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Exploring the effects of social network dynamics on patients receiving ‘hospital at home’ care in a rural environment.

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Abstract

Global aging places pressure on traditional models of healthcare such as inpatient wards. Part of UK government's resilience plans involves an emphasis on community services such as HaH but this risks transforming pressure onto community based services. HaH is a contemporary service which treats people with acute illness in the context of their own home. Doing so requires patients to undertake substantial self-management with Social Network (SN) involvement. This thesis uses mixed methodology to explore how this works in practice from varying perspectives, in the context of people's everyday lives, and how it is affected by wider factors such as rurality.

Three papers make up the nucleus of this thesis. The first is a metasynthesis which used district nursing services to illuminate how external influences (specifically rurality) affect the way service providers utilise SNs for patients in the community. The paper identified that in rural areas nurses work beyond professional boundaries to provide emotional support, help with daily tasks, and link to others. There was also evidence that nurses embedded within rural localities developed friend-like relationships with patients, and negotiated with existing SN to find more support for patients.

The second paper used interviews with HaH nurses to illuminate the roles of healthcare professionals and how they perceive the work of patients to be completed with the help of SN support. Findings demonstrate tensions between nurse discourse of patient-centeredness and the reality that HaH is a health-focussed service. However, there is recognition (albeit limited) of the positive role of SNs. By developing a deeper understanding of the SNs of HaH patients then nurses can identify gaps in support that could limit the experiences of patients and respond accordingly, especially for people who are vulnerable, with complex needs, living alone, and with limited access to resources.

Finally, a quantitative study from patient perspectives explored correlations between health, demographic, psychosocial, SN data and quality of life for the purpose of mapping patients' SNs and establishing which factors affect the outcomes of patients using HaH. Findings indicate that HaH treats a diverse patient group with equally diverse SN structures. This was largely influenced by having a partner. Where there was not a partner, there was a degree of substitutability, but replacing the partners' roles appears difficult. Weak ties function differently and are less important compared to chronic illness because they are unable to be mobilised quickly enough for HaH use. Regression analysis shows that self-reported health status and self-efficacy were key predictors of quality of life.

This thesis makes a novel contribution to the research literature through illuminating the contribution of HaH patients' SN members of HaH patients and understanding some of the processes and limitations through which they are mobilised. The thesis also identifies the limitations of HaH services, the gaps in care provided to patients and how SN dynamics differ from in chronic illness. HaH nurses should be given the tools and resources to formalise their process of SN exploration in order to understand how best to support patients and therefore provide they patient-centred care they aspire for.

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Research Thesis: Declaration of Authorship

I, Jack Gillham declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

   Gillham, J., Vassilev, I. & Band, R. (2021). Rural influences on the social network dynamics of district nursing services: A qualitative meta-synthesis. *Health Science Reports,* 4, e336.
8. The design, conduct and write up for each of these papers have been overseen by the project supervisors, Dr Ivaylo Vassilev and Dr Rebecca Band. They are therefore listed as co-authors on the above paper.
9. The unpublished papers, titled *What is the work and the (in)formal workforce involved in supporting people using 'Hospital at Home' services?: A nurse perspective* and *Exploring the role of social networks, the quality of life and access to support of people using Hospital at Home services* were designed, analysed, interpreted and written by Jack Gillham with supervision, advice and comments from Dr Ivaylo Vassilev and Dr Rebecca Band. The former is currently being peer reviewed for publication and the latter manuscript is in preparation for submission.
10. This thesis was designed, analysed, interpreted and written by Jack Gillham with supervision, advice and comments from Dr Ivaylo Vassilev and Dr Rebecca Band.

Signed: ....

Date: 09/02/2024

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It feels appropriate that the focus of this thesis is on the support needed from others to achieve goals because there are many people, who without, I would not be in the position to complete my PhD. Firstly, I would like to personally, and profoundly thank the wonderful Dr Ivaylo Vassilev and Dr Becky Band for their academic supervision. The support they provide has gone beyond academia into counselling, encouragement and emotional support through harder times; there is no doubt I would not have got to this stage without their guidance. Secondly, as a clinical-academic fellowship, I need to thank my clinical colleagues for the time they have afforded me to complete my work and the interest they have shown in it. I would also like to thank all the participants who have spared their time to complete questionnaires and talk to me during interviews, many of whom welcomed me into their own homes to talk about their experiences of delivering Hospital at Home treatments. I hope this thesis and its associated publications allows your voices to be heard.

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1.0 Chapter 1: Background: Taking a network perspective in understanding the professional and user contexts in supporting people with acute needs in community contexts

1.1 Introduction

Aging populations, improved technologies, and a shift towards higher prevalence of chronic illness has created a financial and care delivery strain on the National Health Service (NHS). This is in part due to positive societal changes leading to improved living conditions and a greater understanding and management of health conditions, but also has the potential to limit the quality of treatment that people receive especially given the dominantly inpatient models of care that are used (Caplan et al., 2017). In the United Kingdom (UK), government policy and planning has increased the emphasis on illness prevention and treatment outside of hospital settings in order to decrease spending, maintain health outcomes and increase patient satisfaction (NHS England, 2022). The NHS 'Long Term Plan' (2019) established how a budget increase of £4.5bn would be allocated to community health services (which represents a budget increase that grows faster in percentage terms than the overall NHS budget (Department of Health and Social Care, 2019)) which would be used to treat and support patients with acute and complex health needs outside of hospital settings (NHS England, 2019). More recently such changes have also been prioritised in response to the Covid-19 pandemic whereby bed pressure and the need to avoid iatrogenic infection were exacerbated (England, 2022, Nundy and Patel, 2020). Despite this long term policy ambition to move care closer to home achieving this appears complex (Charles et al., 2018). Furthermore, to date, the policy shift has come without sufficient recognition of how relocating acute and complex treatments into community settings places an increased time, resource, and skill pressure on patients and their family and other social network (SN) members to complete illness management tasks; and on healthcare professionals (HCPs) to understand and deliver assessments and support that meets people's illness and illness related practical and social needs within the context of their homes (Chilton and Bain, 2018). This is likely to result in a transfer of the burden from hospital settings onto individuals and/or their SN and on the services involved with delivering community based support, as opposed to removing or reducing it.

In terms of the focus for this thesis, establishing Hospital at Home (HaH) services forms part of the government resilience plans (NHS England, 2022) as one of the aforementioned community services which will reduce burden and pressures on traditional inpatient models of care. There is some evidence that there are challenges for patients using such services to mobilise resources and support from primary care-givers and formal support to meet health related need (Mäkelä et al., 2020, Leff et al., 2006). The wider literature on community based support and the management of long-term conditions has demonstrated the important role that the wider SNs play in providing illness management support (Walker et al., 2018, Vassilev et al., 2014, Vassilev et al., 2019, Rogers et al., 2011b, Vassilev et al., 2013). The range and level of support (such as illness, emotional and practical) provided by different SN members (family, friends, acquaintances, colleagues, neighbours and HCPs) is currently not well understood. The knowledge produced within this thesis will aim to improve understanding of the context in which HaH services are delivered and to extend knowledge about supporting patients living in community settings. This is achieved by taking a SN perspective in exploring the acute illness management of HaH users. This thesis will also explore the role of rurality, individual socio-demographic characteristics, health status and psychosocial characteristics (such as quality of life, loneliness, self-efficacy and collective efficacy) in shaping service users' experiences.

1.1.2 Growing policy emphasis on NHS community services

Moving services from inpatient to outpatient community services is seen within policy discourse as a process that is unproblematic and automatically successful but in reality, it tends to largely redirect pressures from the former to the latter (Bades, 2020, McKinless, 2020). For example, such a transformation pressurises community based professionals and healthcare services to adapt quickly, often unsupported, (Haycock-Stuart et al., 2010) in order to effectively support patients with ever increasing levels of acuity in their own homes. This is in a context where provision has a long history of being focussed on being as cost-effective as possible (Griffiths, 1997, NHS England, 2014) .

What is often overlooked by policy makers is that this transformed pressure is then exacerbated in the community by environmental challenges such as travel times, clinical isolation and poor infrastructures (Bades, 2020). Furthermore, there is an expectation that HCPs working in community settings would be able to become generalists in order to support increasingly varied patient groups but without additional support such as the time needed to develop the necessary skills, ongoing education and supervision appropriate for the role (Effken and Abbott, 2009). The challenges experienced by HCPs in community settings can be quantified by evidence which shows that community-based services experience marginally higher levels of staff turnover secondary to burnout, compassion fatigue and reduced job satisfaction compared to inpatient settings (Begic et al., 2019). Between 2010 and 2018 the number of qualified district nurses working in the UK fell by 42% (The Kings Fund, 2018) which equates to what NHS data shows; that in England, as of June 2022, there is an above average 12.2% rate of vacancies (n=1042) (average nursing vacancies across all specialties = 11.9%, n=47272) (National Health Service, 2022).

This may indicate tensions between what is being expected of community-based services and their capacity to deliver it (Griffiths, 2017). Therefore, questions can be raised regarding the feasibility of such healthcare models (i.e. district nurses and HaH) to provide a service that is acceptable to patients, their families and HCPs. Further understanding is needed in terms of how to best develop the needed resource and support infrastructure (including access to SNs) that can help to treat more acutely unwell patients in community settings.

1.1.3 Hospital at Home: an example of a service offering acute treatment in the home

In pursuit of achieving the goals set out for community based services (i.e. reducing costs and increasing satisfaction whilst sustaining health outcomes at inpatient standard (NHS England, 2019)) and to support an increase in delivery of care in community settings, the Royal College of Nursing (RCN) distinguishes between three domains of care: end-of-life care at home, complex care at home, and acute care at home (Chilton and Bain, 2018).

The focus of this study is the latter, often referred to as ‘Hospital at Home’ (HaH). HaH services are one of the potential areas that are likely to grow in importance because early evidence has shown it can help overcome some of the challenges facing community based healthcare services; it is a cost-effective and patient accepted service for providing acute medical treatment away from traditional inpatient settings (Leticia María Dopico, 2018, Schultz et al., 2021, UK Hospital at Home Society, 2021, Schiff et al., 2022). What has been researched to date has focussed on outcomes in terms of comparing the success of treatments with financial and patient satisfaction data and has found results to be positive (Shepperd et al., 2009, Shepperd et al., 2016, Shepperd et al., 2022, Mas et al., 2016, Rossinot et al., 2019). Patients value being in familiar surroundings, with home comforts and increased interaction with family members being some of the main reasons for higher levels of satisfaction (Saenger et al., 2020, Rossinot et al., 2019). Additionally, there is lower risk to patients, for example, the potential to avoid iatrogenic disease caused by cross infection or a reduction in physical fitness and function and therefore using HaH has the potential to increase quality of life compared to inpatient wards (Caplan et al., 2005, Mas et al., 2016).

HaH services are widely described in international literature. However, these are diverse in terms of context and focus, and there is limited understanding as to the best way of implementing such services in practice (Leff and Montalto, 2004). Typical properties are shown in Figure 1 but there are variations, which result in some services focussing solely on the elderly and frail whilst others provide more wide-ranging treatments (such as intravenous antibiotics, short-term home oxygen and rehabilitation) for equally wide ranging specialties (such as respiratory, stroke, oncology, orthopaedic and endocrinology) (Qaddoura et al., 2015). Additionally, some services see patients remotely whilst others provide treatment face-to-face up to four times a day (Arsenault-Lapierre et al., 2021, Qaddoura et al., 2015). Decisions regarding the focus of provision and treatment pathways that specific HaH services would provide tend to be based on limited evidence. This is primarily grey literature and the experiences of those who have recently established such services. This is mainly used as a way to guide conversations about need at local level whilst decisions tend to be based on logistical factors such as rurality and the demographics of the population (Chilton and Bain, 2018). From the perspective of this project, these variations in application and contextual factors will affect the experiences of patients depending on the style of HaH service and therefore the methodological approaches to data collection and analysis were chosen in acknowledgment of this.

