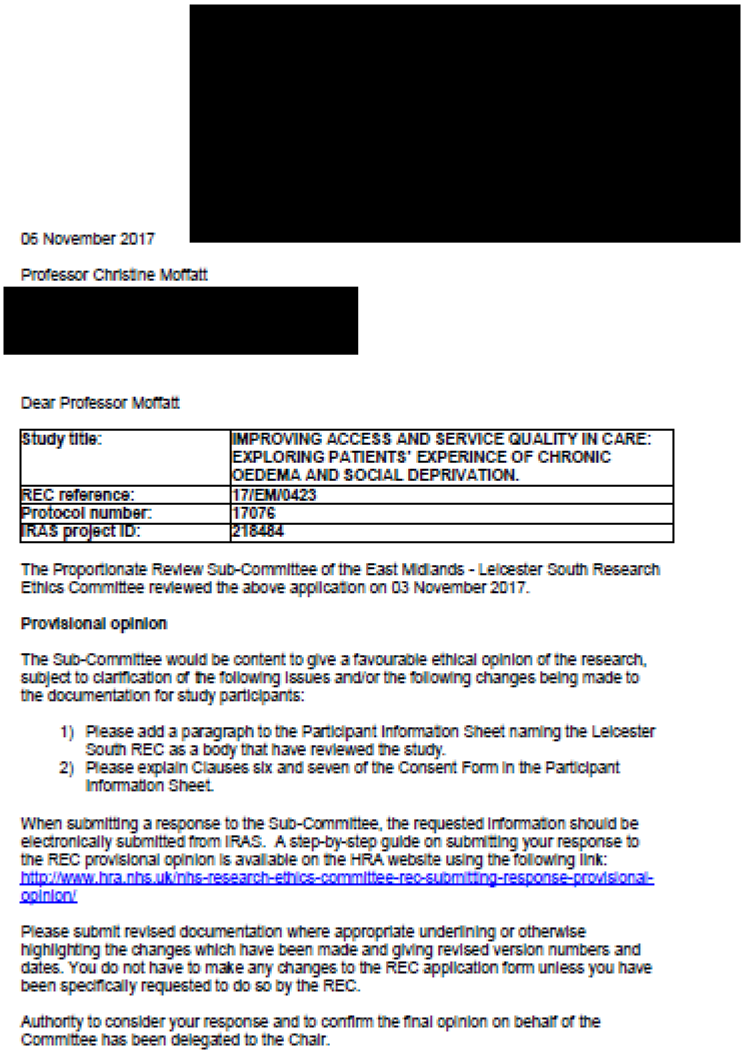
				of 20 local women on a research project as representatives of local immigrant women.	
134.	2019	Holland-Hart, Addis, Edwards, Kenkre & Wood	Primary Research	How coproduction is viewed by clinicians and the public, to identify perceived barriers and enablers to its implementation. Design: Using qualitative research methods, interviews and focus groups were also conducted with the public and clinicians	Coproduction/Health
135.	2019	Palmer, Weavell & Callander,	Primary Research	An explanatory theoretical model of change to examine coproduction studies in the future.	Coproduction/Health
136.	2019	Palumbo, Annarumma & Manna et al.	Systematic Review	Systematic review: discusses the pros and the cons of health care co-production and insightful directions to deal with the engagement of patients in value co-creation	Coproduction/Health
137.	2019	Bevir, Needham & Waring	Editorial	Philosophy of co-production and meaning and practicality of co-production.	Coproduction/Public Services
138.	2019	Elwyn, Nelson, Hager & Price	Commentary	Healthcare to use technology to monitor and give feedback.	PPI
139.	2019	National Institute of Health Research	Standards	UK Standards for Public Involvement in Research Better public involvement for better health and social care research	PPI

140.	2019	Fricker	Theory Paper	Definition of identity power and epistemic injustice, exploring testimonial injustice, when a speaker feels their credibility is negated by the response of a listener	Relevant Theory
141.	2019	Nairn, Dring, Aubeeluck	Discussion Paper	Explores the idea that chronic oedema is a condition without scientific capital or social capital	Social Capital/Health
142.	2020	Marston, Renedo & Miles	Commentary	Discussion of coproduction during the 2020 pandemic	Coproduction/Health
143.	2020	Park	Theory Paper	Proposal of a framework theorising service co-production for providers to use in health and social service fields caring vulnerable and stigmatised service users.	Coproduction/Health
144.	2020	Rezaei Aghdam, Watson & Cliff et al.	Systematic Review	Introduces a theoretical discussion for better understanding of online health communities & health care organizations use for empowering patients	Coproduction/Health
145.	2020	Salisbury	Thesis	Exploring coproduction and health inequalities the use of co-production in an intervention designed to reduce inequality in access to antenatal care.	Coproduction/Health
146.	2020	Steen & Brandsen	Commentary	The relevance of coproduction under COVID-19 and argues for the need for coproduction initiatives to persist well beyond the pandemic.	Coproduction/Health

147.	2020	Williams, Robert, &, Martin et al.	Discussion Paper	Analysis of important distinctions between co-production and Patient and Public Involvement (PPI) in applied health research	Coproduction/Health
148.	2020	Hasson, Nicholson, & Muldrew, et al.	Systematic Review	Identification of gaps in research around palliative care, and opportunities to involve patients and families in priority setting	Health
149.	2020	Brand, Bramley, Dring & Musgrove	Report of A Scoping Exercise	Using patient and public involvement to identify priorities for research in long-term conditions management A group of 15 PPI representatives were invited to attend a meeting to discuss research priorities for LTC management. The aim was achieved, in a non-paternalistic and tokenistic approach	PPI
150.	2021	Dixon, Lar & Dean	Commentary	Need for implementation research to address health system barriers placing people and communities at the centre, as essential in the coproduction of health and social care, to drive this agenda forward	Coproduction/Lymph
151.	2021	Care Quality Commission	Website	Independent regulator of health and adult social care in England. Identification of regulated services within the home.	Health

152.	2021	Ocloo, Garfield &	Systematic Review	Literature review: evidence for theories, barriers and enablers in PPI across health, social care and patient safety that could be used to strengthen PPI and address a perceived knowledge and theory gap with PPI in patient safety	PPI

Appendix 6: REC Approval



[redacted]

06 November 2017

Professor Christine Moffatt

[redacted]

Dear Professor Moffatt

Study title:	**IMPROVING ACCESS AND SERVICE QUALITY IN CARE: EXPLORING PATIENTS' EXPERINCE OF CHRONIC OEDEMA AND SOCIAL DEPRIVATION.**
REC reference:	**17/EM/0423**
Protocol number:	**17076**
IRAS project ID:	**218484**

The Proportionate Review Sub-Committee of the East Midlands - Leicester South Research Ethics Committee reviewed the above application on 03 November 2017.

Provisional opinion

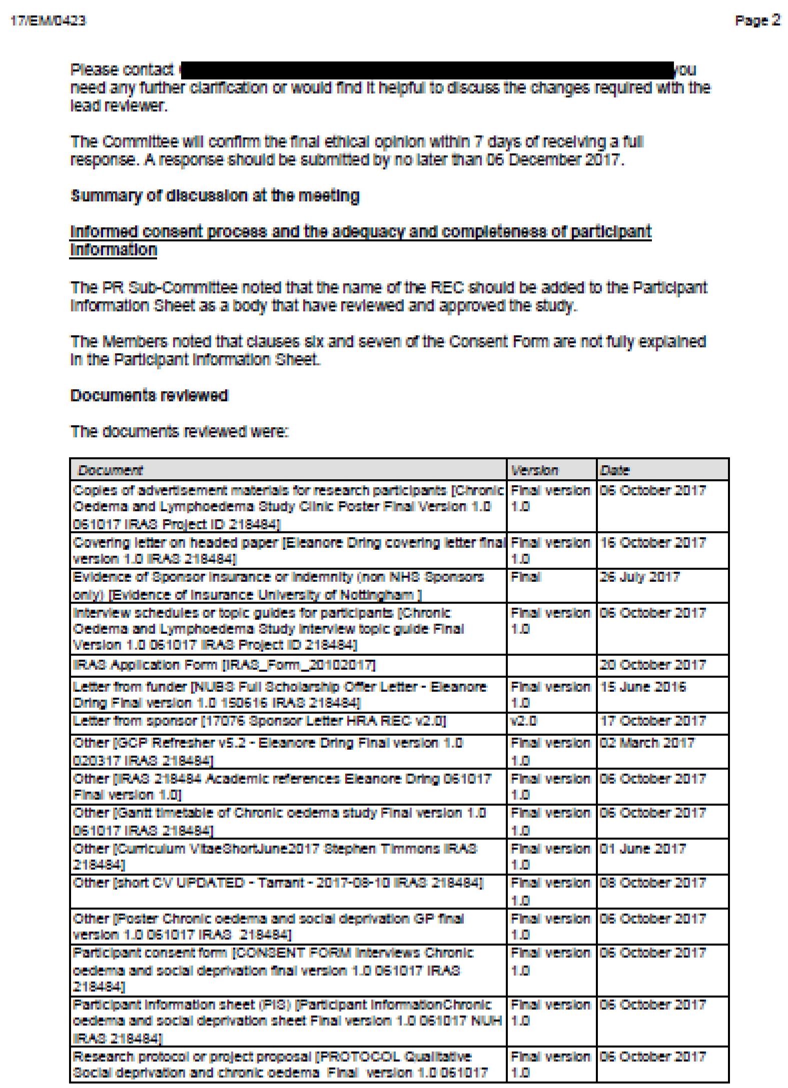
The Sub-Committee would be content to give a favourable ethical opinion of the research, subject to clarification of the following issues and/or the following changes being made to the documentation for study participants:

1) Please add a paragraph to the Participant Information Sheet naming the Leicester South REC as a body that have reviewed the study.
2) Please explain Clauses six and seven of the Consent Form in the Participant Information Sheet.

When submitting a response to the Sub-Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link: http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

Authority to consider your response and to confirm the final opinion on behalf of the Committee has been delegated to the Chair.



Please contact [redacted] you need any further clarification or would find it helpful to discuss the changes required with the lead reviewer.

The Committee will confirm the final ethical opinion within 7 days of receiving a full response. A response should be submitted by no later than 06 December 2017.

Summary of discussion at the meeting

Informed consent process and the adequacy and completeness of participant information

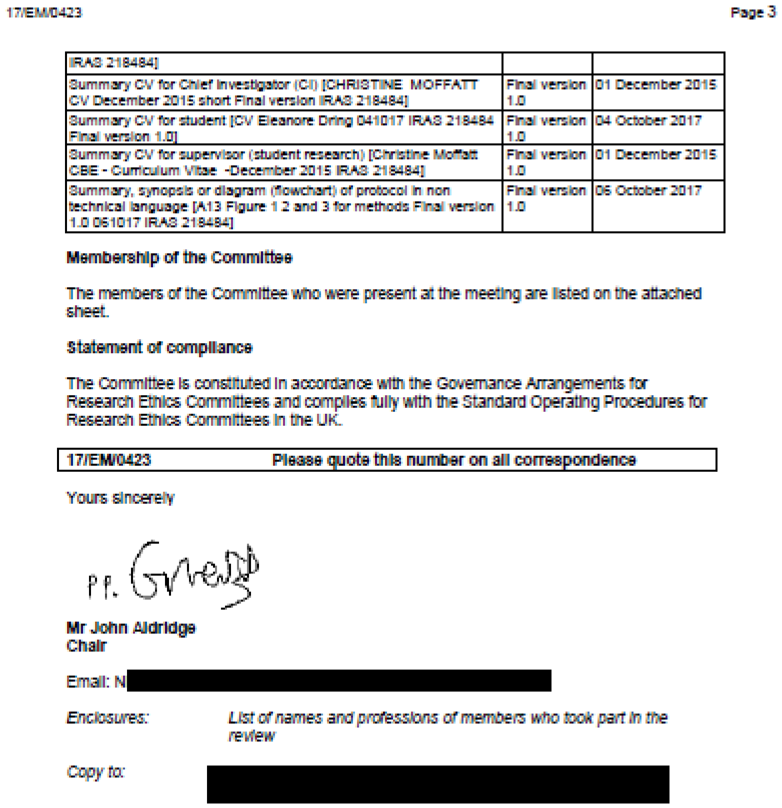
The PR Sub-Committee noted that the name of the REC should be added to the Participant Information Sheet as a body that have reviewed and approved the study.

The Members noted that clauses six and seven of the Consent Form are not fully explained in the Participant Information Sheet.

Documents reviewed

The documents reviewed were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Chronic Oedema and Lymphoedema Study Clinic Poster Final Version 1.0 061017 IRAS Project ID 218484]	Final version 1.0	06 October 2017
Covering letter on headed paper [Eleanore Dring covering letter final version 1.0 IRAS 218484]	Final version 1.0	16 October 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Insurance University of Nottingham]	Final	26 July 2017
Interview schedules or topic guides for participants [Chronic Oedema and Lymphoedema Study Interview topic guide Final Version 1.0 061017 IRAS Project ID 218484]	Final version 1.0	06 October 2017
IRAS Application Form [IRAS_Form_20102017]		20 October 2017
Letter from funder [NUBS Full Scholarship Offer Letter - Eleanore Dring Final version 1.0 150616 IRAS 218484]	Final version 1.0	15 June 2016
Letter from sponsor [17076 Sponsor Letter HRA REC v2.0]	v2.0	17 October 2017
Other [GCP Refresher v5.2 - Eleanore Dring Final version 1.0 020317 IRAS 218484]	Final version 1.0	02 March 2017
Other [IRAS 218484 Academic references Eleanore Dring 061017 Final version 1.0]	Final version 1.0	06 October 2017
Other [Gantt timetable of Chronic oedema study Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Other [Curriculum VitaeShortJune2017 Stephen Timmons IRAS 218484]	Final version 1.0	01 June 2017
Other [short CV UPDATED - Tarrant - 2017-08-10 IRAS 218484]	Final version 1.0	08 October 2017
Other [Poster Chronic oedema and social deprivation GP final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Participant consent form [CONSENT FORM Interviews Chronic oedema and social deprivation final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Participant information sheet (PIS) [Participant InformationChronic oedema and social deprivation sheet Final version 1.0 061017 NUH IRAS 218484]	Final version 1.0	06 October 2017
Research protocol or project proposal [PROTOCOL Qualitative Social deprivation and chronic oedema Final version 1.0 061017	Final version 1.0	06 October 2017



IRAS 218484]		
Summary CV for Chief Investigator (CI) [CHRISTINE MOFFATT CV December 2015 short Final version IRAS 218484]	Final version 1.0	01 December 2015
Summary CV for student [CV Eleanore Dring 041017 IRAS 218484 Final version 1.0]	Final version 1.0	04 October 2017
Summary CV for supervisor (student research) [Christine Moffatt CBE - Curriculum Vitae -December 2015 IRAS 218484]	Final version 1.0	01 December 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [A13 Figure 1 2 and 3 for methods Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017

Membership of the Committee

The members of the Committee who were present at the meeting 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.