Key features of Hospital at Home

Most commonly applied features

Acuity and Complexity The acuity and complexity of the patient condition differentiates Hospital at Home from other community services	Hospital Level diagnostics It provides urgent access to hospital level diagnostics (endoscopy, radiology) and may include bedside tests such as point of care blood tests and ultrasound	Hospital level interventions It provides hospital level interventions such as access to intravenous fluids, therapy and oxygen
Daily input It requires daily input from a multidisciplinary team and sometimes multiple visits and provisions for 24 hour cover with the ability to respond to urgent visits	Specialist leadership It requires secondary care level specialist leadership and clear lines of clinical responsibility	Inclusion and exclusion criteria Defined inclusion and exclusion criteria, with defined target population, for example for patients aged over 18 or over 65 years. These programs deliver a time-limited, short term intervention

Figure 1: *A summary of general principles of HaH services that services may be modelled on (UK Hospital at Home Society, 2021)*

More recently, NHS England has published its first official guidance on the implementation of HaH services nationally which is aimed at narrowing the gap between the demand and capacity for acute care in the community (NHS England, 2022). The guidance suggests that in the UK, where models already exist, for every 50 HaH 'beds' services can deliver treatment to a group equivalent to 31 secondary care beds (the imbalance is due to admission lengths being 5 days longer on average in HaH compared to traditional inpatient settings (Arsenault-Lapierre et al., 2021)). 86% of Integrated Care Systems (partnerships of local organisations that come together to plan and deliver joined up healthcare services (NHS England, 2023)) either already have an established HaH service or are planning to implement one in 2023. As part of the drive to increase HaH service provision, NHS England has a target that by the end of 2023 virtual wards (of which HaH makes up a significant proportion) should be accommodating 40-50 patients per 100,000 population (equivalent to 24,000 nationally) (NHS England, 2022, NHS England and NHS improvement, 2022).

However, a lack of consensus about best practice presents challenges for those establishing new services to meet these targets. The focus of this thesis will aim to contribute to such understanding by exploring what support patients require when using HaH services. This will help inform NHS guidance on how to structure and implement HaH services, and how to limit potential disparities caused by socioeconomic factors (such as living in rural areas or having limited access to formal/informal support at home) that may result in inequalities in how the service can be provided (this is discussed further in chapters 1.1.4 and 1.1.5). Improving the understanding of the role of SNs is likely to be of value. For example, while in hospital patients do not need to worry or manage any work related to daily practical task like preparing meals and cleaning whereas the default within HaH services is that it is the patient’s responsibility to self-manage. However, there is no reference as to how they should be supported to do so given that this will need to be achieved during an acute illness. Some existing literature has started to identify these gaps in research noting the work done by informal care-givers (such as partners and children) (Leff et al., 2022). However, the support that could be provided from members of the wider networks such as neighbours, community groups and friends, and the processes through which network support is mobilised, has been given limited attention.

1.1.4 Self-management, social capital and the movement towards a social network approach in the context of Hospital at Home services

Self-management

The narrative and evidence to this point has indicated that HaH services offer promise in reducing the burden on inpatient settings. However, the infancy of such services has created a disparity between the acuity of patients HaH services are treating and the understanding of how they will self-manage their illness, emotional and practical work in the absence of the more proximal HCP staff who, in traditional inpatient settings such as hospital wards, undertake the majority of illness and practical work. Self-management of health is an increasingly common expectation placed upon patients by healthcare services and is primarily seen (from a professional and policy perspective) as a means of reducing healthcare costs and the burden on healthcare professionals (van der Gaag et al., 2022). Self-management activities include medicines adherence, lifestyle changes (e.g. exercise), communicating needs to HCPs and self-monitoring (e.g. checking blood glucose levels if diabetic), dealing with emotional, practical and relational aspects of the everyday life related to living with an illness (Corbin and Strauss 1985, van der Gaag et al., 2022). However, the capacity of an individual for self-management is shaped by a number of factors and processes operating on the level of individuals (e.g. health literacy, co-morbidities, depression, health beliefs and income), networks (e.g. access to informal support), and wider environment (e.g. availability of access to services, competing duties, local access to healthy lifestyle provisions such as gyms and supermarkets) (Ahola and Groop, 2013). The heterogeneity of individual circumstances and inequalities in access to services and support makes standardising the support people require to self-manage difficult for HCPs (Bourbeau et al., 2015). Furthermore, self-management is likely to be even more challenging for those using HaH services due to the increasing levels of acuity and the infrequency of nurse-patient interaction inherent with these community based services, and therefore there may be an even greater need for informal support among this group (Chilton and Bain, 2018, Lemelin et al., 2007).

A social network approach to self-management

The self-management literature has not sufficiently acknowledged the role of network members and processes in supporting people to manage their health (Derose and Varda, 2009, Vassilev et al., 2013) despite the more recent evidence that shows that social involvement from a variety of network members improves self-management (Reeves et al., 2014, Vassilev et al., 2016). Furthermore, the seminal work of Christakis and Fowler (2011) demonstrated that people’s behaviours and quality of life are better understood as a collective network process, not an individual one. Research into SNs to date has primarily focussed on the role of what Granovetter (1983) termed ‘strong ties’ such as partners and close family. Health literature on SN engagement and building and sustaining social support has indicated the importance of SN support (Berkman et al., 2000, Heijmans et al., 2017) and that strong ties are hugely relevant for self-management (Graven et al., 2014, Dunbar et al., 2008). However, wider literature demonstrates that over-reliance on strong ties often results in physical and emotional fatigue of the carer, depersonalisation and a loss of personal fulfilment which then negatively impacts on the person they support (Pérez and Marqués, 2018, Gunnell et al., 2000). Therefore, there has been little emphasis placed on engaging with the wider network members such as neighbours, colleagues, community and hobby groups and acquaintances; 'weak ties' (Granovetter, 1983). Access to weak ties (e.g. colleagues, neighbours, acquaintances, professionals) can be beneficial in the context of health because such members can influence health behaviours and help reduce pressure on more intimate ties (Rogers et al., 2014, Brooks et al., 2012). Equally, those who are primarily reliant on support from 'weak ties' (including HCPs) are also likely to face challenges, although ones different to those whose networks are focussed on strong ties. These are more likely to be related to difficulties accessing support for practical everyday tasks, such as shopping or cleaning because they place additional and unrealistic expectations on this type of network (Crotty et al., 2015b). Therefore, there is emerging evidence that SNs and SN processes are best understood as a whole system (rather than as dyadic relations in isolation), and that it is diverse networks that include a wide range of relationships, including a range of strong and weak ties (especially hobby and community groups) that are the most likely to provide acceptable support for patients (Rogers et al., 2011b, Reeves et al., 2014, Long et al., 2013). Having access to such networks (when compared to other network types, e.g. family-centred networks) has also been associated with better health, well-being, and self-management outcomes than other network types (Litwin and Shiovitz-Ezra, 2011, Litwin, 2010). This may be because workloads can be more widely shared, increased access to wider sets of knowledge and skills (Vassilev et al., 2013, Kang and Ellis - Hill, 2015), and increased capacity for navigation and negotiation of acceptable support within people's personal community (Kennedy et al., 2015). The latter is more likely to be harder if confounded by poor health when managing increasingly complex health needs at home.

Social Networks and Social Capital

The extensive literature on social capital has articulated some of the processes through which social network engagement and support might be mobilised. Broadly, social capital can be defined as a resource that can facilitate cooperation to create individual and mutual benefits and is derived from a network of meaningful relationships and shared values. For example, those who have a relationship with a lot of people who have access to larger amounts of valuable, and different, resources will have higher social capital) (Bourdieu and Richardson, 1986, Dubos, 2017, Bhandari and Yasunobu, 2009). At the heart of social capital lies a focus on understanding and conceptualising different aspects of relationships and their properties (Dubos, 2017). Within the context of this thesis, the distinction between bridging, bonding and linking capital is especially valuable as it helps distinguish between relationships and roles of network members in terms of accessing different types of support, resources, and information (Carpiano, 2006, Ehsan et al., 2019). Specifically, bonding social capital refers to strengthening the relationships that may already be in the network whereas bridging relates to the development of new ties outside of the preexisting social circle. Finally, linking social capital refers to the way others can connect individuals with influential people, services or groups who can leverage their power for the benefit of the individual (Carpiano, 2006). The different types of social capital can play a different role within networks depending on their structure. For example, there is evidence that SN characteristics that are most likely to result in an improvement in health, quality of life and self-management network size and network diversity (Vassilev et al., 2011, Carpiano, 2006). Bridging, bonding, and linking capital can activate different processes depending on the network structure and relationships through which it operates. For example a strong tie such as a partner is likely to *bond* to other homogenous relationships (such as a friend who is likely to provide emotional support) whereas weak ties are more likely to *bridge* to heterogenous relationships (such as formal support or community groups) (Mishra, 2020, Ehsan et al., 2019). This has been confirmed by literature reviews which have found that SNs consisting of diverse, valuable and meaningful relationships can increase social capital and positively impact on the health of people with cardiovascular disease, diabetes, obesity, infectious diseases and cancers as well as on their more general self-reported health status (Rodgers et al., 2019). Although there is evidence that SNs and social capital are important in understanding how support is mobilised it is also known that this can vary between contexts (Kamphius et al., 2019). This thesis has sought to apply this existing knowledge into supporting people with acute illness by HaH services and living in rural areas. These themes will be further discussed in the following chapters.

1.1.5 External influences on the social network dynamics of Hospital at Home services: rural areas

Defining rurality

Rurality is an important aspect of this thesis that requires consideration. It is, however, a disputed concept with varied definitions and as such poses a challenge to researchers, policy makers and practitioners with community size and proximity to urban areas the most widely used yet contested quantitative measures (Cloke, 2006) (Nelson et al., 2021). Variable definitions include that of New Zealand where an area is determined to be ‘rural’ if it is further than a one-hour drive from a settlement of 30,000 people, yet the European Union (EU) uses a grid consisting of one-kilometre squares to map which of these grid-spaces have less than 20% of its population living in an urban settlement to classify it as rural (European Forum for Geography and Statistics, 2023).. Even within one country, rural areas and definitions are heterogeneous. Within the UK, rurality is defined variably by the different nations; In Scotland, rurality is defined as an area with a population of less than 3,000 compared to a population of 10,000 in England. The English definition is set by The Department for Environment, Food and Rural affairs (DEFRA) and provide scope for further sub-categories within the urban-rural continuum (there are six sub-categories. *Significantly rural, Largely rural, Urban with significant rural, Urban with city and towns, Urban with minor conurbation, and Urban with major conurbations*) (Department for Environment Food and Rural affairs, 2017). These sub-categories are used to define the rural status of local authorities, which have been relevant within this research for partly guiding the area for data collection. Despite the conflicting policy and research perspectives of rurality there does appear to be a consensus that such areas experience higher healthcare costs per patient (which are not compensated for by funders) caused by poor staff retention, poor infrastructure and reduced links with specialist support and a greater healthcare need among a typically older population (Palmer et al., 2019, Department for Environment Food and Rural affairs, 2021).

Moreover, others argue that the sole use of quantitative definitions are inadequate and that ‘rurality’ is a *social* phenomenon that can only be truly defined with a consideration of the identity and values of a community (Asad et al., 2021). For example, the characteristics of rural areas such as everyone speaking the same language, religions and social customs (i.e. there are more homogenous relationships in rural areas) tends to create less barriers to informal social support provision whereby social groups and institutions (such as neighbourhoods, schools and churches) act as effective social network (Jaye et al., 2023). However, as discussed in previous chapters, a network consisting of predominantly homogenous strong ties can be problematic regarding health management (Rodgers et al., 2019) because it is likely to result in support that is dominated by emotional and practical work whilst neglecting health work and the beneficial bridging roles provided by weak ties (such as creating links to informal support, new resources and diverse information) that can build on the already good levels of social capital in rural areas (Mishra, 2020, Ehsan et al., 2019).

These factors are important from the perspective of healthcare providers who to date largely ignore the qualitative aspects of rurality which has created irrelevant policies and practices which are threatening community healthcare sustainability and the equity of access to services (Nelson et al., 2021). For example, generalised policy (grounded on quantitative viewpoints) appears to ignore the aforementioned social factors that people in rural areas have more social cohesion, a greater social capital and a willingness to support their neighbours (Avery et al., 2021) and how this may be used to overcome challenges in accessing formal support services (Cyr et al., 2019, Avery et al., 2021). Therefore, instead of defining rural healthcare as for those outside of an “*arbitrary*” 60-minute drive from a hospital (Palmer et al., 2019), if rural healthcare were structured more closely to an individual’s perceptions of their local, rural healthcare provision, the ability of individuals to access core and specialist services and the relationships between the members of the community instead of population density (Allen, 2012) it would be more likely to balance health within the context of traditional values which would improve experiences . This section has made it clear that rurality is a challenging concept to define across many disciplines and contexts. What is clear is that applying both quantitative and qualitative approaches within healthcare may help to create a definition that is more acceptable to individuals and communities. This thesis has acknowledged these varied and conflicting definitions of rurality (that rural areas can provide opportunities for social network support through the shared values and willingness of the neighbourhood but challenges such as finances of healthcare services, poor infrastructure and reliance on strong ties and informal support remain) and acknowledges the importance of context when analysing data (as part of a critical realist perspective). Therefore, a combination of quantitative and qualitative data is used to create a clearer context for the findings of this study, ensuring that rural factors are considered when exploring and analysing the roles of SN support among HaH patients.

Hospital at Home services in rural areas

The discuss above is relevant within the context of HaH services because, internationally, HaH services have been primarily utilised in rural areas such as the Australian outback (Montalto, 2010) and Mid-Western states of the USA (Levine et al., 2021). Moreover, as a response to the increasing number of smaller, local hospitals, closing down under financial pressure it could be expected that in the UK HaH services are as likely to be implemented in rural as in urban areas. However, research into HaH services tends to disproportionately focus on urban areas (Levine et al., 2021). Therefore, a further consideration for this project is how such community-based services are shaped by factors outside the control of the patient and their SN of which rurality is one such example. Specifically, experiences are likely to be shaped by the way HaH services are structured and the resources that are available to them; these are likely to differ in rural areas compared to urban ones. Therefore, improving the understanding of the contexts in which HaH services operate is a key focus that can help identify the underlying processes and add to the transferability of the findings.

There is a constellation of factors and processes specific to rural areas that have been shown to have an impact on the effectiveness of community-based services (Thomas et al., 2014, Terry et al., 2015, Rechel et al., 2016, Papali, 2016). These include, the informal workforce (the patient's personal network) that is available to provide support to individuals is often demographically different in rural and urban areas (Lauckner and Hutchinson, 2016); the populations in rural areas have a higher proportion of aging members than in urban areas. There is also significant poverty (Smith et al., 2022) and a dearth of healthcare services in many rural areas due to large geographical distances and poor infrastructure (Kennedy et al., 2015, Todd, 2013). The service is also likely to be delivered in the context of varying psychosocial needs of residents of rural areas. Finally, there is evidence that 13% of older adults living in rural areas report feeling lonely and 49% report geographical isolation from their family; citing widowhood, financial difficulties, deprivation of infrastructure and physical health as causes (De Koning et al., 2016, Kaasalainen et al., 2014).

On the other hand, there is contradictory evidence as to how living in rural areas may positively shape network processes and support. Thus, it may be the case that SNs are more engaged in rural (compared to urban) areas due to a stronger sense of belonging to the community and shared values potentially leading to more diverse networks and acceptable support (Devik et al., 2015). Pre-existing relationships with HCPs who are embedded into the community, whose roles are often qualitatively different (when compared to those in urban areas), is also evidenced to positively shape SN processes in rural areas (Reed et al., 2016). These factors can affect the social capital of people living in rural areas (Agnitsch et al., 2006) but, the impact is not automatically positive. Networks in rural areas are more likely be dominated by strong, homogenous, ties who are more likely to offer bonding but not bridging links to others. Such a network structure might have a negative impact on individuals self-management capabilities due to the often closed nature of these communities which limits the breadth of information, resources, and types of support available (Salehi et al., 2019, Agnitsch et al., 2006). Therefore, there is need to further explore the positive and negative aspects of SNs within the context of HaH services delivered in rural areas.

1.1.6 Chapter 1.1: Summary

There is growing recognition that healthcare services are required to manage complex health needs in community settings using services such as HaH in order to manage the growing demand on traditional inpatient settings. However, structured advice on how to establish such services is limited and is likely to result in a shift in burden onto patients and their SN to self-manage whilst being acutely unwell. For successful development and implementation of HaH services then a better understanding of patients' self-management capabilities and engagement with their SN of support will be needed. This can help reduce the burden on patients, increase their social capital and help ensure that HaH services are effective (from health, experience and financial outcome perspectives) and can fulfil patient and professional needs and expectations. Such improved understanding can inform policy about appropriate infrastructure and support systems that should be embedded into the services and led to improved patient experiences and outcomes (Chilton and Bain, 2018). This study aimed to contribute to this understanding by exploring the process of patient and network engagement when providing HaH support to patients in the context of varying service structures, psychosocial factors and geographical contraints (such as rurality).

1.2 Aims and objectives

The background discussion has justified a research project that meets the following aims:

1. To develop understanding of the structural and logistical processes operating at the interface of the HaH services and the way this affects the support, experiences, and health outcomes of patients.
2. To map the informal and formal workforce of HaH patients and the work that they do to provide support.
3. To further build upon existing literature which focusses on chronic illness to explore the type of SN dynamics of HaH patients and how these shape the outcomes of service users
4. To identify candidate pathways to engaging SNs that can enhance the HaH service experience for patients, HCPs and the SN members.

These questions are explored in three stages: in a literature review, and in an empirical study that will include qualitative and quantitative parts.

1.3 The three-paper thesis format

It is claimed that up to 50% of the success of a PhD research project relies on the quality of the writing process (Dunleavy, 2003). Therefore, having designed the subject of the study based on the gaps in knowledge identified in chapter 1, thoughts turn towards how best to document and present the findings. As a piece of primary research, the thesis that accompanies the field work will take the form of a critical explanation of the findings and will aid in the dissemination of them (Booth et al., 2016), but will also become a principle measure of the success of the PhD candidature.

In order to complete the project aims, and the academic needs of the PhD student (outlined in chapter 1.2) a ‘three paper’ format has been deemed most appropriate. Therefore, this thesis consists of three substantive papers that demonstrate core research has been undertaken that contributes to existing knowledge. The three papers, that are of publishable standard, are self-contained and substantial in their own right; yet, they are also interrelated and relevant to one other. Adjoining chapters within the thesis as a whole has allowed each article to become part of a coherent body of work that meets the requirements of the University Of Southampton *Code Of Practice for Research Degree Candidature and Supervision* (University Of Southampton, 2019).

The first of the three papers included in the thesis is in the form of a qualitative metasynthesis that allows further context to the two empirical studies. The first of the empirical studies qualitatively explores, from a HCP perspective, themes around the work and experiences of patients, their SN and that of the HCP. The final research chapter analyses and explores the demographic, health and psychosocial tendencies from quantitative results of the patient participants.

1.4 Summary of thesis chapters

- Chapter 2: *Theoretical and methodological influences and considerations*

  This chapter details the influences on the design of the study (the researcher, PPI, ethical considerations, the Covid-19 pandemic and theoretical perspectives) which, in part, explains the decision to use the ‘three-paper format’ for this thesis.

Reflections on such issues, and iterations between the researcher, the supervisory team and the ethical approval committee resulted in the clear methodological plan that was developed for both a literature review and a primary, mixed-methods, multi-perspective study. The specifics are detailed in the following chapters.

- Chapter 3: *Paper One: Literature review: Rural influences on the social network dynamics of district nursing services: A qualitative meta-synthesis*

  This chapter utilises the rigorous qualitative synthesis technique, Metasynthesis, to integrate the themes identified in chapter one. In doing so, a paper was created that added a unique perspective of these themes and gave more context and background to the empirical papers (Gillham et al., 2021).

- Chapter 4: *Empirical research: the design and implementation of the primary research phases*

  This chapter outlines the methods and techniques used for data collection and analysis of the qualitative and quantitative papers in chapters five and six respectively.

- Chapter 5: *Paper Two: Qualitative study: What is the work and the (in)formal workforce involved in supporting people using 'Hospital at Home' services?: A nurse perspective*

  This chapter contains the second of three papers produced in a publishable format. Qualitative, semi-structured interviews with nursing staff from a HaH service are used to greater understand the roles of varying SN members. At the time of submission of this thesis, this paper is undergoing its second iteration of the peer review process in *Health and Social Care in the Community*. However, for the purpose of discussion in this thesis it will be cited as follows (Gillham et al., 2023).

- Chapter 6: *Paper Three: Quantitative study: Exploring the role of social networks, the quality of life and access to support of people using Hospital at Home services.*

  The final empirical study is presented as a publishable journal article in this chapter. This quantitative study used answers to a questionnaire of patients at the point of discharge from a HaH service to improve knowledge of the experiences patients have when using such services and what effect it and the wider SN and psychosocial factors had on the participants' quality of life during their admission. At the time of submission of this thesis, the study was yet to be submitted for publication. Its target journal is *PlosOne* and, for the purpose of discussion, will be cited as follows within this thesis (Gillham et al., in preparation).

- Chapter 7: *Discussion and conclusions*

  This chapter offers a synthesis of the findings from all three studies and how they have informed the aims of the thesis as a whole. The chapter recaps the findings before presenting the novel themes that have arisen from the synthesis. What implications the themes will have on practice and any future research that is required to further develop the findings has also been highlighted in this final chapter.

2.0 Chapter 2: Theoretical and methodological influences and considerations

2.1 Introduction to chapter

This chapter will explain how and why this exploratory, multi-perspective study, uses a mixed method research approach to better understand the role of SN support of people using HaH services. Taking a mixed methods approach allows the study to develop a better understanding of the work involved in addressing people's needs when being supported to manage acute illness in their own homes, and the SN dynamics and negotiations at the interface between patient, healthcare professionals and other members of people's SNs (Sowicz, 2017, Sandelowski, 2000, Şahin and Öztürk, 2019).