17/EM/0423	**Please quote this number on all correspondence**

Yours sincerely

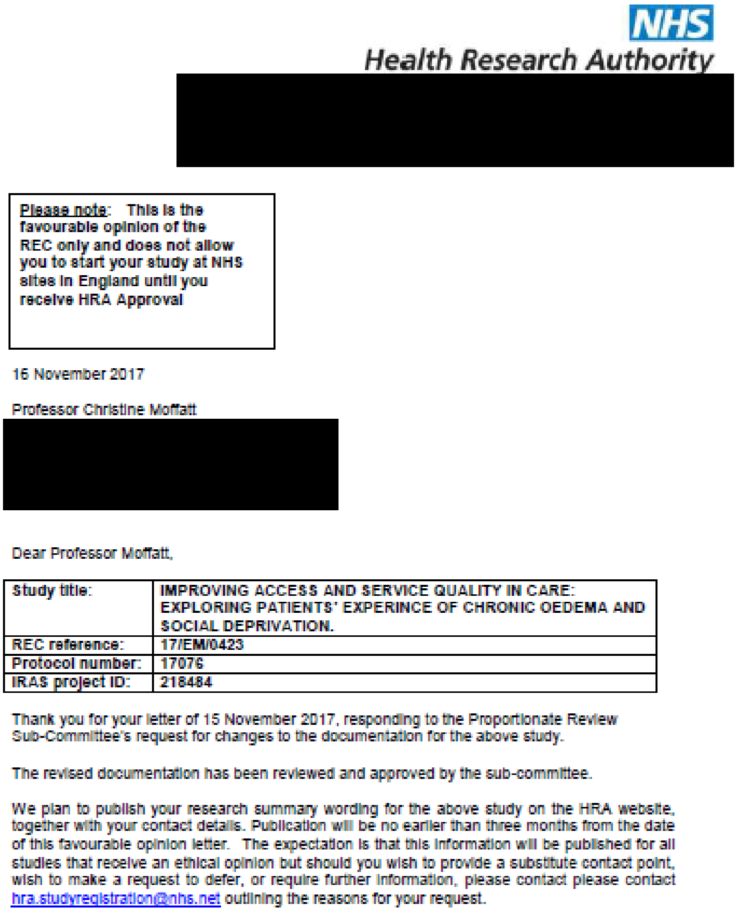
Mr John Aldridge
Chair

Email: N[redacted]

Enclosures: *List of names and professions of members who took part in the review*

Copy to: [redacted]

Appendix 7: REC Approval for changes



NHS
Health Research Authority

[redacted]

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

16 November 2017

Professor Christine Moffatt
[redacted]

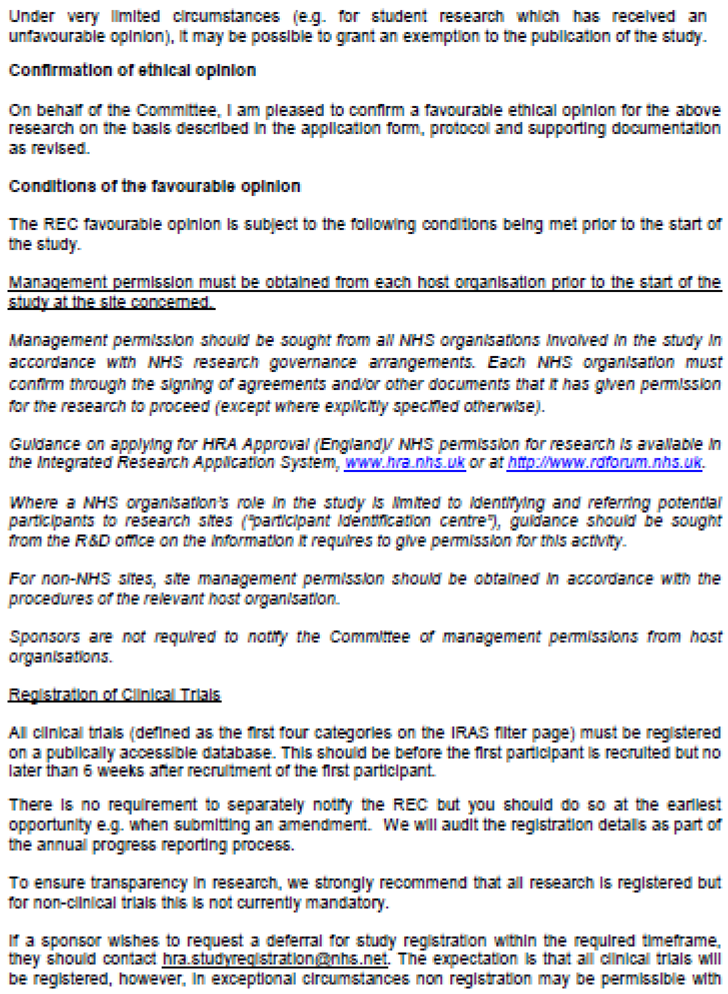
Dear Professor Moffatt,

Study title:	**IMPROVING ACCESS AND SERVICE QUALITY IN CARE: EXPLORING PATIENTS' EXPERINCE OF CHRONIC OEDEMA AND SOCIAL DEPRIVATION.**
REC reference:	**17/EM/0423**
Protocol number:	**17076**
IRAS project ID:	**218484**

Thank you for your letter of 15 November 2017, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.



Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

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

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk 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 management permissions from host organisations.

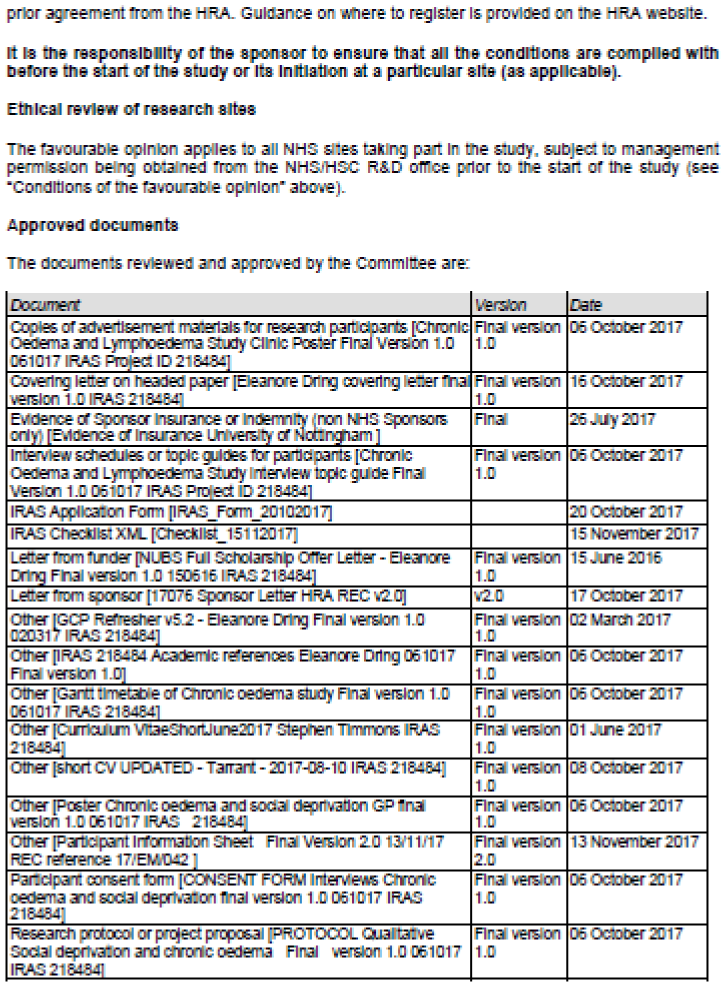
Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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 request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with



prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Chronic Oedema and Lymphoedema Study Clinic Poster Final Version 1.0 061017 IRAS Project ID 218484]	Final version 1.0	06 October 2017
Covering letter on headed paper [Eleanore Dring covering letter final version 1.0 IRAS 218484]	Final version 1.0	16 October 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of insurance University of Nottingham]	Final	26 July 2017
Interview schedules or topic guides for participants [Chronic Oedema and Lymphoedema Study Interview topic guide Final Version 1.0 061017 IRAS Project ID 218484]	Final version 1.0	06 October 2017
IRAS Application Form [IRAS_Form_20102017]		20 October 2017
IRAS Checklist XML [Checklist_15112017]		15 November 2017
Letter from funder [NUBS Full Scholarship Offer Letter - Eleanore Dring Final version 1.0 150616 IRAS 218484]	Final version 1.0	15 June 2016
Letter from sponsor [17076 Sponsor Letter HRA REC v2.0]	v2.0	17 October 2017
Other [GCP Refresher v5.2 - Eleanore Dring Final version 1.0 020317 IRAS 218484]	Final version 1.0	02 March 2017
Other [IRAS 218484 Academic references Eleanore Dring 061017 Final version 1.0]	Final version 1.0	06 October 2017
Other [Gantt timetable of Chronic oedema study Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
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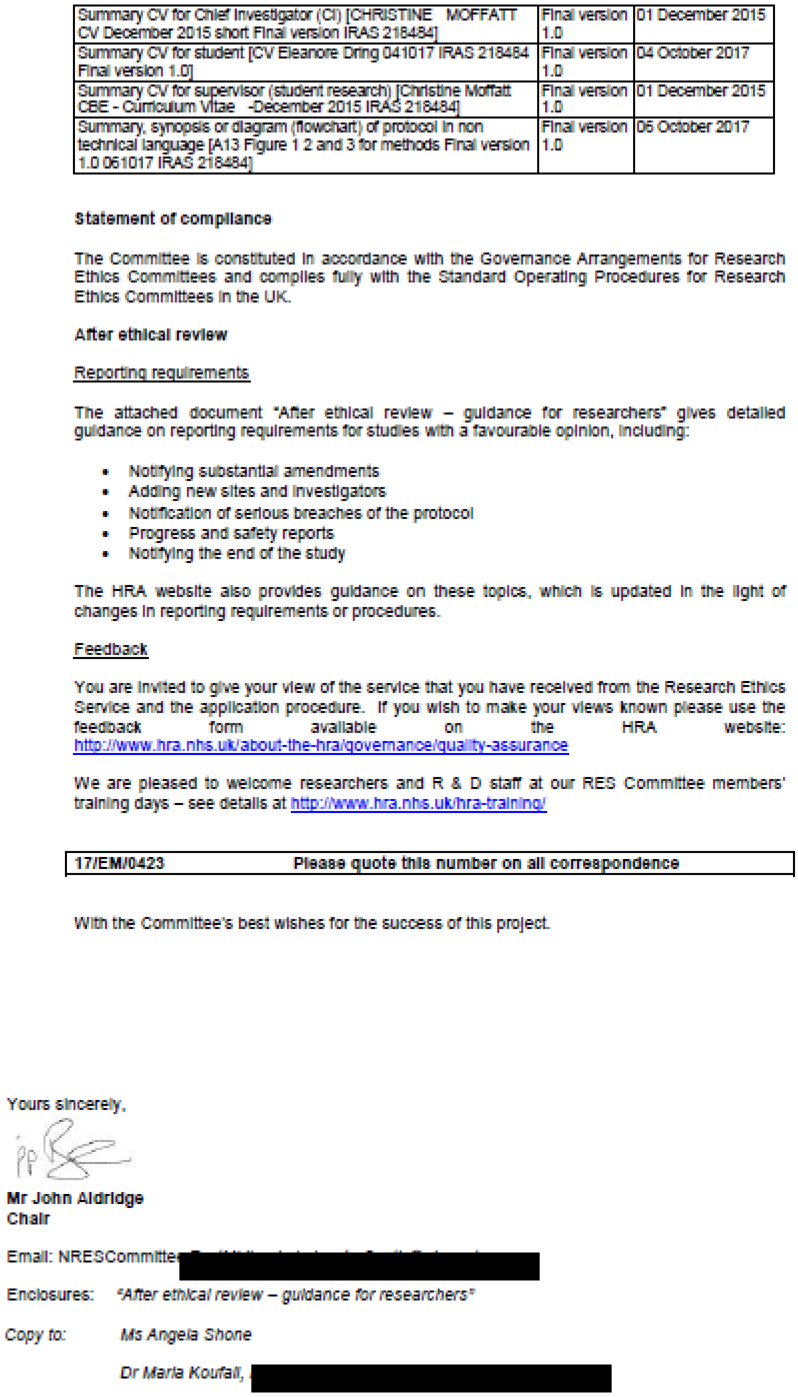
Other [short CV UPDATED - Tarrant - 2017-08-10 IRAS 218484]	Final version 1.0	08 October 2017
Other [Poster Chronic oedema and social deprivation GP final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Other [Participant Information Sheet Final Version 2.0 13/11/17 REC reference 17/EM/042]	Final version 2.0	13 November 2017
Participant consent form [CONSENT FORM Interviews Chronic oedema and social deprivation final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Research protocol or project proposal [PROTOCOL Qualitative Social deprivation and chronic oedema Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017



Summary CV for Chief Investigator (CI) [CHRISTINE MOFFATT CV December 2015 short Final version IRAS 218484]	Final version 1.0	01 December 2015
Summary CV for student [CV Eleanore Dring 041017 IRAS 218484 Final version 1.0]	Final version 1.0	04 October 2017
Summary CV for supervisor (student research) [Christine Moffatt CBE - Curriculum Vitae -December 2015 IRAS 218484]	Final version 1.0	01 December 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [A13 Figure 1 2 and 3 for methods Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017

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 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 RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/EM/0423 **Please quote this number on all correspondence**

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

Yours sincerely,

pp

Mr John Aldridge
Chair

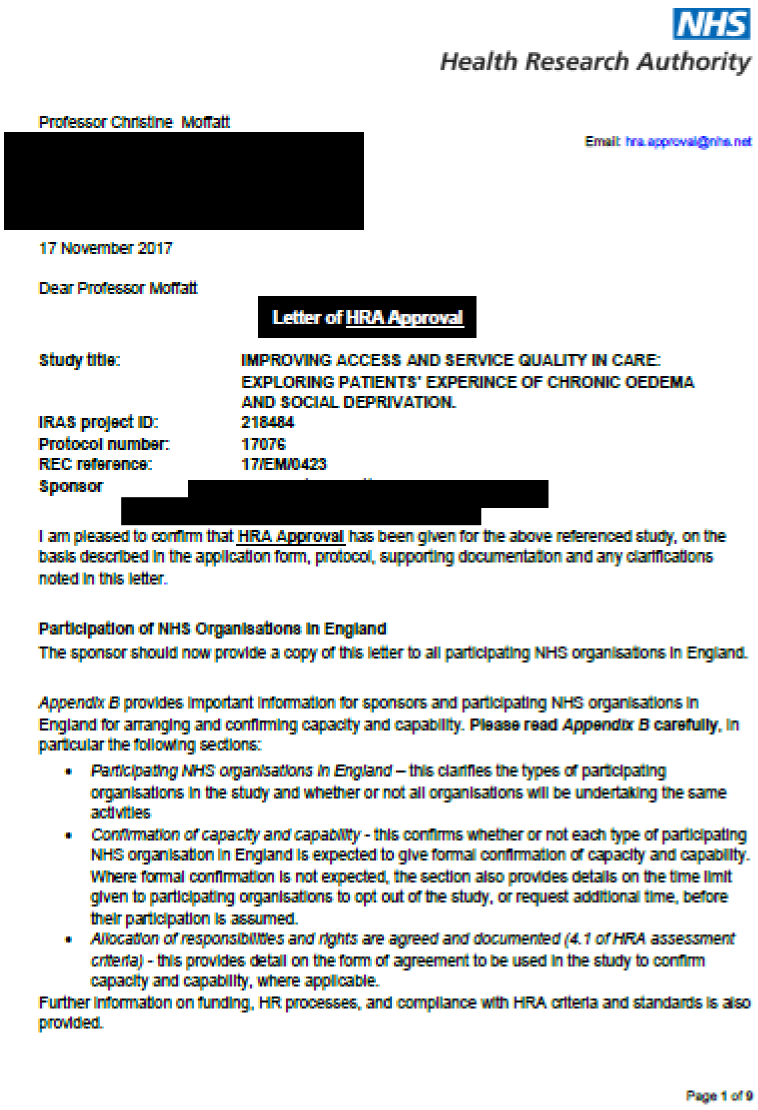
Email: NRESCommitte[redacted]

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Ms Angela Shone*

Dr Maria Koufali, [redacted]

Appendix 8: HRA Approval



NHS
Health Research Authority

Professor Christine Moffatt
[redacted]

Email: hra.approval@nhs.net

17 November 2017

Dear Professor Moffatt

Letter of HRA Approval

Study title:	**IMPROVING ACCESS AND SERVICE QUALITY IN CARE: EXPLORING PATIENTS' EXPERINCE OF CHRONIC OEDEMA AND SOCIAL DEPRIVATION.**
IRAS project ID:	**218484**
Protocol number:	**17076**
REC reference:	**17/EM/0423**
Sponsor	[redacted]

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

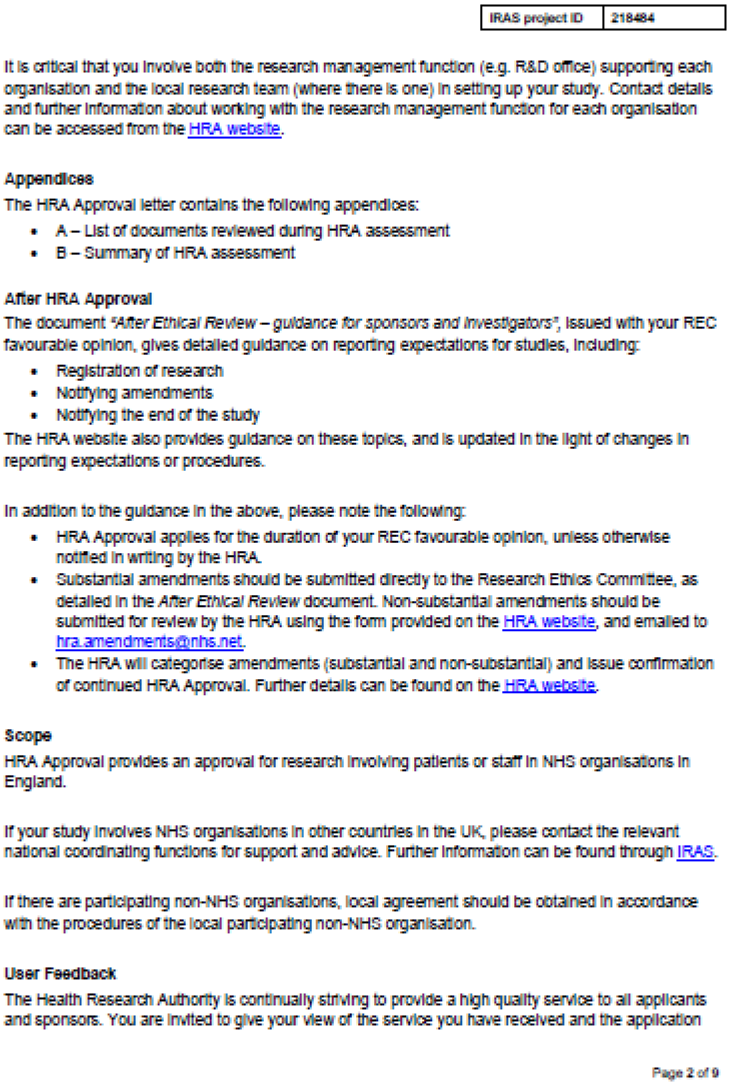
The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Page 1 of 9



It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the HRA website.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

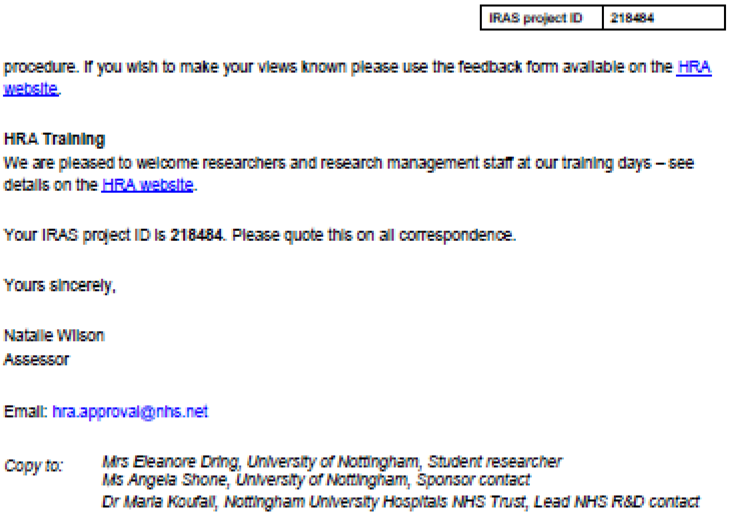
HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through IRAS.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application



procedure. If you wish to make your views known please use the feedback form available on the HRA website.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the HRA website.

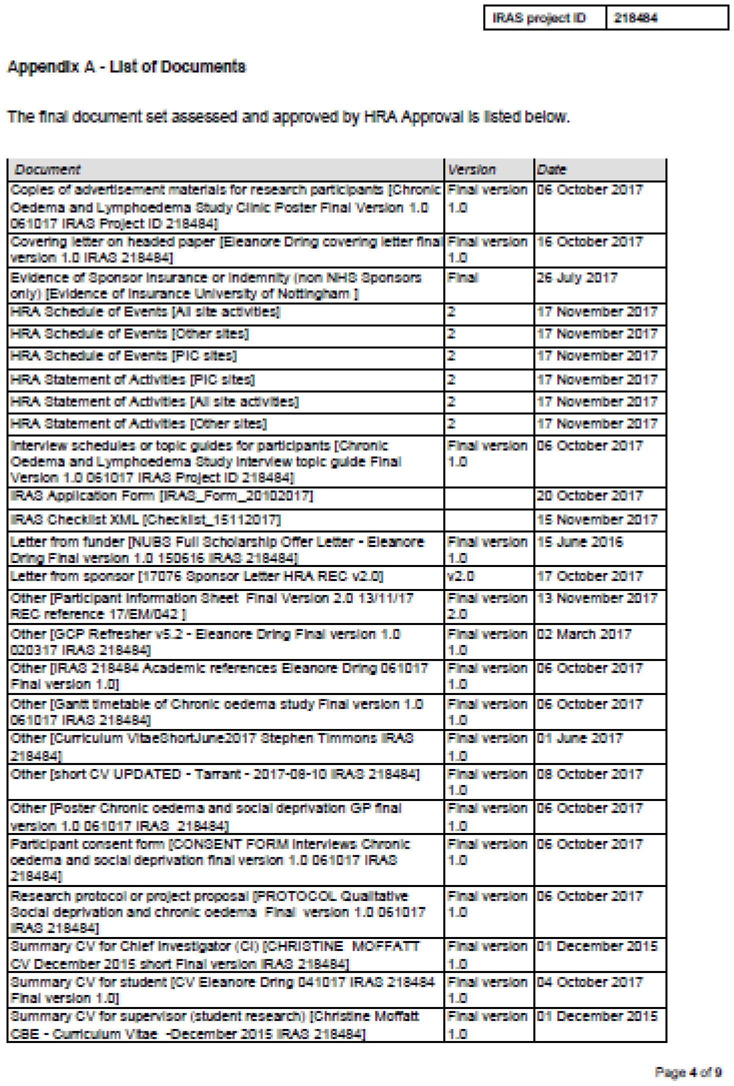
Your IRAS project ID is **218484**. Please quote this on all correspondence.

Yours sincerely,

Natalie Wilson
Assessor

Email: hra.approval@nhs.net

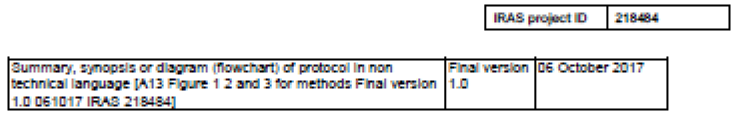
Copy to: *Mrs Eleanore Dring, University of Nottingham, Student researcher*
Ms Angela Shone, University of Nottingham, Sponsor contact
Dr Maria Koufali, Nottingham University Hospitals NHS Trust, Lead NHS R&D contact



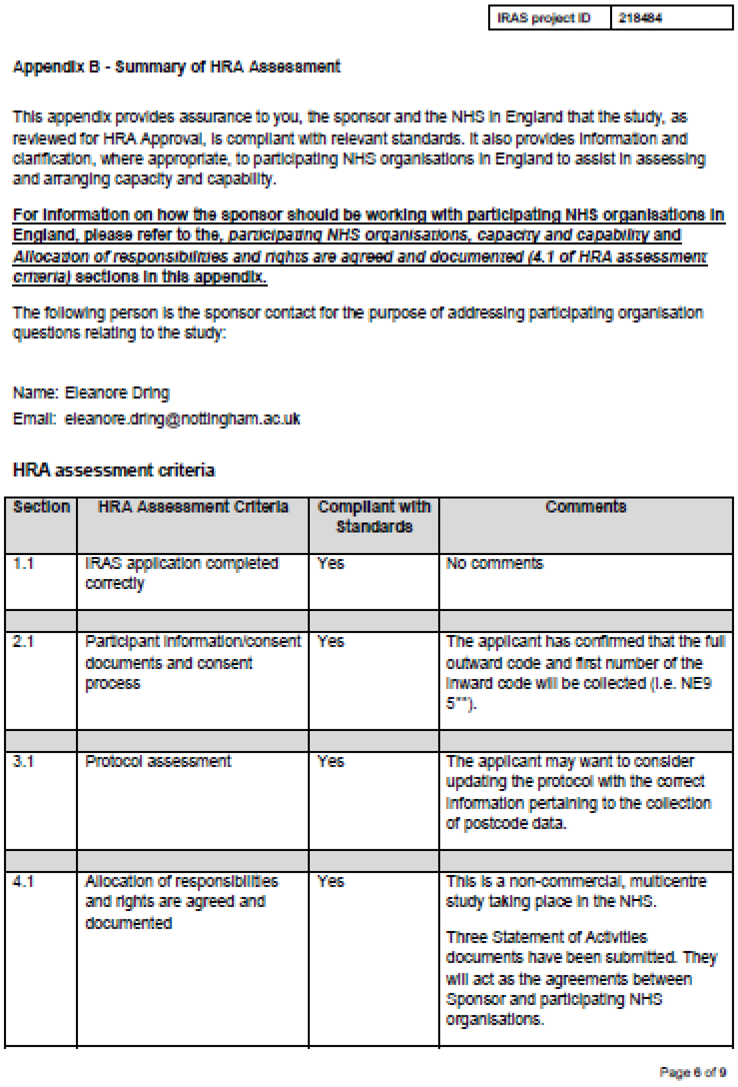
Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Chronic Oedema and Lymphoedema Study Clinic Poster Final Version 1.0 061017 IRAS Project ID 218484]	Final version 1.0	06 October 2017
Covering letter on headed paper [Eleanore Dring covering letter final version 1.0 IRAS 218484]	Final version 1.0	16 October 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of insurance University of Nottingham]	Final	26 July 2017
HRA Schedule of Events [All site activities]	2	17 November 2017
HRA Schedule of Events [Other sites]	2	17 November 2017
HRA Schedule of Events [PIC sites]	2	17 November 2017
HRA Statement of Activities [PIC sites]	2	17 November 2017
HRA Statement of Activities [All site activities]	2	17 November 2017
HRA Statement of Activities [Other sites]	2	17 November 2017
Interview schedules or topic guides for participants [Chronic Oedema and Lymphoedema Study Interview topic guide Final Version 1.0 061017 IRAS Project ID 218484]	Final version 1.0	06 October 2017
IRAS Application Form [IRAS_Form_20102017]		20 October 2017
IRAS Checklist XML [Checklist_15112017]		15 November 2017
Letter from funder [NUBS Full Scholarship Offer Letter - Eleanore Dring Final version 1.0 150616 IRAS 218484]	Final version 1.0	15 June 2016
Letter from sponsor [17076 Sponsor Letter HRA REC v2.0]	v2.0	17 October 2017
Other [Participant Information Sheet Final Version 2.0 13/11/17 REC reference 17/EM/042]	Final version 2.0	13 November 2017
Other [GCP Refresher v5.2 - Eleanore Dring Final version 1.0 020317 IRAS 218484]	Final version 1.0	02 March 2017
Other [IRAS 218484 Academic references Eleanore Dring 061017 Final version 1.0]	Final version 1.0	06 October 2017
Other [Gantt timetable of Chronic oedema study Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Other [Curriculum VitaeShortJune2017 Stephen Timmons IRAS 218484]	Final version 1.0	01 June 2017
Other [short CV UPDATED - Tarrant - 2017-08-10 IRAS 218484]	Final version 1.0	08 October 2017
Other [Poster Chronic oedema and social deprivation GP final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Participant consent form [CONSENT FORM Interviews Chronic oedema and social deprivation final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Research protocol or project proposal [PROTOCOL Qualitative Social deprivation and chronic oedema Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017
Summary CV for Chief Investigator (CI) [CHRISTINE MOFFATT CV December 2015 short Final version IRAS 218484]	Final version 1.0	01 December 2015
Summary CV for student [CV Eleanore Dring 041017 IRAS 218484 Final version 1.0]	Final version 1.0	04 October 2017
Summary CV for supervisor (student research) [Christine Moffatt CBE - Curriculum Vitae -December 2015 IRAS 218484]	Final version 1.0	01 December 2015