All research is taken from a certain position and requires awareness of and reflexivity on the influence of wider, external contexts (Adu-Ampong and Adams, 2019). This chapter acknowledges and explores such questions in relation to the background and interests of the researcher, patient and public involvement (PPI), underlying philosophical perspectives and concepts that have informed the project and the methods used, ethical considerations, and finally the Covid-19 pandemic as the specific context within which the study was conducted (Liamputtong, 2010, Bowling, 2014).

2.2 Reflexivity of the researcher's position

Acknowledgment and reflection on the researcher's position has increased in prevalence in recent times and has helped highlight how positionality shapes each stage of the research process (Dwyer and Buckle, 2009, Adu-Ampong and Adams, 2019). Therefore, the following paragraphs discuss the PhD researcher's position and offers a critical assessment of how this may have informed and shaped the data collected and analysis within the project. As a practising nurse, whose experience of research was primarily as a 'user of' rather than a 'producer of' evidence, I would have intrinsically developed my relationship with knowledge by prioritising its value to practice. When, I joined the PhD programme I had limited knowledge and preference in relation to research methodology or paradigm, but had a clear focus on finding the best way to develop research that could improve the understanding of the problem that has been identified (Chapter 1). Therefore, I approached the subject with an open mind in terms of the best approach to address it.

Nevertheless, informally, through personal discussions, nurses have been described to me as “fixers” who attempt to solve problems and make things better, often at times beyond their control. Control of this ‘knee jerk’ reaction to problem solving came under the jurisdiction of personal reflection as I distanced myself from ‘fixing’ towards exploration and consideration; which, at times, may of felt to me like an unfamiliar terrain. To overcome my relative inexperience as a researcher, reflection and reflexivity throughout has been integral for allowing an adaptation and enhancement of my personal skills and the project design (Moule et al., 2017). Furthermore, utilising the experience of co-researchers to peer review my approaches to research has ensured rigour was maintained (Pope and Mays, 2006b).

As a practising nurse of nine years (across varying services) I have developed a breadth of experience of working within traditional, inpatient models of care before moving into the rural HaH service that is the subject of this research. Experience across a range of settings allowed for reflection on the different experiences HCPs and patients have and the way contextual factors can affect their lives. Furthermore, the area of research of this thesis is within the community I live in and thus raises concerns around ‘insider’ versus ‘outsider’ approaches to research. Although being an ‘outsider’ may have offered an objective view compared to an ‘insider’ whose shared characteristics and commitments may of influenced data collection and analysis, an ‘insider’ can be viewed as a shared stake-holder of the phenomena, and as such have a greater comprehension of it. This will, in many ways, allowed for reflections, analyses and conclusions to be drawn that are more sensitive to the contexts of the people being supported by the HaH service (Kerstetter, 2012). Furthermore, being an ‘insider’ enabled the development of trusting relationships that were used to enhance the sharing of information during data collection (Kerstetter, 2012, Saidin, 2016). From the perspective of this project, the researcher would be considered an ‘insider’ due to the pre-existing collegial and nurse-patient relationships that had been formed during clinical practice (Kerstetter, 2012, Saidin, 2016).

As this personal reflection suggests, as a practising nurse of relative experience within the chosen topic, then self-critique of insider traits have bettered the impartiality of the research process and harnessed the positives associated with insider research. I was then able to increase awareness of my place on the insider/outsider continuum (Dwyer and Buckle, 2009). This reflection is concisely phrased:

> *There is no neutrality. Only greater or less awareness of one's position within the research. Understanding this aids in the limiting of one's own biases* (Dwyer and Buckle, 2009).

When applying this discussion to the specificities of this project, the insider perspective impacted on several areas of the research process. Firstly, it helped in the identification of participants for qualitative data collection and purposeful sampling. Secondly, there was an increased likelihood of successful recruitment of patient participants due to pre-established relationships and rapport. Furthermore, it was not uncommon for the researcher to have nursed the participant and therefore the interpretation of the data was informed by the lived experience of the patient. Broadly speaking, my clinical experience and conversations with patients and HCPs who become research participants has allowed me to develop lines of enquiry that are pertinent within rural HaH services (for example, the challenges associated with attending hospital appointments, managing daily tasks whilst unwell with the help of SN support and how staff balance logistical constraints alongside the desire to be holistic and patient-centred). As such, this experience and observations have been reflected within the chosen measures for quantitative data collection as well as in the interpretations of the discussion of this thesis (chapter 7). Finally, as a practicing nurse within a HaH service, the implications for practice (chapter 7.4) can be directly discussed and implemented at the research site, thus increasing the impact this research can have in practice.

2.3 Patient and public involvement (PPI)

Research in which patients or other people with relevant experience contribute to how research is planned, conducted and disseminated is the best way to generate new knowledge (Health research authority, 2017). Therefore, PPI has been utilised at different stages of developing this project in order to improve the collection, analysis, and interpretation of data and linking findings to the needs of patients. In doing so, data collection methods have become more comprehensible, topics for inclusion in qualitative interviews have become more relevant and therefore outcomes have been increasingly valid, transferable and practical (Nolan et al., 2007, Chambers et al., 2009).

PPI in research is a relatively contemporary phenomena, which has gained significant momentum as an advancement of the evidence-based practice era in response to the conflicting priorities between researchers and the public that has led to irrelevant research, or misguided practice (Koutroumanos et al., 2013, Chambers et al., 2009). The inclusion of 'consumer experts' can help to overcome this and improve the relevance of research topics, data collection techniques and associated policies (Nolan et al., 2007, Grotz et al., 2020). Funders such as the National Institute for Health Research (NIHR) ensure patients and members of the public are on funding panels and ethical review boards (Evans, 2014) (which was the case for ethical review of this project) and have applied compulsory PPI regulations for proposers to gain commissions (Koutroumanos et al., 2013).

Discussions of PPI have moved from 'if' to 'how' PPI could be best incorporated in research. Many researchers argue that true emancipatory research places the patient and public researchers as leaders and controllers of research projects. However, this is not the universal agreement (Greenhalgh et al., 2019, Jackson et al., 2020). Within this project the PPI (which could include patients, potential patients or people who use any health services (NIHR 2016)) came via people who had not used the HaH service but were local to it. They are therefore *potential* patients, as well as users of other NHS services in the locality who had good understanding of different aspects of the local contexts such as rural factors and the above average age of the population.

This PPI was from a group of voluntary patient research ambassadors (PRAs) at the NHS trust of which the HaH service was within. The group included people of varying gender, age and other demographic characteristics, who were widely and willingly accessible via email, video conferencing (individually and in focus groups) and face to face to assist in the research. The group was initially very large (approximately 30) but some participants become more invested over time, which led to a core of five patient research ambassadors (PRAs) who regularly met with me. At planned meetings with the PRAs I provided updates regarding the project progress with a relaxed and conversational approach that allowed members of the group to contribute regularly to the development of the project and to feel involved as peers and as important stakeholders to the research (Jackson et al., 2020). This resulted in open dialogue where everyone could share their opinions, questions and concerns. Meetings varied in length and frequency but were particularly intensive during project planning to ensure ethical considerations were taken from the patient perspective (for example, one PRA highlighted the potential burden caused by participants posting the questionnaires back to the researcher in the quantitative part of the study) and that written information was comprehensible and well formatted. This support has benefited this PhD work and enabled this project to approach data collection from a position of greater sensitivity, impartiality and with more focus on themes relevant to members of the public such as criticisms of healthcare focussed services and challenges accessing support from HCPs. In doing so, members of the group willingly assisted with the writing of plain English summaries and participant documentation such as information sheets, consent forms and questionnaires. Furthermore, the select group of PRAs reviewed some of the anonymised interview transcripts. Personal interpretations of interview transcripts would be presented and then the group would discuss the differences and similarities of each interpretation until a consensus was reached. This was a valuable step in the analysis process that improved impartiality and offered a ‘real-world interpretation’ of the data and helped identify trends that may have otherwise been overlooked or interpreted differently (Parkes et al., 2014).

However, as volunteers, the PRAs had a proactive desire to be involved in the research that not all members of the public have which raises a potential concern that by solely seeking support from this groups I have potentially limited the perspectives of those less inclined to volunteer due to lack of spare time, ill health or no IT access (Nolan et al., 2007). However, during the regular meetings the group of PRAs were very considerate of others, with the needs of patients from different backgrounds forthright in their discussions.

2.4 Ethical considerations

2.4.1 Introduction

This project, like all research, needed to be undertaken in an ethical manner (Beauchamp and Childress, 2009) and gain approval from the appropriate ethics committees of the Health Research Authority (HRA) (National Institute for Health and Care Research, 2023). The standards of ethics in this research are not the result of chance (Wa-Mbaleka, 2019). Due diligence was undertaken with thorough planning to ensure that the research would be undertaken within the framework that is widely used in health and social research: principalism (Parahoo, 2014). This part of the chapter is structured on the four domains within this ethical model: autonomy, beneficence, non-maleficence, and justice. From a mixed methods perspective, ethical considerations may differ between the qualitative and quantitative approaches.

2.4.2 Autonomy

Before data collection begins researchers are duty bound to ensure that participants are fully informed of the purpose and aims of the study and what is required of them in order to make an informed decision about whether to take part (Wa-Mbaleka, 2019). In this study participants were given the best available information on the study in the form of verbal (from the researcher) and written information (information letter), outlining the key benefits to practice, pertinence to health policy and potential risks to their emotional wellbeing. This knowledge meant participants could give informed consent. The right to discontinue/withdraw without reproach was clearly explained to the participant both verbally and in the Participant information sheet provided. They were also encouraged to contact the research team with any questions they may have.

2.4.3 Beneficence

This principle ensures that the project is designed to maximise the benefits of the research (Miller et al., 2012, Heale and Shorten, 2017). To uphold this principle, participants were informed via information letters and verbal discussion with the researcher that by taking part in the study their involvement would add to the pool of knowledge around HaH services especially because such services are in their infancy and there is therefore many gaps in research that the participants' involvement will help to fill (Leff et al., 2022). The chosen research methodology (mixed-methods) further improves the likelihood of the data being widely accepted and transferred into practice (Sowicz, 2017) and therefore improving the benefit of taking part. Finally, by taking part participants, as potential future patients, could benefit from a service that is more evidence based and improve an increasingly common service style which they and others may access in the future.

Researchers are entitled to compensate participants for their time and effort (Wa-Mbaleka, 2019). Despite consideration of this it was deemed outside of the scope of this thesis to provide monetary incentive or "promises" (Taylor et al., 2015).

2.4.4 Non-maleficence

The declaration of Helsinki in 1964 states that the most important ethical principle is that the patients welfare takes precedence over the interests of the research (Heale and Shorten, 2017). From the perspective of this project several ethical considerations were made at each of the three research stages. During the first stage, the literature review, all included articles had been granted ethical approval and could therefore be deemed to be compliant with the principles of non-maleficence. In the second phase, the first empirical study, it had been considered that the HCP participant undertaking the qualitative interviews may feel unhappy or uneasy discussing their professional practice, their relationships with patients, and their personal networks of support. This was mitigated by adding opportunities to move onto a different question, take a break during the interview or to terminate the interview at any time. This was added to interview schedules to respect the participant's wishes (Beauchamp and Childress, 2009). The interaction with the researcher was minimal, therefore a risk of disrupting other social interactions and any associated psychological damage was considered low. During the quantitative study with patient participants, the time given to complete the study (completing two questionnaires) should have totalled no longer than two hours across a 12-week period. Therefore, any maleficence associated with over burdening was deemed to be relatively low. This was explored during the planning stage by piloting the study with PRAs who found the process to be manageable – although they were not experiencing ill health, which the patient participants are (the insider perspective of the researcher helped to identify those most likely to be burdened by the questionnaires and these individuals were supported as appropriate).