Summary, synopsis or diagram (flowchart) of protocol in non technical language [A13 Figure 1 2 and 3 for methods Final version 1.0 061017 IRAS 218484]	Final version 1.0	06 October 2017



IRAS project ID	218484

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Eleanore Dring
Email: eleanore.dring@nottingham.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	The applicant has confirmed that the full outward code and first number of the inward code will be collected (i.e. NE9 5**).
3.1	Protocol assessment	Yes	The applicant may want to consider updating the protocol with the correct information pertaining to the collection of postcode data.
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	This is a non-commercial, multicentre study taking place in the NHS. Three Statement of Activities documents have been submitted. They will act as the agreements between Sponsor and participating NHS organisations.

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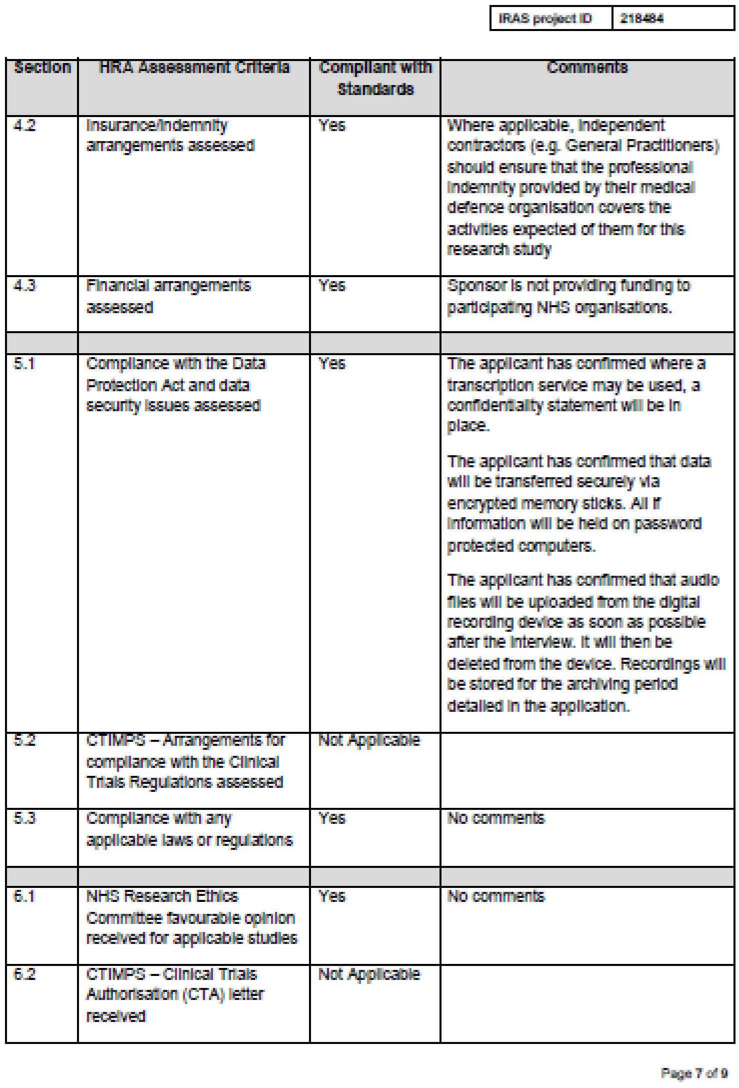

IRAS project ID	218484

Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	Sponsor is not providing funding to participating NHS organisations.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	The applicant has confirmed where a transcription service may be used, a confidentiality statement will be in place. The applicant has confirmed that data will be transferred securely via encrypted memory sticks. All If information will be held on password protected computers. The applicant has confirmed that audio files will be uploaded from the digital recording device as soon as possible after the interview. It will then be deleted from the device. Recordings will be stored for the archiving period detailed in the application.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	

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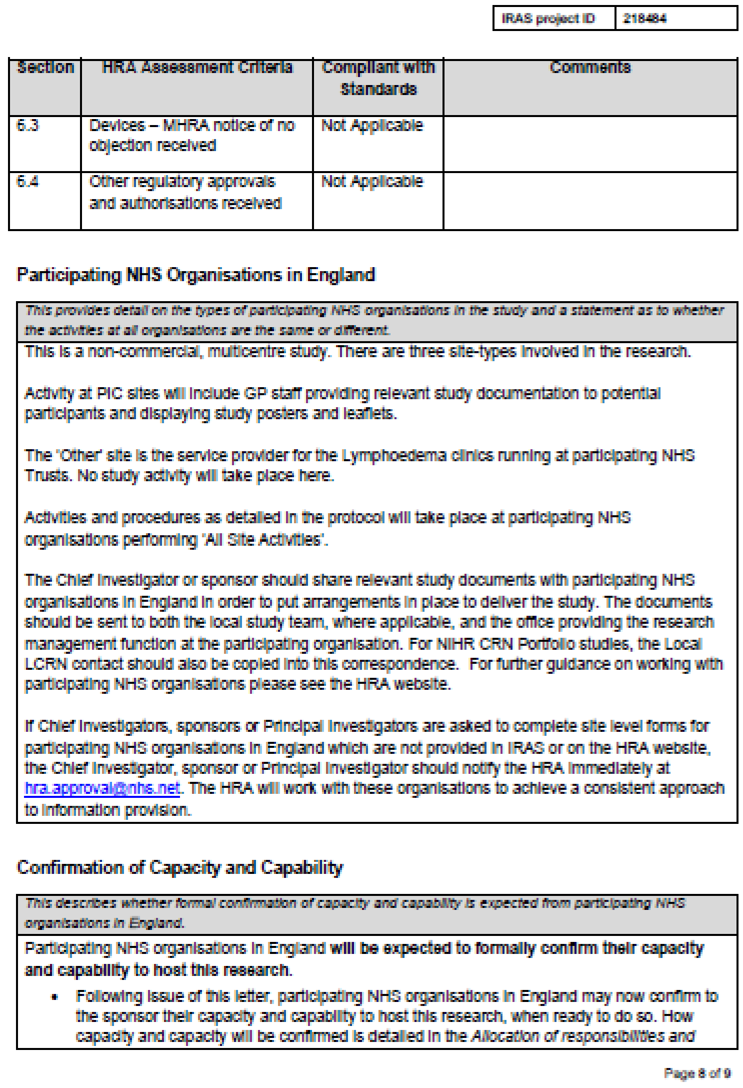


Section	HRA Assessment Criteria	Compliant with Standards	Comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	
6.4	Other regulatory approvals and authorisations received	Not Applicable	

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a non-commercial, multicentre study. There are three site-types involved in the research.

Activity at PIC sites will include GP staff providing relevant study documentation to potential participants and displaying study posters and leaflets.

The 'Other' site is the service provider for the Lymphoedema clinics running at participating NHS Trusts. No study activity will take place here.

Activities and procedures as detailed in the protocol will take place at participating NHS organisations performing 'All Site Activities'.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

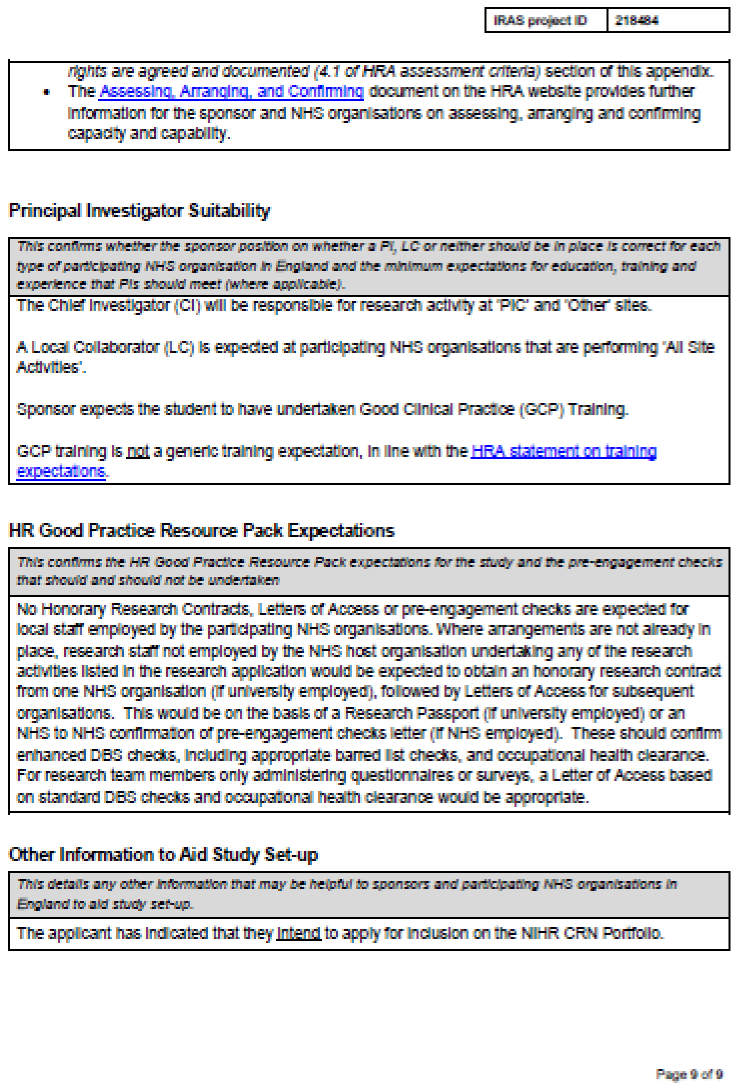
If Chief Investigators, sponsors or Principal Investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the Chief Investigator, sponsor or Principal Investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and*



IRAS project ID	218484

rights are agreed and documented (4.1 of HRA assessment criteria) section of this appendix. - The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).
The Chief Investigator (CI) will be responsible for research activity at 'PIC' and 'Other' sites. A Local Collaborator (LC) is expected at participating NHS organisations that are performing 'All Site Activities'. Sponsor expects the student to have undertaken Good Clinical Practice (GCP) Training. GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members only administering questionnaires or surveys, a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

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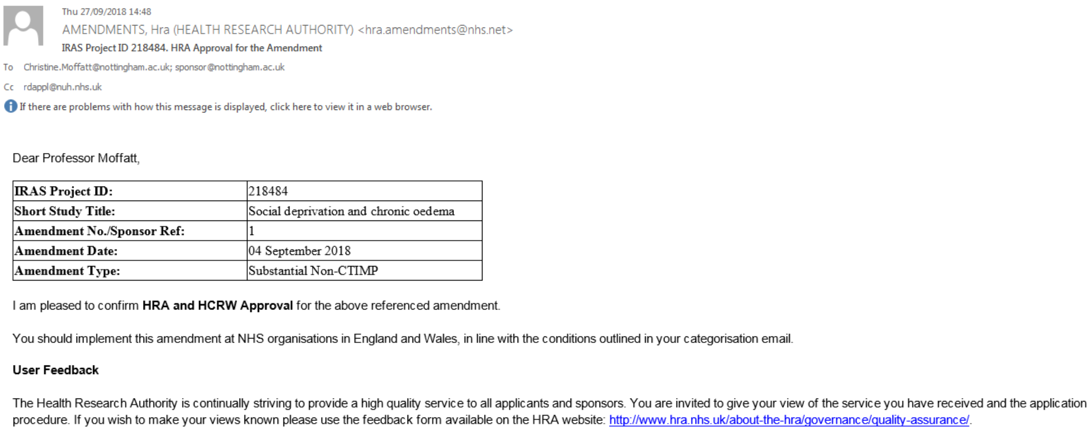
Appendix 9: HRA Approval Substantial Amendment



Thu 27/09/2018 14:48
AMENDMENTS, Hra (HEALTH RESEARCH AUTHORITY) <hra.amendments@nhs.net>
IRAS Project ID 218484. HRA Approval for the Amendment
To Christine.Moffatt@nottingham.ac.uk; sponsor@nottingham.ac.uk
Cc rdappl@nuh.nhs.uk
If there are problems with how this message is displayed, click here to view it in a web browser.

Dear Professor Moffatt,

IRAS Project ID:	218484
Short Study Title:	Social deprivation and chronic oedema
Amendment No./Sponsor Ref:	1
Amendment Date:	04 September 2018
Amendment Type:	Substantial Non-CTIMP

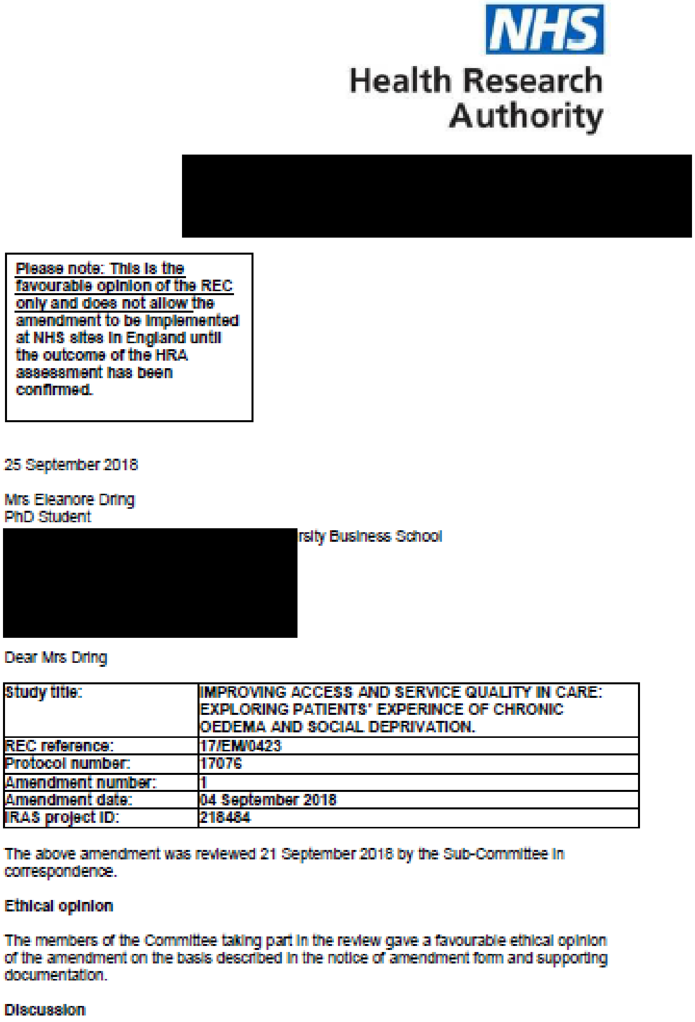
I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received 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/.

Appendix 10: REC Approval Substantial Amendments



NHS
Health Research
Authority

[redacted]

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

25 September 2018

Mrs Eleanore Dring
PhD Student
[redacted]rsity Business School

Dear Mrs Dring

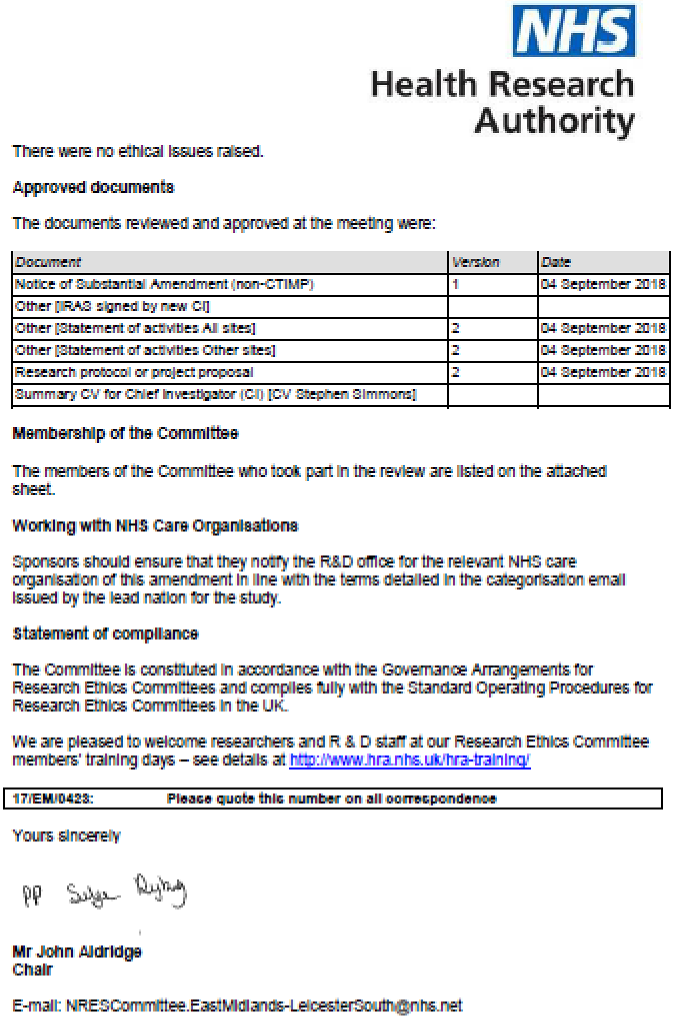
Study title:	**IMPROVING ACCESS AND SERVICE QUALITY IN CARE: EXPLORING PATIENTS' EXPERINCE OF CHRONIC OEDEMA AND SOCIAL DEPRIVATION.**
REC reference:	**17/EM/0423**
Protocol number:	**17076**
Amendment number:	**1**
Amendment date:	**04 September 2018**
IRAS project ID:	**218484**

The above amendment was reviewed 21 September 2018 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Discussion



There were no ethical issues raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP)	1	04 September 2018
Other [IRAS signed by new CI]		
Other [Statement of activities All sites]	2	04 September 2018
Other [Statement of activities Other sites]	2	04 September 2018
Research protocol or project proposal	2	04 September 2018
Summary CV for Chief Investigator (CI) [CV Stephen Simmons]		

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

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.

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

17/EM/0423:	**Please quote this number on all correspondence**

Yours sincerely

Mr John Aldridge
Chair

E-mail: NRESCommittee.EastMidlands-LeicesterSouth@nhs.net

Appendix 11: Study Sponsor Agreement

[redacted]

Our reference: RGS 17076
IRAS Project ID: 218484

[redacted]

Health Research Authority
Research Ethics Committee

Dear Sir or Madam,

Sponsorship Statement
Re: 'Social determinants of health (SDH) social capital: social deprivation, socio-economic status and access to care': An empirical study of Chronic Oedema

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

The duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

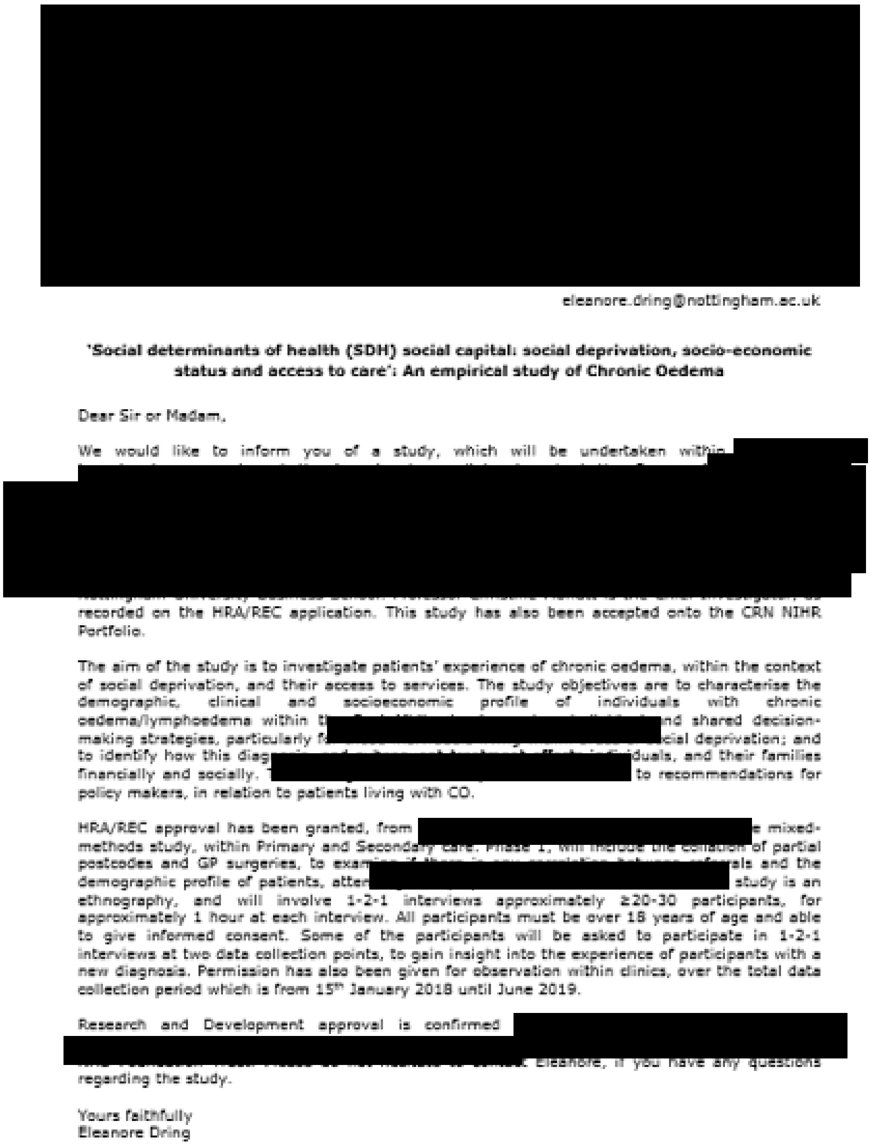
Yours faithfully

Angela Shone
Head of Research Governance

[redacted]

[redacted]

Appendix 12: Letter of request to Service provider NHS Trust



[redacted]

eleanore.dring@nottingham.ac.uk

'Social determinants of health (SDH) social capital: social deprivation, socio-economic status and access to care': An empirical study of Chronic Oedema

Dear Sir or Madam,

We would like to inform you of a study, which will be undertaken within [redacted] recorded on the HRA/REC application. This study has also been accepted onto the CRN NIHR Portfolio.

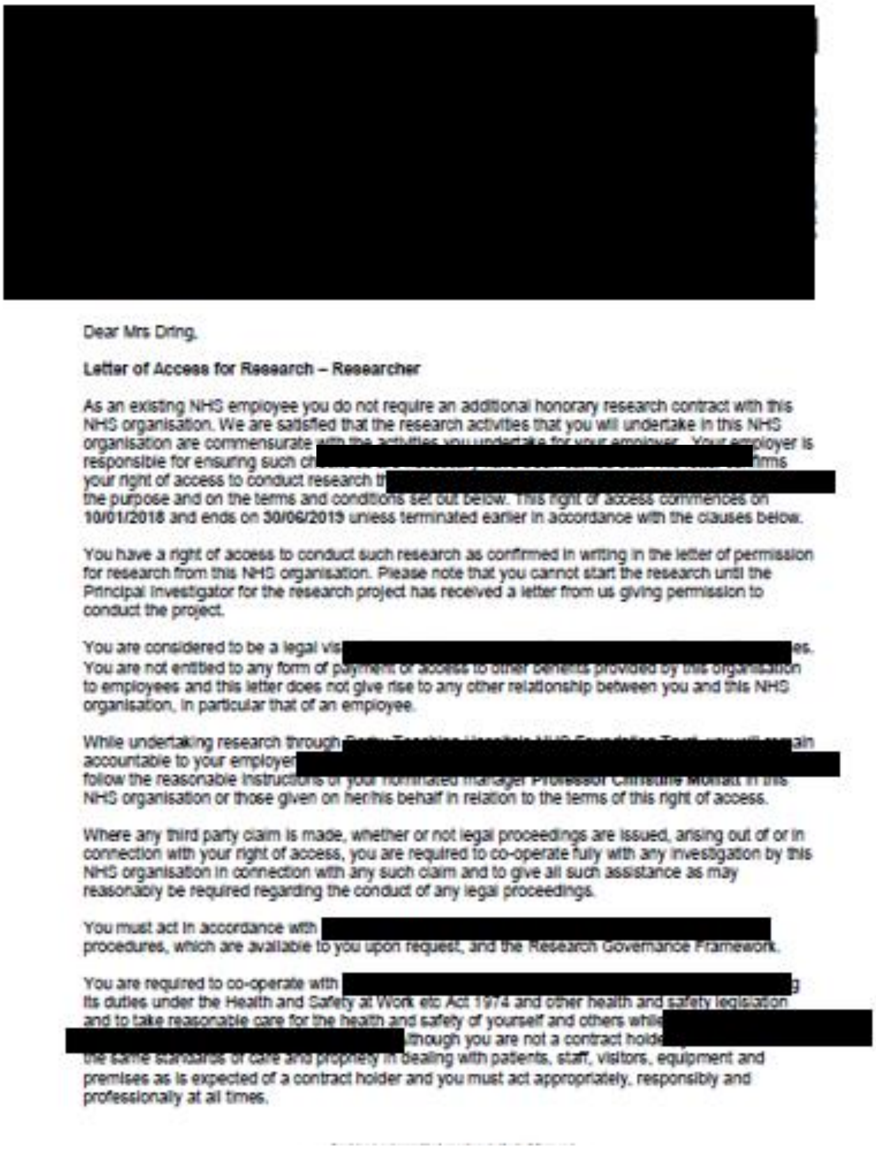
The aim of the study is to investigate patients' experience of chronic oedema, within the context of social deprivation, and their access to services. The study objectives are to characterise the demographic, clinical and socioeconomic profile of individuals with chronic oedema/lymphoedema within [redacted]and shared decision-making strategies, particularly [redacted]cial deprivation; and to identify how this [redacted]iduals, and their families financially and socially. [redacted] to recommendations for policy makers, in relation to patients living with CO.

HRA/REC approval has been granted, from [redacted] mixed-methods study, within Primary and Secondary [redacted] of partial postcodes and GP surgeries, to exam[redacted]rals and the demographic profile of patients, atten[redacted] study is an ethnography, and will involve 1-2-1 interviews approximately ≥20-30 participants, for approximately 1 hour at each interview. All participants must be over 18 years of age and able to give informed consent. Some of the participants will be asked to participate in 1-2-1 interviews at two data collection points, to gain insight into the experience of participants with a new diagnosis. Permission has also been given for observation within clinics, over the total data collection period which is from 15th January 2018 until June 2019.