Finally, anonymity is a key principle of all research (Parahoo, 2014). In this study, all quantitative and qualitative participant data were anonymised in order to protect the participants from any reproach (from either health services or members of their personal network).

2.4.5 Justice

This final core principle as presented by Parahoo (2014) requires researchers to ensure that research is conducted fairly in a way that does not favour or add disproportionate weight to one participant (and their data) over another (Heale and Shorten, 2017). From a patient participant perspective, the quantitative surveys were disseminated to all patients who fit the criteria outlined in later chapters of this thesis and therefore no discrimination can occur. Less clear-cut is the process of the qualitative, semi-structured interviews of HCP participants. This project approached all nursing staff from the chosen HaH site and invited them to take part but the chosen methods of data collection was ‘purposeful sampling’. Purposeful sampling is a method that contests the notion that exhaustive sampling is the most legitimate form of data collection (i.e. that all potential participants actively take part) (Suri, 2011). Purposeful sampling is widely used in qualitative research and is ethically sound because it ensures that a diverse and information rich sample is included that represents the population as a whole (Palinkas et al., 2015). However, in the interest of fairness, and to maintain ethical standards, the research method allowed anyone (who met the inclusion criteria) to take part if they have a proactive desire to have their voice heard. All of these decisions were communicated with the potential participants (Beauchamp and Childress, 2009).

2.5 The effects of COVID-19 on this project plan

As with all healthcare services, the COVID-19 pandemic created significant challenges for the research design of this PhD study. The pandemic and compulsory suspension of data collection that ensued in light of government social distancing measures during the early stages of the pandemic in the UK, and the clinical demands placed upon HCPs, resulted in a delay to starting data collection for this project. Subsequently, practice protocols for this project which had been developed before the COVID-19 pandemic required amendments to be made that ensured effective, safe and beneficial practice could be maintained (Health Research Authority, 2020).

The study was required to adapt to enable aims to be met whilst ensuring the safety of the patient and HCP participants and the PhD researcher. Such amendments ensured that the project could continue within the legal requirements of social distancing which would avoid exposing either party to avoidable social contact, especially when considering the nature of healthcare services means most participants find themselves self-isolating when deemed to be a ‘vulnerable person’ (National Health Service, 2020). In order to prevent participants having to leave their home, an online version of the questionnaire was developed and the option of postal or online participation was given to the participant. Similarly, qualitative data collection was offered remotely to those who felt more comfortable being interviewed via telephone (Ward et al., 2015). For the researcher this meant considering the debate on the quality of telephone interviews whereby researchers are unable to use or interpret body language to guide the interview (Pope and Mays, 2006a). To reduce potential limitations, best practice was followed. This meant listening back to interviews and self-critiquing the level of directiveness used (Whyte, 1982, Farooq, 2015) as a part of reflexivity exercise to ensure lessons could be learnt and techniques improved for subsequent interviews (Pope and Mays, 2006a, Jacobsen, 2016, Farooq, 2015). Since amendments had been made to the protocol (appendix 1) and supporting documentation (appendix 2 and 3), ethical approval needed to be sought for a second time.

Beyond such disruption to the timetable of the project it was clear that government imposed social distancing laws would, by their very nature, disrupt and transform the themes that this project was investigating including SN support and dynamics (Snyder and Worlton, 2021, Saltzman et al., 2020, Comas-Herrera et al., 2020), quality of life (Guida and Carpentieri, 2021), loneliness, the opportunities available to HCPs to provide relational work and therefore the experience of using community services (Schultz et al., 2021, Nunan et al., 2020, Mitchell et al., 2021, Heller et al., 2020). The way these factors may have influenced the findings and informed the interpretation which, where appropriate, is built upon in the discussions of each paper and in the overarching discussions in chapter seven.

Finally, it has been argued that the Covid-19 pandemic has strengthened the need for patients to remain in their own homes where possible to avoid iatrogenic infection and reduce inpatient pressures caused by the hospitalisations of the virus (Schultz et al., 2021, Schiff et al., 2022, Pericàs et al., 2021, Nundy and Patel, 2020). This recognition is noticeable at national and local policy level where the drive to expand HaH services and diversify the type of patient that can be supported has gained tangible interest and momentum as a result of new national guidance and public attention in the main-stream media (Donnelly and Turner, 2023, BBC, 2023). This feels, anecdotally, and through personal experience, that the rapid increase of targets and demand for HaH services at management and policy level has been expedited by Covid-19 associated pressure.

2.6 Theoretical perspectives

2.6.1 Introduction

When choosing the approach to answering a research question it is imperative this is done in such a way that it aligns with the researcher's philosophical assumptions (Burns et al., 2022, Rehman and Alharthi, 2016). Guba and Lincoln (1994) define a research paradigm as the worldviews and beliefs that determine the researcher's view of reality. As a researcher there must be an awareness of how to interpret and understand the nature of reality (Rehman and Alharthi, 2016, Guba and Lincoln, 1994). There are many ways of thinking and explaining an occurrence and the implications of a phenomena which is mostly underpinned by differences in ontology, epistemology and methodology (Adom et al., 2016, Doyle et al., 2009). By applying this thinking and explanation in relation to the research aims, the choice of the most appropriate paradigm and methodology has been identified (Doyle et al., 2009). Furthermore, as a researcher, the theoretical lens used to view the world is necessary in order to interpret the findings and has thus, also, identified approaches for analysis (Rehman and Alharthi, 2016).

In summary, paradigm differences influence how we develop knowledge, our interpretation of the reality and our values and methodology within research (Doyle et al., 2009). Although, there are many research paradigms grown from the roots of interpretivism and positivism respectively, this section of the thesis will clarify how the study was informed by arguments and concepts developed within constructivist (a contemporary evolution of interpretivism (Adom et al., 2016)) and critical realist perspectives. Drawing on these perspectives has helped in keeping focus on identifying and interpreting the interrelations between complex processes, asking critical questions throughout the research process, theory building and, improving understanding.

2.6.2 Drawing on Constructivism and Critical Realism

Constructivism

Constructivist views suggest that there is no single reality or truth but the way in which we view the world is, instead, created by individuals or groups (a researcher or a research group). In other words, constructivism elicits that what we might think of as reality is not fixed, or objective in a strictest sense, but it is instead constructed according to particular perspectives (Smelser and Baltes, 2015). This view sensitises researchers to the key role that experiential knowledge has in understanding the complexity of the world and in identifying invisible mechanisms and power relations that shape the individual and social framing and understanding of phenomena (Burns et al., 2022). Therefore, as in their everyday lives, researchers will interpret the world and the findings of research by exploring the experiences of others and developing in-depth engagement with the worlds and narratives of their respondents. This paradigm also appeals to researchers' curiosity of the world (Adom et al., 2016) and encourages them to explore what might be taken for granted, although from a positivist perspective this may feel as if they "reinvent the wheel" (Dogru and Kalender, 2007). Research with a constructivist stance is best undertaken in 'the real world' and not in controlled settings, and the best knowledge is thought to be developed through 'doing' (Adom et al., 2016). The thought behind this philosophical approach is well captured by the philosopher Confucius: *"I hear and I forget, I see and I remember, I do and I understand"* (Adom et al., 2016). Furthermore, it is argued that this paradigm lends itself to 21st century ethics of inclusivity within the diversity and multiculturalism of contemporary times (Neimeyer and Winter, 2015).

However, despite its increased application, constructivism is not without its critics. Mostly from those with the philosophical perspectives of 'positivism'. These criticisms suggest that there may be detrimental effects of adopting a radical constructivist view within which 'anything goes' and becomes difficult to distinguish between rival explanations about the world. Such a view of the world could risk or delay implementing new interventions in health and social care by undermining understandings of truth and objective meaning (Neimeyer and Winter, 2015).

Critical realism

Critical realism is relevant in this thesis through its understanding of reality as complex and multi-layered and of our knowledge about it as necessarily limited, and through the emphasis on understanding and developing explanations (that incomplete but plausible) rather than on predictions. Critical realism offers a middle way to view the world born in consideration and criticism of the 'paradigm war' between positivism (that there is a single reality that can be fully understood through data) and constructivism (that reality is not fixed but constructed by an individual or group depending on their perspectives and contexts) (Bhaskar, 2013). More broadly, critical realism is considered to be an all-inclusive philosophy that can adopt aspects of constructivism and positivism to acquire a better understanding of unobservable (and therefore unmeasurable) issues and the generative mechanisms in the context of social interactions and when practically applied is less dichotomised by the traditions of either (Lawani, 2021). Critical realists are therefore able to go beyond barriers with the aim of placing explanations at the centre of the phenomena in question to consider the empirical (observed findings), the actual (which extends beyond the empirical to place them within the context they occur) and the real. The real, refers to the causal and contextual mechanisms which are often invisible but have the power to affect the outcomes being measured but cannot be fully understood by using quantitative study alone (Lawani, 2021). Therefore critical realist perspectives have guided this research by sensitising the researcher to the incompleteness of all knowledge and that the complexities and nuances of reality can only be better understood through further enquiry which is best undertaken with a consideration of social contexts by using multiple research methods (Lipscomb, 2011).

Furthermore, from a critical realist perspective, our theories of the world are best tested by their practical adequacy (i.e., if they are helpful in explaining the problem under investigation and if they are better than other existing theories) rather than by their fallibility. Such a focus offers more promise in terms of ability to explain the phenomena of interest in real-world contexts (Lennox and Jurdi-Hage, 2017). This philosophical perspective informed the research methods but also sensitised this project to the unique potential critical realism has to investigate the 'social reality' and interpret the findings beyond empirical data towards a greater explanation of the project aims (i.e. that social relations are central to explaining a phenomena) (Lennox and Jurdi-Hage, 2017). Therefore, critical realism insists that the research methods should be chosen depending on what is most appropriate to answer the research questions and on what is most likely to develop an understanding that is better than what already exists (Sayer 1992). Within this study, both quantitative and qualitative methods were deemed necessary to explore trends in the engagement of network members (i.e., demi-regularities) but also the social context within which these relationships take place. This is consistent with the critical realist view that research need not be limited to one methodology and that combining quantitative and qualitative methods is not insurmountable (Lipscomb, 2011), while the use of methods needs to be guided by the question under investigation. The use of mixed methods is consistent with critical realism as it offers the opportunity to gain the broadest range of views that can assist in the formulation of an explanation of a phenomenon. In this study, from a critical realist point of view, quantitative data were not used to uncover regularity (as per positivist perspectives) but to confirm the findings of qualitative aspects and further deepen the understanding. To maximise the benefits of this approach, the mixed methods research techniques used in this project collected and analysed data in the real-life context of patients (best described as open systems in which different mechanisms interact and change over time) (Buch - Hansen, 2014). Finally, Lawani (2021) advocates that the first stage of critical realist research should be comprised of a literature review. The relevance of which is to establish trends, identify relevant conceptualisations and theories, and define research questions that are focused on explanations and are theory driven. This has been adopted as the first stage of the project plan.