Research and Development approval is confirmed [redacted] regarding the study.

Yours faithfully
Eleanore Dring

Appendix 13: Letter of Service provider NHS Trust



[redacted]

Dear Mrs Dring,

Letter of Access for Research – Researcher

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate [redacted] the purpose and on the terms and conditions set out below. This right of access commences on **10/01/2018** and ends on **30/06/2019** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

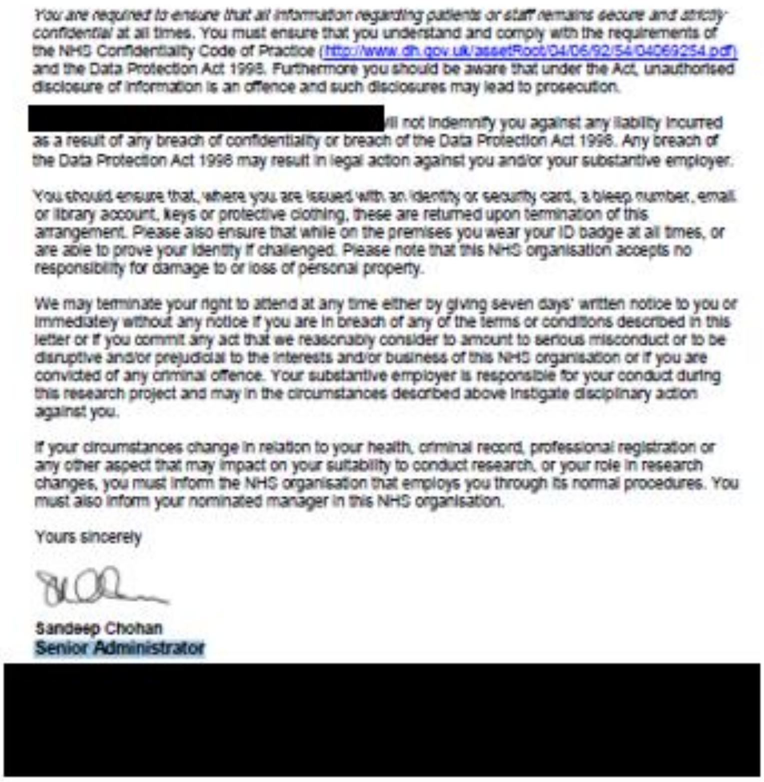
You are considered to be a legal vis[redacted]es. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [redacted] NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [redacted] procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [redacted] its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while [redacted]lthough you are not a contract holde[redacted] the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.



You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

[redacted]ill not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

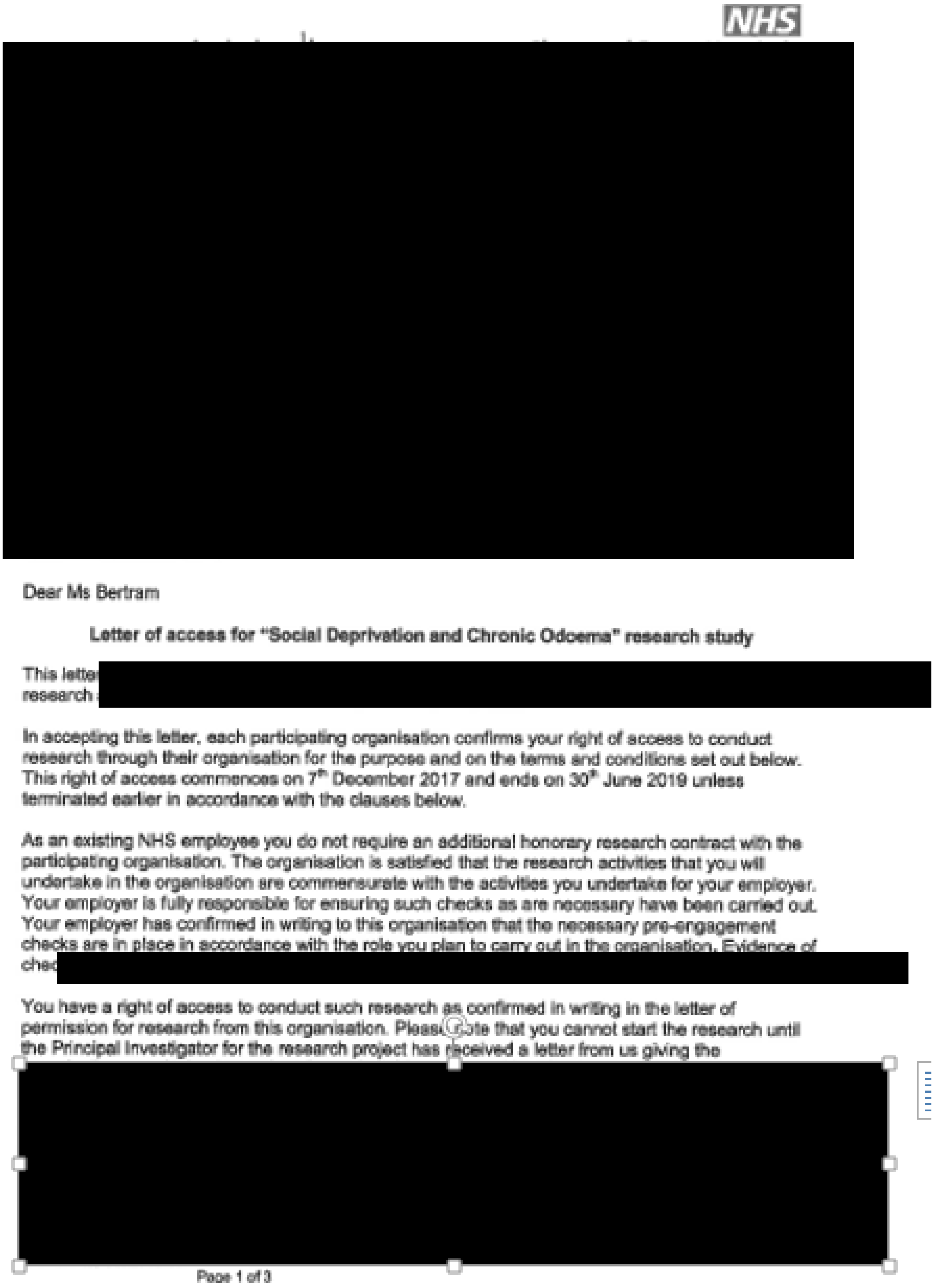
If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Sandeep Chohan
Senior Administrator

[redacted]

Appendix 14: Letter of Access to NHS Trust Site 2



[redacted]

Dear Ms Bertram

Letter of access for "Social Deprivation and Chronic Odoema" research study

This letter [redacted]
research [redacted]

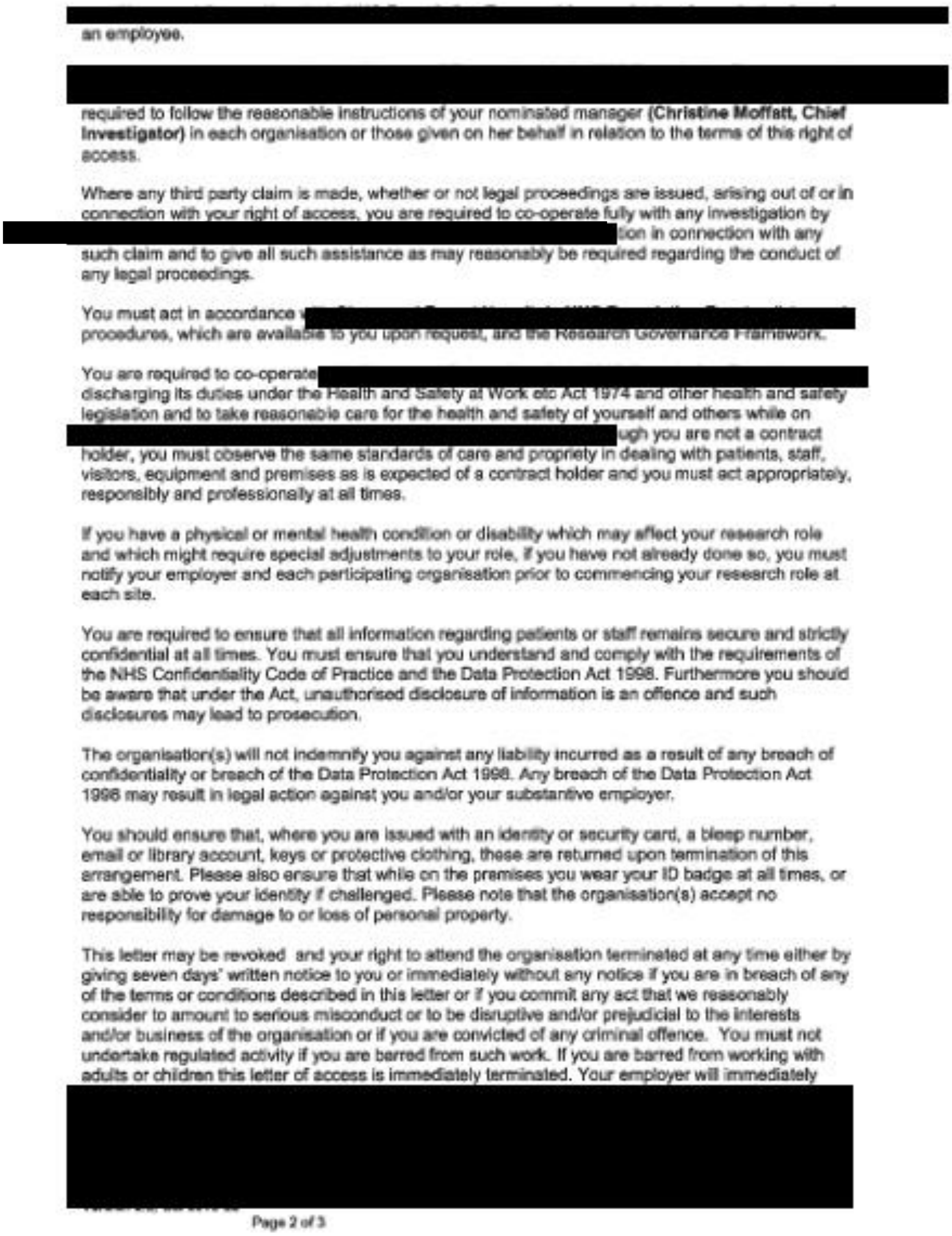
In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on 7th December 2017 and ends on 30th June 2019 unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with the participating organisation. The organisation is satisfied that the research activities that you will undertake in the organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the organisation. Evidence of chec [redacted]

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving the

[redacted]

Page 1 of 3



[redacted] an employee.

[redacted] required to follow the reasonable instructions of your nominated manager **(Christine Moffatt, Chief Investigator)** in each organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by [redacted] tion in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance [redacted] procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate [redacted] discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [redacted] ugh you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each participating organisation prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The organisation(s) will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) accept no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately

[redacted]

Page 2 of 3

withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

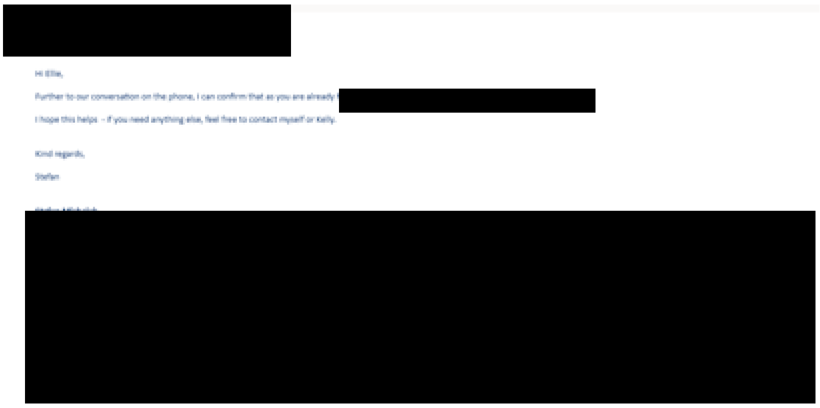
Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation..

Yours sincerely

[redacted]

Appendix 15: Letter of Access NHS Trust Site 1



[redacted]

Hi Ellie,

Further to our conversation on the phone, I can confirm that as you are already [redacted]

I hope this helps – if you need anything else, feel free to contact myself or Kelly.

Kind regards,

Stefan

[redacted]

Appendix 16: GCP Certificate 2017

NHS
National Institute for
Health Research

Certificate of Completion

Eleanore Dring

has completed

Good Clinical Practice (GCP) Refresher

A practical guide to ethical
and scientific quality standards in clinical research

on

02 March 2017

Modules completed:

Recent and Forthcoming Changes
Introduction to Research and the GCP standards
Study set-up at site
Delegation of Duties and PI Oversight
Participant Eligibility
Electronic Source Data and Site Files

This course is worth 3 CPD credits

Delivering research to make patients, and the NHS, better

Appendix 17: GCP Certificate 2020

NHS
National Institute for
Health Research

CERTIFICATE of ACHIEVEMENT

This is to certify that

Eleanore Dring

has completed the course

Good Clinical Practice (GCP) Refresher: eLearning

6 April 2020

A practical guide to ethical and scientific quality standards in clinical research

Including EU Directives, Medicines for Human Use (Clinical Trials) Regulations & the Department of Health UK Policy Framework for Health & Social Care Research, as applied to the conduct of Clinical Trials & other studies conducted in the NHS

Modules completed:

Core
Team Roles
Eligibility
Safety Reporting
Electronic Studies and Source Text
Summary

This course is worth 3 CPD credits

Delivering research to make patients, and the NHS, better

Appendix 18: Participant Information Sheet

Local Letterhead to be added

Participant Information Sheet
(Final Version 2.0 13/11/17)

IRAS Project ID: 218484

Title of Study: Chronic oedema and social deprivation

Name of Researcher(s): Eleanore Dring

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done, and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of this study is to learn more about the experience of people diagnosed with chronic oedema, how it affects their lives, so that we can learn more about how to plan services and care, which meet their needs. We would like to know what would make receiving your treatment better for you and how the care you receive could be improved, for example clinics nearer to your home, or home visits.

We would like to know more about how you found out about your condition and where and how you receive your treatment and care. This will include where you live, which clinics/doctors/nurses you go to, and if your family, friends and/or carers help to look after you. We are very interested in how much having chronic oedema costs you financially, for example your medical prescriptions, your travel, whether you are able to work or if having chronic oedema stops you from working, or stops you from coming to clinic appointments. We would also like to know how having chronic oedema affects you socially, for example, going out shopping, and being with your friends and family. This study is being undertaken as part of a PhD

Why have I been invited?

You are being invited to take part because you have attended the Lymphoedema clinic and might have a diagnosis of chronic oedema or lymphoedema. We are inviting up to 30 participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

A nurse working in your clinic will ask you if you would like to take part in some research, asking patients about what it is like living with lymphoedema. The researcher would like to conduct an interview with you and then interview you again about 3-6 months later. The interview will take about 1 hour, and will be with just you, although you are welcome to have a family member/friend or carer with you during the interview. The researcher will then contact you, at first by telephone and then by e-mail, if you have one. We will use a Dictaphone to record the interview.

We will give you a choice for where you would like to be interviewed as the researcher would be able to come to your home, or we use a room near to the clinic you attend.

By agreeing to take part in the study, we would really like you to attend each interview, and let us know if you are not possible to take part at the time arranged.

You will be asked general questions about your gender, age, ethnicity, education employment and income at the beginning of the interview. We would then like you to explain, in your own words how having lymphoedema affects your life, especially in terms of your financial situation, if you work and the amount you feel you have to spend on extra items you need because of your lymphoedema. The flow chart on page 5 describes the interview process and explains more about what to expect.

Expenses and payments

Participants will not be paid to participate in the study. Travel expenses, outside of clinic appointments will be offered for any visits incurred because of participation.

What are the possible disadvantages and risks of taking part?

The disadvantages of taking part are that this may be inconvenient for you, and therefore we want to interview you at the place most convenient for you, and you are able to withdraw from the study at any time. You may find some of the questions very personal, however we would like you to answer as honestly as you can, or want to. You may find answering some of the questions upsetting, and therefore we can stop the interview at anytime, for you to decide if you want to continue. There are no other potential disadvantages or risks.

Before we interviewed any participants, we asked members of the public and other patients for feedback.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help you, and others in the future. We would like to know much more about how having chronic oedema affects people financially, especially in terms of where you live and the care that you receive. We know that there is not very much research into this in the United Kingdom and by finding out more, we can plan and design chronic oedema (lymphoedema) services which care for people with this condition in the best way possible.

What happens when the research study stops?

When the research study stops, we will then write about what we have found and report this information back to you, if you accept point 5 of the consent form. You can also initial the consent form at point 6 to confirm if you would like the opportunity to participate in future studies and allow us to contact you again. Both points 5 and 6 are optional and should be left blank if you do not wish to consent to these points. We also ask you to initial point 7 on the consent form, to say that you understand that the information collected about you will be used to support other research in the future, and may be shared anonymously with other researchers. This is because the we hope that our results and findings will contribute to other research, and help to plan services and care which meet the needs of people living with chronic oedema and lymphoedema. Therefore, the findings of this study may also lead to other research on this topic.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting: (Local PALS details to be inserted here)

Will my taking part in the study be kept confidential?

Your confidentiality will be safeguarded during and after the study.

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of your medical records and the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information, which is collected about you, during the course of the research, will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database. Any information about you, which leaves the hospital, will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it. The interviews will be transcribed by the researcher or a transcription service, both of which adheres to all requirements for confidentiality and data security. Any identifying information will be removed when the interview is transcribed

Your personal data (address, telephone number) will be kept for over 3 years after the end of the study so that we are able to contact you about the findings of the study *and possible follow-up studies* (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time, your data will be disposed of securely. During this time, all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the interview is confidential, should you disclose anything to us, which we feel, puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

The results of this research will be written up as part of a PhD thesis, which will lead to doctoral educational qualification. A copy of the thesis will be held by the University of Nottingham. The results will also be published within academic journals. If you agree to the interview, you can initial the consent form to show that you would like to obtain a copy of the published results from the researcher. You will not be identified in any report/publication.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by The Health Foundation. The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the East Midlands - Leicester South Research Ethics Committee.

Further information and contact details

Principle Investigator/Researcher
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Chief Investigator:

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Professor of Health Services Management and Director, Centre for Health Innovation, Leadership and Learning;
Nottingham ESRC DTC Training Director;
Visiting Professor, Universidade de São Paulo
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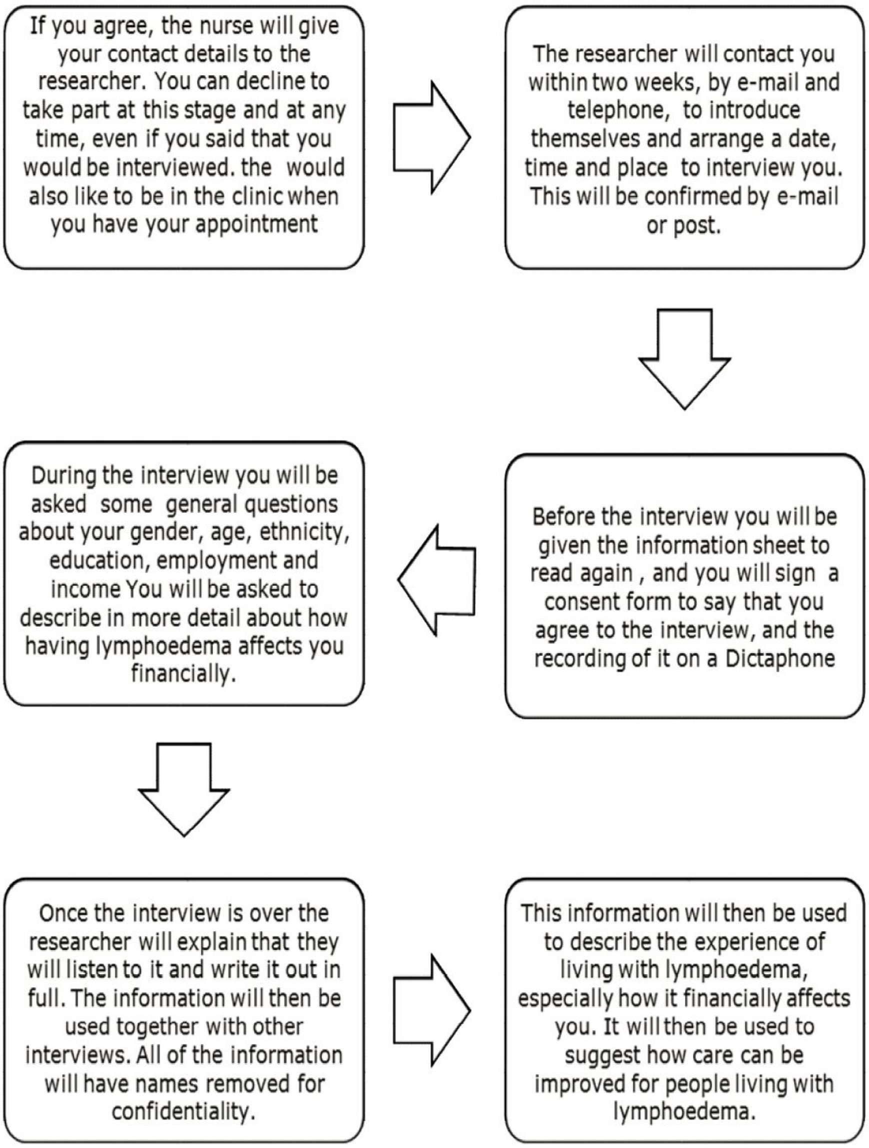
Nottingham
NG8 1BB
+44 (0) 115 8466635
Stephen.Timmons@nottingham.ac.uk

Flow chart describing the interview process



If you agree, the nurse will give your contact details to the researcher. You can decline to take part at this stage and at any time, even if you said that you would be interviewed. the would also like to be in the clinic when you have your appointment

The researcher will contact you within two weeks, by e-mail and telephone, to introduce themselves and arrange a date, time and place to interview you. This will be confirmed by e-mail or post.

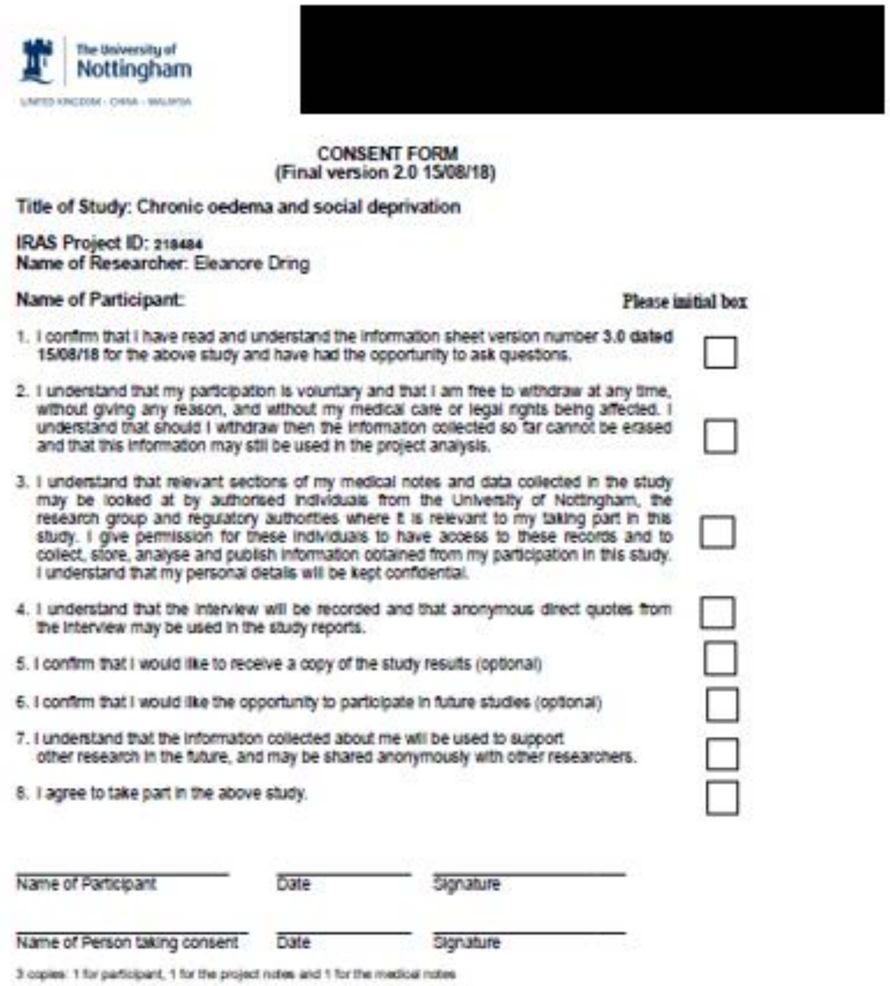
Before the interview you will be given the information sheet to read again , and you will sign a consent form to say that you agree to the interview, and the recording of it on a Dictaphone

During the interview you will be asked some general questions about your gender, age, ethnicity, education, employment and income You will be asked to describe in more detail about how having lymphoedema affects you financially.

Once the interview is over the researcher will explain that they will listen to it and write it out in full. The information will then be used together with other interviews. All of the information will have names removed for confidentiality.

This information will then be used to describe the experience of living with lymphoedema, especially how it financially affects you. It will then be used to suggest how care can be improved for people living with lymphoedema.

Appendix 19: Participant Consent Form



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

CONSENT FORM
(Final version 2.0 15/08/18)

Title of Study: Chronic oedema and social deprivation

IRAS Project ID: 218484
Name of Researcher: Eleanore Dring

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number **3.0 dated 15/08/18** for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I confirm that I would like to receive a copy of the study results (optional) ☐
6. I confirm that I would like the opportunity to participate in future studies (optional) ☐
7. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
8. I agree to take part in the above study. ☐

Name of Participant ________ Date ________ Signature ________

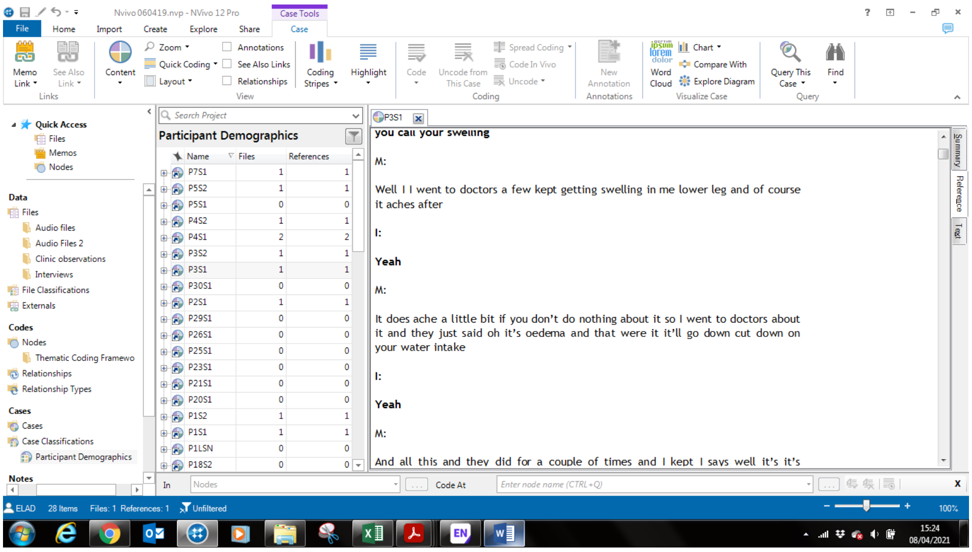
Name of Person taking consent ________ Date ________ Signature ________