2.6.3 Social network analysis

SNs are defined and measured as connections between people, groups, political entities (states or nations), organisations or companies (Marin and Wellman, 2011). To paraphrase Borgatti (2009) “the most potent idea in social sciences is that individuals are embedded in thick webs of social relations and interactions” (Borgatti et al., 2009). SN analysis is a paradigm in its own right and consists of exploring the actors (the people in the network), the links between one to another and, importantly, how the interactions amongst people can be used to understand a phenomena (e.g. a behaviour change or social support) (Scott, 2012, Marin and Wellman, 2011). Such approaches are based on the assumption that people are influenced by their relationships with others to act and change above and beyond their individual level capabilities and characteristics (Valente, 2010, Christakis and Fowler, 2009). However, what this entails and where such ideas sit within the differing philosophical perspectives is still debated (Buch - Hansen, 2014). For example, SNs are frequently modelled and counted using information technology and are therefore appears to be a mostly quantitative approach with positivist tendencies (Buch - Hansen, 2014). However, an increase in calls for a qualitative analysis of SNs has led to richer, more in-depth, constructivist data being used alongside quantitative and mathematical SN maps or ‘sociograms’ (Bellotti, 2014, Crossley, 2010). Drawing on critical realist and constructivist positions offers a productive way for using SN conceptualisations and methods in addressing the research questions of this work.

A prominent critical realist research view is that the study of SNs is a versatile theoretical field that can adopt both qualitative and quantitative perspectives as part of mixed method approaches to research leading to explanation and theory building. In the context of illness management taking a SN approach can help develop a greater understanding of how illness, practical and emotional tasks are shared between network members to achieve desired outcomes (Scott, 2012) or how different SNs can offer support that is acceptable (or not) and thus have different levels of collective efficacy (Vassilev et al., 2019). Taking such SN approaches is of particular interest to this project because it can be used to explore and compare processes within relatively 'closed systems' such as hospital wards or 'open systems' such as communities without such clear boundaries (Kadushin, 2012). HaH services that can be seen as a relatively closed system (particularly from the perspective of HCPs embedded into it), but also an open system for those receiving treatment through HaH who will need to access support from wider communities or their more nuanced 'personal communities' of which patients will be at the centre of. An egocentric network approach has been taken in this thesis within qualitative (including a visualisation and reflection of a network diagram) and quantitative (using a name generator) method designs (Scott, 2012).

Constructivist and critical realist perspectives assert that outcomes of a social phenomena are caused by complex interactions and mechanisms that are unlikely to be bound within closed systems. Therefore researching HaH services as if they were a 'closed system' within highly structured relationships and a single logic would have been of limited use in understanding the lived experiences when using such services (Doreian, 2001). What is known from research into chronic illness is that social support is rarely bound to closed systems such as healthcare services and is likely to reach beyond formal support to family members, friends and wider communities (Walker et al., 2018). By engaging with those within the service (either providing or receiving HaH services) this thesis has aimed to explore and understand the relational meaning of SN ties, the mechanisms through which SN support is mobilised, how and why. This could only be achieved by applying a qualitative aspect as part of mixed methods research (Bellotti, 2014, Fries, 2009).

2.6.4 The impact of theoretical perspectives on methodology: Mixed-method research

Bruner, whose seminal work is widely referenced with regard to a constructivist view, states that knowledge is a model that we construct depending on specific purposes (Bruner, 1957). As such, researchers need to utilise a methodological model that best suits that specific purpose (i.e. what knowledge is being sought). Constructivists and critical realists favour qualitative data collection methods and analysis or, alternatively, a combination of both qualitative and quantitative methods (i.e. mixed methods research). Within social sciences this sentiment is echoed as a means to broaden the approaches to social enquiry (Creswell and Clark, 2007, Fries, 2009) and improve their theoretical scope (Sayer, 1992). Defined as *'research in which the investigator collects and analyses data, integrates the findings and draws inferences using both qualitative and quantitative approaches or methods in a single study'* (Tashakkori and Creswell, 2007) mixed methods research uses qualitative data to address the complexities of healthcare research whilst the quantitative data is utilised in a way which supports or expands upon qualitative data and adds transferability to the descriptions (Mackenzie and Knipe, 2006). This is a favourable methodology among critical realists by, for example, applying a social lens to qualitative investigation to understand how friendships are gained and sustained whilst quantitative measurement will elicit the size and characteristics of friendship networks.

Mixed methods research remains debated in health and social science research despite this method increasing in prevalence (Shorten and Smith, 2017, Sowicz, 2017). Further writings in this area seek to elicit the importance of *complete* integration of the two approaches (Tashakkori and Creswell, 2007, Creswell and Clark, 2007) and argue that social science research “need not be dichotomized” (Fries, 2009). In doing so, researchers have recognised that the two methodologies bring value in the form of new knowledge, yield different perspectives to findings and therefore be a powerful approach for informing policy and practices (Ritchie and Lewis, 2003). Certainly, the use of both quantitative and qualitative research has been utilised to inform policy documents (DePoy and Gitlin, 2019) and practice guidelines for HCPs. Each of the two research approaches will be used in this thesis to provide distinctive evidence and illuminate different aspects of HaH which are not yet fully explored. However, for this to be successful, considerations of the best practices when using mixed methods research will need to be considered.

Earlier discussion emphasised this research is informed by constructivism and critical realism. Rigid application of a constructivist paradigm would create a tension in applying quantitative aspects of mixed methods research into this project as quantitative work may be seen as an overly simplified representation of people's SNs. It may be argued that the main value of such methods is limited to natural sciences (Ernest, 1998). However, constructivism does not simply abandon quantitative research but rather recognizes that any method used in research is imperfect and subjective (Willis et al., 2007, Doyle et al., 2009). Considering this, constructivism opens the door for quantitative aspects that either precede, accompany or follow-up from qualitative research (Johnstone, 2004). Such a constructivist position is also consistent with critical realism and is the approach used here. Within this PhD work qualitative methods were used in the earlier stages of this project. Quantitative data collection (questionnaires seeking the amount and type of support received from patients' SN members) will follow on from qualitative stages with a focus on the themes that have been identified in the rich qualitative data. This 'follow-up' application of quantitative enquire helps improve the quantitative stage of the research as it has been informed by real-world interpretations of the needs and discourses of respondents (Ernest, 1998, Johnstone, 2004). Specifically, here qualitative work precedes statistical enquiry and helped to devise the areas of questioning because HaH is an underdeveloped area of research to date and has therefore be used to confirm, refute, or further theorise plausible explanations based on the qualitative findings. This is because qualitative research can be of value in understanding the complex nature of the underlying constructs, which, in turn, can formulate questions and hypotheses for the statistical, quantitative stages (Ritchie and Lewis, 2003). Findings form quantitative research are here seen as tendencies or demi-regularities of the meanings which are not self-evident but require interpretation to inform theory building (Archer et al., 2013). It is important to note that the qualitative and quantitative parts of this study have value in their own right, and have become substantive, empirical research papers. The qualitative study is not seen simply as a preliminary study to guide quantitative research stages but was revisited throughout the analysis to illuminate the statistical findings and add explanatory power to the research questions of the thesis. This focusses on the role of SNs and has been developed in the discussion chapter as part of a triangulation process (chapter 7) (Fries, 2009). The term ‘triangulation’ is used in this context to describe the way mixed methods research findings was analysed and synthesised in chapter 7 (Figure 2). Triangulation involves the use of different methods and sources of data to check the integrity of the inferences drawn from each (Ritchie and Lewis, 2003) and forms “a bridge” between quantitative and qualitative epistemologies and answer questions that, alone, one approach can not (Denzin, 2012). In this context, triangulation has been central to validating the qualitative evidence through quantitative enquiry and vice-versa.

The theoretical framework adopted here is that real-world phenomena are complex, and our understanding is necessarily limited and incomplete. However, while trying to create one definitive answer to the research aims is futile, there are some answers and explanations that are better than others in terms of their practical adequacy (Sayer 1992). Combining (triangulating) and critically interrogating the findings of each stage of this project has helped to develop plausible theories and improve the breadth, depth and transferability of the findings (Heale and Forbes, 2013).

2.6.5 Applying theoretical and methodological perspectives to this project

It is argued in this discussion that quantitative and qualitative methods can complement one-another in order to improve the quality and transferability of data that informs health and social care services (Mackenzie and Knipe, 2006). This supports the project aims that seek to explore the way SN structure and processes shape HaH patients’ experiences when interacting with the service. Such aims can be productively addressed by using and a mixed methods research approach within an approach informed by constructivist and critical realist perspectives. For example, from a SN perspective, this paper did not seek to ‘map’ a network model of individual participants but has utilised the theoretical frameworks associated with SNs in order to quantify those of HaH patients (such as the amount of interactions, type of relationships and the work undertaken by each) but also qualitatively explore, from HCP perspectives, the ways in which different network members are mobilised and navigated by patients.

Thus, a multi-perspective, mixed methods research approach has been applied throughout the design, research and analysis stages of this project as described within this chapter. Literature searches into the application of mixed methods research found that there is a lack of such design and guidance for its application in this field. Findings are most commonly in the form of separate qualitative and quantitative papers (de Haan et al., 2021) which indicates that there is an additional value to this thesis due to taking a mixed methods research approach.

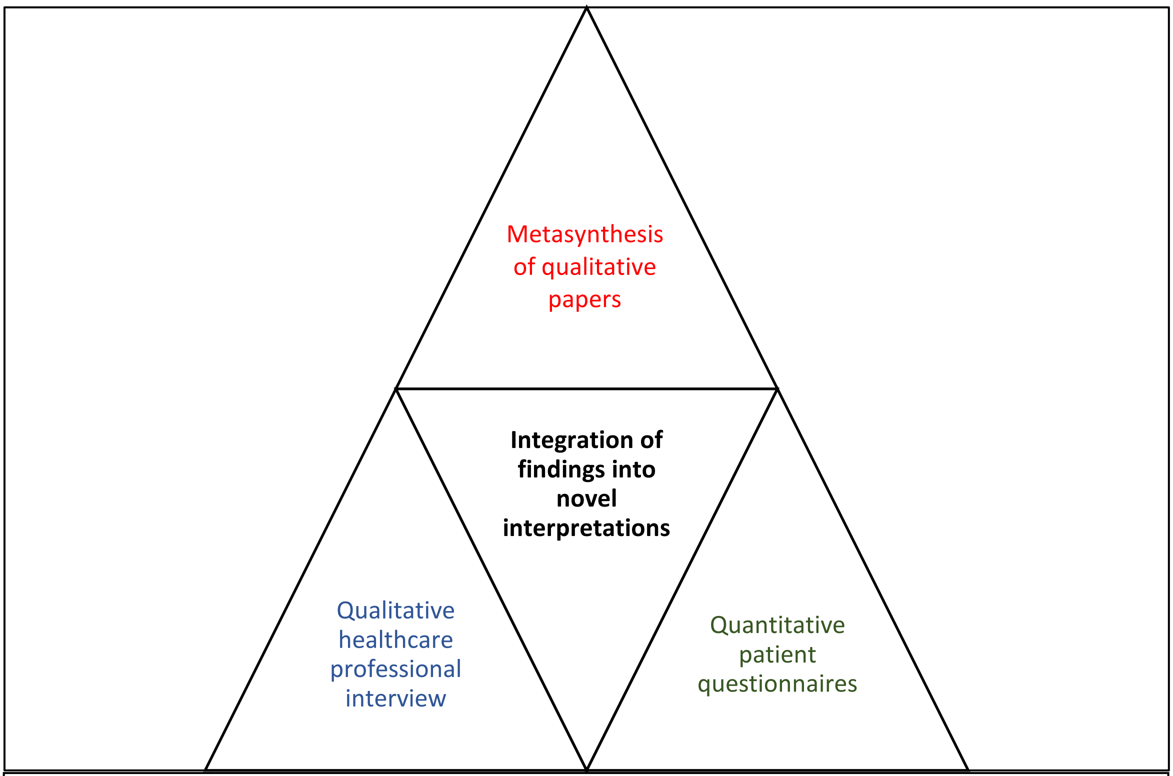

Figure 2: *The triangulation process as applied to this project in order to create new and novel findings from multiple sources. This figure is revisited in chapter 7 with specific reference to the findings of this thesis.*

3.0 Chapter 3: Paper one: literature review: Rural influences on the social network dynamics of district nursing services: A qualitative meta-synthesis

To increase the relevance of the primary research it was appropriate to have a formal understanding of the existing literature and theory in which new knowledge will fit. Researching a relatively contemporary healthcare service (HaH) limits the breadth of existing literature available for synthesis. A literature search that synthesises existing knowledge of the population and contexts of interest (table 1), with the limited data of HaH services, will initiate discussion and identify knowledge gaps that can guide the primary research within this project as well as others. This was undertaken and is included here in the format of the completed journal article; published in *Health Science Reports* (Gillham et al., 2021).