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

Appendix 20: Interview topic guide

- Socioeconomic data: employment status and category, household size and income, impact of lymphoedema on employment status and income.
- Access to health care and longest travel distance to lymphoedema care,
- Reduction in the utilisation of lymphoedema health care due to geographic or financial issues
- Decision making processes, in terms of how the financial effect of the co affects access to care
- The social support available to individuals and families, in terms of formal (social services/private social care) and informal care (family and friends)
- Whether participants have been involved in any service improvements related to both clinics.
- How life at "home" differs in terms of lymphoedema care, in comparison to care at the clinic.
- Cost of lymphoedema healthcare and prospective "out-of-pocket" which may include costs related to
    - ➢ Service-user medical visits (at home and at the clinic)
    - ➢ Service-user nursing and physiotherapist care (at home and at the clinic)
    - ➢ Service-users imaging and biological tests (if private health care)
    - ➢ Service-user care as an "inpatient" (including type of facility and length of stay, if private health care)
    - ➢ Drugs & medical devices, which are not covered by NHS tariff
    - ➢ Medical transportation
    - ➢ Housekeeping and childcare expenses
    - ➢ Creams and other cosmetics, clothes & shoes
    - ➢ Spa treatments
    - ➢ Sick leave
    - ➢ Any other non-medical expenses

Appendix 21: Nvivo Transcripts and coding



Participant Demographics

Name	Files	References
P7S1	1	1
P5S2	1	1
P5S1	0	0
P4S2	1	1
P4S1	2	2
P3S2	1	1
P3S1	1	1
P30S1	0	0
P2S1	1	1
P29S1	0	0
P26S1	0	0
P25S1	0	0
P23S1	0	0
P21S1	0	0
P20S1	0	0
P1S2	1	1
P1S1	1	1
P1LSN	0	0
P18S2	0	0

you call your swelling

M:

Well I I went to doctors a few kept getting swelling in me lower leg and of course it aches after

I:

Yeah

M:

It does ache a little bit if you don't do nothing about it so I went to doctors about it and they just said oh it's oedema and that were it it'll go down cut down on your water intake

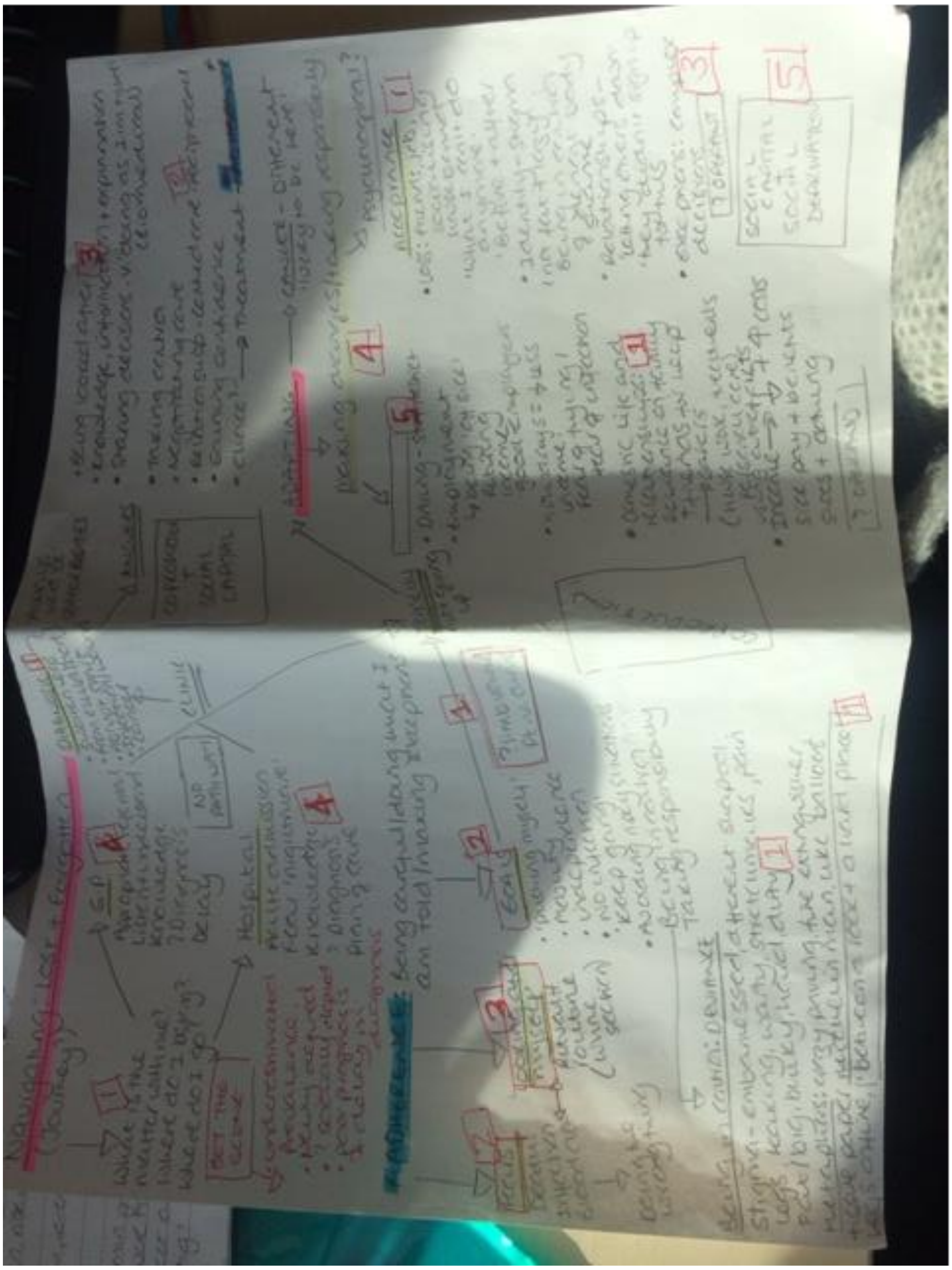
I:

Yeah

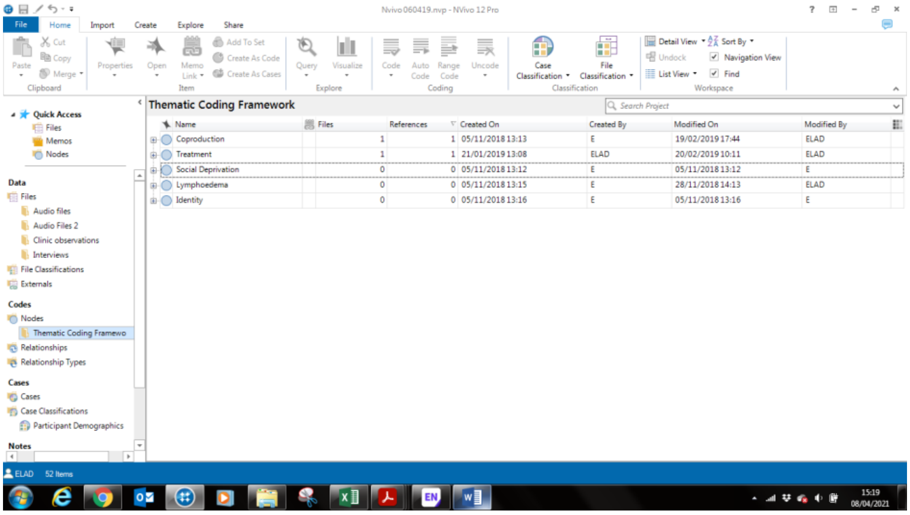
M:

And all this and they did for a couple of times and I kept I says well it's it's

Appendix 22: Initial thematic framework (raw themes from Nvivo and transcripts)

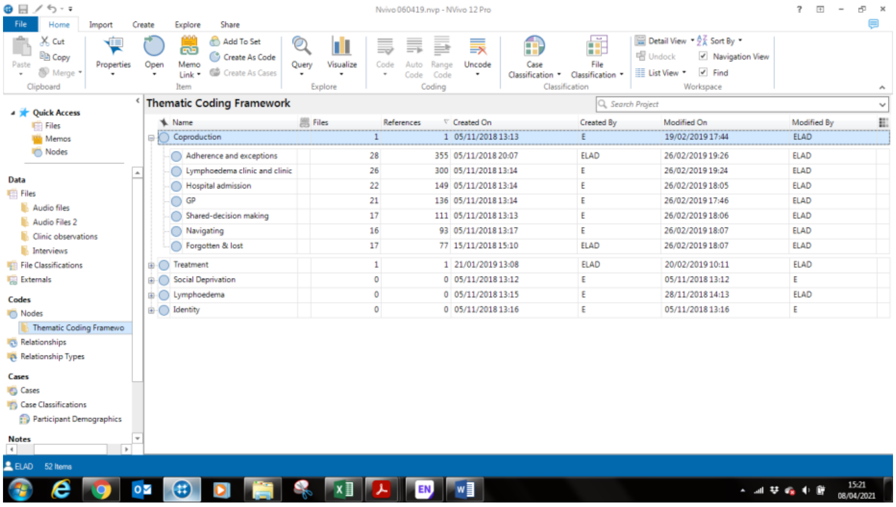


Appendix 23: Nvivo thematic codes



Thematic Coding Framework

Name	Files	References	Created On	Created By	Modified On	Modified By
Coproduction	1	1	05/11/2018 13:13	E	19/02/2019 17:44	ELAD
Treatment	1	1	21/01/2019 13:08	ELAD	20/02/2019 10:11	ELAD
Social Deprivation	0	0	05/11/2018 13:12	E	05/11/2018 13:12	E
Lymphoedema	0	0	05/11/2018 13:15	E	28/11/2018 14:13	ELAD
Identity	0	0	05/11/2018 13:16	E	05/11/2018 13:16	E



Thematic Coding Framework

Name	Files	References	Created On	Created By	Modified On	Modified By
Coproduction	1	1	05/11/2018 13:13	E	19/02/2019 17:44	ELAD
Adherence and exceptions	28	355	05/11/2018 20:07	ELAD	26/02/2019 19:26	ELAD
Lymphoedema clinic and clinic	26	300	05/11/2018 13:14	E	26/02/2019 19:24	ELAD
Hospital admission	22	149	05/11/2018 13:14	E	26/02/2019 18:05	ELAD
GP	21	136	05/11/2018 13:14	E	26/02/2019 17:46	ELAD
Shared-decision making	17	111	05/11/2018 13:13	E	26/02/2019 18:06	ELAD
Navigating	16	93	05/11/2018 13:17	E	26/02/2019 18:07	ELAD
Forgotten & lost	17	77	15/11/2018 15:10	ELAD	26/02/2019 18:07	ELAD
Treatment	1	1	21/01/2019 13:08	ELAD	20/02/2019 10:11	ELAD
Social Deprivation	0	0	05/11/2018 13:12	E	05/11/2018 13:12	E
Lymphoedema	0	0	05/11/2018 13:15	E	28/11/2018 14:13	ELAD
Identity	0	0	05/11/2018 13:16	E	05/11/2018 13:16	E

Appendix 24: Development of themes for findings and discussion

Global theme	Organising themes	Basic themes	What does this mean for the coproduction of care?
Coproduction of care (as defined by clinical outcomes),	Experience of illness	Identity and biographical disruption: What is the matter with me? Context What are the definitions health that people value?	What does this mean for coproducing care?
		Visible but hidden:, hidden and recognised condition	
		Stigmatization of self: “otherness”, the body as deviant and/or an inanimate object	
		“This is war”: the struggle, the battle	
		Goals for management (choice)Being in control: not getting worse, Living well, no infections	How coproduction is genuinely achieved when choices are limited? What can be prioritised: what does that mean for self-management?
		Fears and consequences – drivers to compliance	
		Maintain function: mobility, safety and independence (shoes)	
		Choice - what when choices are limited?	
		Developing expertise (“operant resources”), Keeping safe: Routines and rituals, seeking help	How are decisions being made at home?
		Resisting help, making exceptions, knowing self,	
		Autonomy, trust and acceptance	
		Intentional and non-intentional adherence	
	Interface with healthcare professionals (relational exchange)	Finding a way, when there is no path: Lack of consistency as no clear pathway, clinicians” lack of knowledge	Coproduction is challenged, is the patient is the expert?
		Specialist professionals: Valuable/important relationship; recognising autonomy and expertise of the individual and patient activation negotiating non-adherence or “doing as I am told”?	
		Context of healthcare system: Power, blame and judgement. Clinicians perceived as not having “operant resources” Hospital admissions and access to care and choice. Who has the operant resource?	
	Socioeconomic impact (“operand resources”).	Social capital: Specialist professionals, family, friends, carers, support group	How do “operand resources” impact on coproduction?
		Economic impact: Employment, income, daily life, adapting, capacity to use operant resource	
		Before and after: Social isolation, restricted, relationships, loss	

1. Experience of illness

- **What are the definitions health that people value?: context of the condirtion** What are the goals for management of the condition?
- **Visible but hidden:** biographical disruption, stigmatization of self, what the condition is like and how it is experienced. hidden and recognised condition
- **use of metaphors and symbolism:** describe and stigmatize self
- **What does this mean for coproducing care?**

Fears and consequences – drivers to compliance

- **maintain function:** mobility and independent, and maintain identity (before and after?)
- **What can be prioritised:** what does that mean for self-management?
- **Choice** - what when choices are limited limited because of limited treatment options
- **what are clinical outcomes?**

3. Developing expertise and “operant resources”

- **What keeps me safe?** Compliance rituals and routines, recognising when to seek help (even if this is met with barriers)
- **Resisting help: What is best for me?** wanting independence and perceived ‘normality’ even when this means non-adherence
- **Making exceptions** – social capital and identity, awareness of consequences, mitigating – even when this means risking a worsening of the condition. How are decisions being made at home?
- intentional non-adherence and unintentional non-adherence

4. Interface with healthcare professionals

- **Specialist professionals:**
- valuable/important relationship
- negotiating non-adherence
- recognising autonomy and expertise of the individual, and patient activation
- Power: blame, judgement
- **Context of healthcare system:**
- Lack of consistency as no clear pathway, clinicians’ lack of knowledge, where coproduction is challenged
- Powershift loss of controlwith healthcare professionsal who do not understand
- coproduction is challenged, is the patient is the expert?

5. Social Deprivation and Resources

- how do individuals recognise and have the capacity to use operant resource
- impact upon employment
- hidden costs
- social capital and coproduction relationship
- social deprivation and choice?

Appendix 25: Thematic Networks (Attride-Stirling, 2001)