Population of interest	District nurses and users of community nursing services
Context of interest	District nursing roles within the personal network of services users
	The impact of rurality on the nurse's role within the personal network of service users.
Outcome of interest	How experiences of the givers and receivers of care is affected by rural contexts.

Table 1: *Population and contexts of interest for literature review adapted from PICO, this PCO table shows the areas of interest identified for this qualitative review*

Abstract

Background and aims: As demands on healthcare services grow, fiscal restrictions place increased emphasis on services outside of traditional healthcare settings. Previous research into long-term-conditions suggests that social network members (including weaker ties such as acquaintances, community groups, and healthcare professionals) play a key role in illness management. There is limited knowledge about the engagement of social networks in supporting people who are receiving medical interventions at home.

This qualitative metasynthesis explores the work and the interactions between district nurses (DN) and informal network members supporting people who are receiving medical interventions at home and living in rural areas.

Methods: A search was undertaken on CINAHL, Medline and PsychINFO for qualitative research articles from 2009-2019. Studies that examined DN in rural locations and/or social network support in rural locations were eligible. 14 articles were selected.

Results: Thematic analysis of results and discussion data from the studies resulted in four themes being developed: The development of both transactional and friend-like nurse-patient ties in rural localities; Engagement of the wider network in the delivery of good care; Blurring of professional boundaries in close community relationships; Issues accessing and navigating formal and informal support in the context of diminishing resources in rural areas

These findings suggest that DNs in rural localities work beyond professional specialties and experience to provide emotional support, help with daily tasks, and build links to communities. There was also evidence that nurses embedded within rural localities developed friend-like relationships with patients, and negotiated with existing support networks and communities to find support for the patient.

Conclusions: Findings indicated that developing strong links with patients and members of their networks does not automatically translate into positive outcomes for patients, and can be unsustainable, burdensome, and disruptive. DNs developing weak ties with patients and building awareness of the structure of individual networks and local sources of support offers avenues for sustainable and tailored community-based nursing support.

KEYWORDS: nursing, district nurse, community nurse, rural, rurality, social networks, social support.

3.1. Introduction

Aging populations, driven by falling infant death rates, longer life expectancies, and increased availability of medical and pharmaceutical interventions (Taylor and Bury, 2007) - coupled with uncertain financial climates, rising populations and increased comorbidities has led to escalating costs, a high demand on hospital beds (NHS England, 2019) and profound changes in how healthcare is delivered (Taylor and Bury, 2007). Rising healthcare need and a slowdown in funding has led to NHS debt rising to £13.4billion in 2020 (Anandaciva, 2020).

As a way of addressing this gap in funding more patients are being treated in community settings for increasingly complex conditions to reduce the costs associated with inpatient admission (Barrett et al., 2016, Kennedy et al., 2016). Understanding the consequences of this shift in healthcare delivery style is set to increase in pertinence as wider policy moves health and social care closer to home and community settings (Pearson et al., 2013). For example, the implementation of the 'Long Term Plan' in the NHS in the UK (2019) emphasises community healthcare by stating an annual primary care budget increase of £4.5bn. These policies aim to increase service capacity and establish new provisions (such as HaH services, online consultation services, increased GP training, and 'same day emergency care' units) that overcome barriers currently preventing some health conditions being treated at home by, for example, guaranteeing online tele-health consultations, and direct referrals to community services that means unnecessary visits to hospital can be avoided (NHS England, 2019).

3.1.1 Social networks and self-management

The role of social networks in supporting self-management has most extensively been researched in the context of long-term condition management (Vassilev et al., 2011, Kennedy et al., 2007). This research has focused on how the structure of people's networks and the types and range of relationships shape the way in which people access different types of support with their health, practical and emotional needs (Vassilev et al., 2013). Such studies have found that people who have access to diverse types of relationships, including both 'strong', intimate ties (e.g. family members, close friends) and 'weak', more distant ties (e.g. HCPs, acquaintances and community group members) are most successful in managing their long term conditions (LTC) and receiving acceptable health, emotional and practical support (Vassilev et al., 2014, Reeves et al., 2014, Walker et al., 2018). This might be in part due to such networks being able to share the burden of illness work, sustain valued relationships and have better access to relevant knowledge, skills and experience (Rogers et al., 2014). Consequently, access to SN support that is acceptable to people may facilitate improved use of medications, healthier lifestyles (e.g. smoking cessation or healthy eating practices) (Christakis and Fowler, 2007, Christakis and Fowler, 2009), improved experiences of poor health (e.g. by managing adjustment; sharing the burden of health, emotional and practical work; and advocating/liaising with HCPs) (Pescosolido, 2006), and improved physical and mental wellbeing (Reeves et al., 2014).

The increased focus on the community provision of healthcare is likely to result in a widening of the types of conditions and issues that require patients to self-manage. Beyond LTCs, this is likely to include potentially complex and acute conditions, both of which will require further research into the specific roles of social networks in these different contexts.

3.1.2 The healthcare professional's role in self-management support

Previous research has suggested that in a community context, HCPs may facilitate self-management by offering not only health work, but emotional and practical work too (Vassilev et al., 2013, Rogers et al., 2014). However, the quality and acceptability of such support is often studied in isolation without considering how HCPs interact with the wider network members and the support they provide. Although there are a range of HCPs that are involved in providing good care for patients at home, it is most frequently the district nurse caring and treating that person (Aldridge-Bent, 2014). Therefore, exploring the relationship dynamics between patients and district nurses may be beneficial when taking a social network approach to exploring healthcare at home. This may include how patients engage with network support when interacting with district nurses; the role of different ties and how network engagement might be in tension or complement district nursing support; how such processes and relationships co-shape the provision of community services; and how dynamics might differ from what is already known about LTC self-management support when self-managing increasingly complex health conditions at home.

Furthermore, primary services like district nursing and other community nursing services such as HaH are more likely to occur in rural contexts where adapting to financial challenges has resulted in the scaling back of smaller, more remote hospitals (Rechel et al., 2016); and as such, these localities must also be considered when exploring the role of district nurses in patient social networks. The definition of 'rural' varies globally with, for example, the UK describing it as areas that fall outside of settlements with more than 10,000 residents (Department for Environment, 2017); and in Australia, as all areas outside of major cities (Australian Institute For Health And Welfare, 2019). Similarly, there is no standard definition of 'rural' within healthcare (Hunsberger et al., 2009) but there is a consensus that the pressures and complexities of district nursing are exacerbated by rurality. This is in part because HCPs need to become generalists, healthcare services appear underfunded, operating in a context of poor infrastructure and services provided over long distances (Roberts et al., 2014, Robinson et al., 2009). Furthermore, the lack of peer support paired with the diverse patient group that district nurses treat can cause stress and poor staff retention among the workforce (Robinson et al., 2009, Daniels et al., 2007), all of which could impact on district nurses' ability to provide self-management support in rural areas. There is some evidence to suggest that district nurses often live within, or near, the communities they serve (Barrett et al., 2016) which may offer an opportunity for drawing on existing relationships, shared values and local embeddedness to provide a motivation to overcome rural challenges. Whether this affects the way SN support is provided or whether it is qualitatively different from other urban settings, requires further exploration.

These factors contribute to the growing demands and complexity of healthcare and self-management support in rural areas and the growing pressures on healthcare professionals, individuals and other members of their personal communities. The pressure on community based services in particular is likely to increase because of the overwhelming demands on inpatient care, and current strategies and policies outlined in the NHS Long Term Plan (NHS England, 2019) which encourage community based public health interventions for increasingly complex and acute needs. These require patients and their social network to take greater responsibility for the management of their health conditions, which previous research has shown is a challenging prospect for patients when confounded by reduced function caused by poor health (Vassilev et al., 2014). This qualitative metasynthesis will explore the role that district nurses can play within the wider networks of people who are currently receiving professional medical care at home, for a diverse range of conditions, whilst living in rural areas. It will aim to identify the formal and informal processes that shape the involvement of HCPs with the self-management support of patients and the engagement with members of their social networks.

3.2 Aims

The review will synthesise the available evidence on the use of district nursing services to explore:

1. The way in which district nurses develop relationships with service users to mobilise and/or become part of their personal network and what impact this has on the ability to deliver good care.
2. How rurality affects professional-patient interactions, social network dynamics and the ability to fulfil social, emotional and practical needs.

3.3 Methods

Metasynthesis offers a rigorous and systematic approach to reviewing and analysing the literature that allows the development of novel interpretations while ensuring that the findings are reliable and transferable (Lachal et al., 2017),

3.3.1 Search strategy

The literature search was undertaken by JG in CINAHL, Medline and PsychINFO using terms related to social networks, rurality and community nursing, as guided by an abbreviated version of the PICO (Population, Intervention, Context/Comparison, Outcome) framework (see Table 1 for search terms). The search was completed on 25/07/2019 using the article title and abstracts only. Initial scoping searches identified limited articles contained all three themes (i.e. social networks, rurality and community nursing) therefore, the decision was made to undertake two separate searches: the first combining ‘social networks’ and ‘district nursing’, and the second searching for articles related to ‘rurality’ and ‘district nursing’. A systematic hand search was conducted on the reference lists of existing literature reviews within the search results to find any other relevant articles that may have been missed by the search strategy or poorly indexed (Noblit and Hare, 1988).

S1	AB "Social Participation" OR AB "Social Inclusion" OR AB "social exclusion" OR AB "social Isolation" OR AB "Social relationship" OR AB "Social support theory" OR AB "Social support network" OR AB "Social support" OR AB "Social network"	129,777
S2	AB "community nurs*" OR AB "District nurs*" OR AB "Hospital at home" OR AB "hospital in the home"	7,132
S3	S1 AND S2	125
S4	AB "Rural health" OR AB "rural healthcare" OR AB "Rural*" OR AB "Rural nursing"	241
S5	S4 AND S2	229
S6	S3 OR S5	354

Table 2: *Search strategy used to search databases for relevant articles.*

Inclusion criteria	Exclusion criteria
• Relevant to themes (social networks and synonyms, district nursing and synonyms, rural and synonyms) • Published since 2009 • Written in English • Qualitative study (or qualitative data of a mixed methods study) • Originate from UK, Europe, USA, Canada, Australia, New Zealand	• Doesn't include relevant themes • Published before 2009 • Not written in English • Quantitative study • Does not originate from UK, Europe, USA, Canada, Australia, New Zealand • Existing literature review

Table 3: *The inclusion and exclusion criteria used during the screening process.*

3.3.2 Article selection

To be eligible for inclusion, studies had to originate from the United Kingdom (UK), Europe, United States of America (USA), Canada, Australia and New Zealand and be published from 1st January 2009 to 1st May 2019. This was to ensure cultural consistency between the data and to ensure the synthesis was relevant to current practice. Only qualitative or MIXED METHODS RESEARCH studies that were written in English were included (see table 2). Articles reporting MIXED METHODS RESEARCH were included (n=1 (Reed et al., 2018)) but only the qualitative data (quotations from district nurses' reflective accounts through semi-structured interviews; and the interpretations made by the original authors) was extracted when reading the full texts. Social networks were defined as personal communities of individuals that provide emotional, practical or health support, therefore any articles relating to online networks (such as social media, often referred to as 'social networks') or telehealth approaches were excluded. Rurality was included regardless of the defining characteristic chosen by the authors of the original research (e.g. population, distance to urban centres) and acknowledged during analysis. Figure 1 outlines the number of studies included and excluded at each stage of the identification and screening process. JG screened the full 354 articles found from the search at abstract level and at full text level if uncertainty remained. To ensure quality control, IV and RB each reviewed a separate 25% of the search results and the included/excluded studies were discussed until consensus was reached. Studies were excluded (n=343) for not including relevant themes (n=179), from outside the aforementioned westernised countries (n=66), not including research data (e.g. scoping searches or opinion) (n=45), on paediatric care or midwifery (n=38) or if it was an existing literature review (n=16). 13 articles met the criteria for inclusion. A further article was included after hand-searching from existing literature reviews: a total of 14 studies were therefore included in the final review. The articles were assessed for quality using the recognised *'Criteria for the evaluation of qualitative research'* tool for sociological research (Blaxter, 1996) (see table 3 for acknowledged limitations related to quality criteria of each study). Five articles focused primarily on the community healthcare professional's role, five on rurality's impact on healthcare and three articles addressed both themes (see Table 3 for an overview of included studies).

3.3.3 Data extraction and translation

Two data types were extracted from the articles and organised in a table that also enabled the key information of each study, such as authors, publication dates, methodology and country of study to be easily managed (table 3). Of the two types of data, in the first order, data included direct quotes from participants and verbatim extracts from the results chapters of each paper. Second order constructs (the theories developed by the researchers of the original studies) were extracted from the discussions and analyses chapters of the original articles. As is best practice when conducting a metasynthesis, in order to assess reliability, 30% of articles from each search were data extracted by members of the study team; IV and RB (Lachal et al., 2017). The findings were discussed and consensus reached on the data that should be included, and any areas of contention throughout data extraction was discussed between the research team. From the 14 included papers, 220 first order quotations relevant to personal relationships, support and relationships provided by district nurses or rural factors were included to answer the aims of this literature review. A further 83 second order constructs by the original authors were extracted.

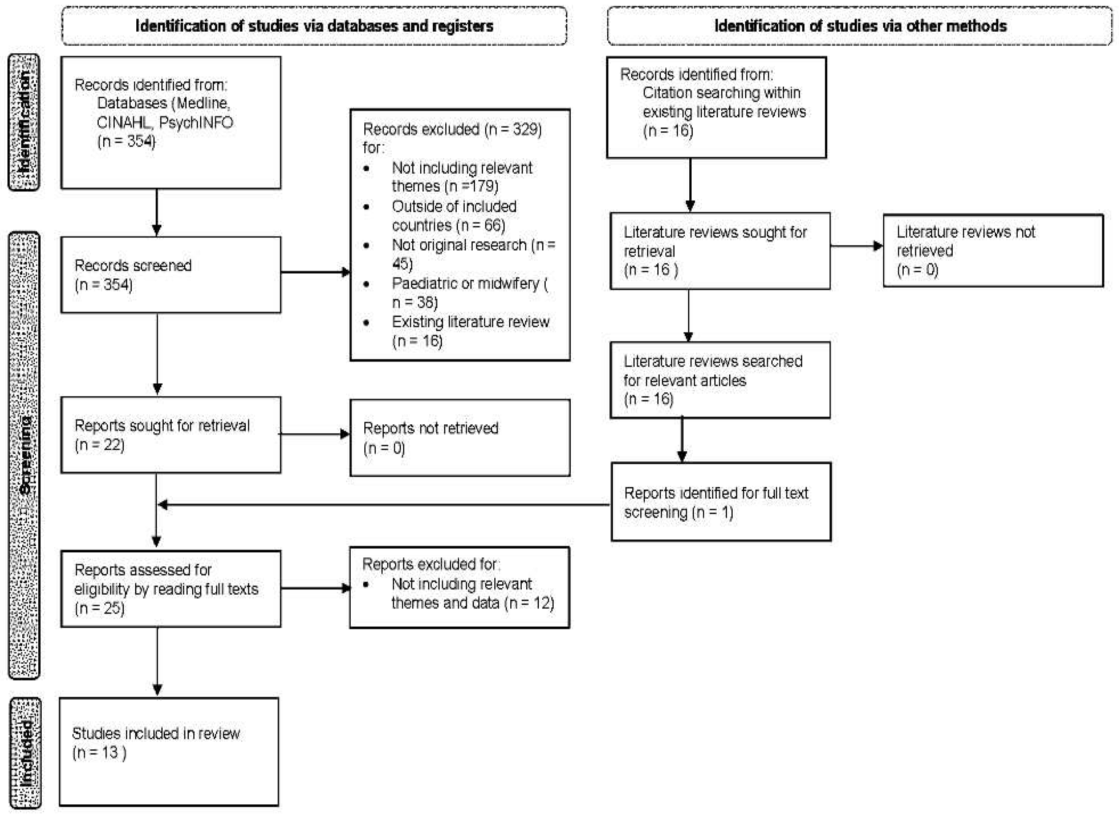

Figure 3:
An adapted PRISMA flow diagram of the article selection and screening process (Page et al., 2021)

Table 4: *Overview of included studies*

Number, Author, year, country	Study aims and objectives	Sample and context	Methodological approach	Data collection and analysis	Content supporting social networks (SN)	Limitations
1 Findlay et al. (2017) **Scotland**	To increase the knowledge of emotional effects of living with frailty	N=11. semi structured interviews with patients at a medical day	Longitudinal qualitative study. Semi structured interviews	Secondary analysis of data from PhD study (n=13). Thematic analysis	Patients wish to stay in their home but only find contentment in doing so if they are able to connect with family and friends. Their health needs often become a barrier to maintaining relationships due to reduced mobility and district nurse visits restricting their free time.	Secondary analysis (n.b. original author on research team)
2 Crotty et al. (2015) **South Australia**	To explore the experiences of patients with MH conditions and LTCs on their social network support.	N=29. Users of community mental health services.	Semi structured interviews	Potential Participants screened by community nurse. Grounded theory	Spouses are an important member of social networks, interacting and increasing the role of formal support. However, those in this group (LTCs and MH problems) have smaller networks and often befriend DNs for their practical and emotional work. This group shows mostly transient relationships and a degree of isolation.	Convenience sampling limits rigour and single site limits transferability
3 Griffiths et al. (2013) **England**	How and why do DNs construct early support visits in EoL care?	DNs (n=58) and patients (n=10) who give or receive EoL care at home	Multiperspective. Qualitative focus groups, semi-structured interviews, observation	Self-selected nurses and patient Recordings and written field notes (collected by nurse researchers) transcribed and thematically analysed	During EoL care at home, district nurses intertwined their health tasks with ‘having a chat’. This created an egalitarian and humanistic relationship. Nurses felt this empowered the patients and their carers to take a lead role in their treatment. Themes emerging from the data were enlightenment, explanation and education, advice and instruction.	Self-selected participants patients likely to be most skilled and confident practitioners
4 Grunberg et al. (2016) **Sweden**	To use the experiences of DNs on detection and delivering mental health care to increase knowledge of good care	N =25 DNs from Swedish community setting	Qualitative focus groups and interviews	Recruited using ‘snowballing’ chain sampling. Same interviewer throughout. Transcriptions thematically analysed	District nurses offered emotional support through informal dialogue by trying to lift their mood and express emotions, This was important for successful integration into the SN which gave the district nurse the ability to advocate, mobilise others and meet emotional needs.	‘Snowballing’ recruitment means participants encourage only those with the same values.

5 Gossett- Zakrajsek et al. (2013) USA	How do older adults and HCPs experience and perceive transitions from hospital or integration back into communities?	HCPs (n=7) from a 'home health service' and patients (n=6) recent discharged from inpatient care	Participatory Action Research. In context observation and interviews (conducted in pairs or triads)	Purposeful sampling. Field notes and interview transcriptions. Thematic analysis	Three main themes emerged on transition home: social support, communication, and reintegration. Informal care was valued by patient and HCP. Informal support allows for greater personalization, flexibility and planning of care but relies on good communication/ collaboration between patient, carer and HCP.	Observations abandoned after 6. Carer involvement unplanned for. Lack of sample diversity
6 Devik et al. (2015) Norway	To explore the views of patients on the effect long distances and poor infrastructure has on their EoL care.	Patients over 65 diagnosed with advanced cancer (n=9) and receiving EoL care at home in rural Norway.	Narrative, semi structured interviews with patients. Using open ended questions	Convenience sampling. Phenomenological hermeneutic approach to analysis. Iterative approach from naïve to comprehensive interpretations	Despite being aware of worsening health outcomes patient would rather stay at home in the rural community. They feel they are able to remain a part of the community and hold some social capital and as such can draw on their relationships for support. Conversely, nursing visits restrict freedom of the patient	Authors have preconceptions as practising nurses. Small cohort
7 Hunsberger et al. (2009) Canada	Considering staff and resources shortages paired with varied and complex nature of rural healthcare practices, there is need to evaluate the workforce and how to sustain/improve it.	Nurse administrators (n=21) and Staff nurses (n=44) from Local Health Integrated Network, Ontario. Approximately 100 miles to a large hospital	Qualitative, Semi structured interviews using previous research to guide themes for discussion	Recruitment using flyers and 'snowball' technique. Transcripts thematically analysed	The rural district nurse is likely to find challenges unique to rural healthcare a stressor. These often outweigh the positives and result in changing posts. The expectation to perform tasks outside of health work disgruntles staff. Demands, aging workforce and poor resources suggest rural nursing difficulties will worsen. Recruitment should target those from a rural background and education should have rural healthcare modules.	Self-selection and Snowballing recruitment means nurses encourage those with shared values to participate. Increasing bias
8 Terry et al. (2015) Australia	To identify which health and safety issues impact on the provision and quality of rural DN care What strategies to DNs adopt to overcome these?	Experienced district nurses (n=15) from 3 rural care areas, Australia	Phenomenological approach. Semi-structured interviews	Sample spread across 3 recruitment sites. Conducted interviews face to face (n=4) or telephone (n=11). Transcripts thematically analysed and consensus reached.	Health and safety issues for rural DNs are primarily environmental; mainly long distances, isolation, poor infrastructure and patient families creating difficulties. Management processes are poor so district nurses felt they had to 'make do'. A strategy was to rotate caseloads to share burden of long distances to some patients and overburden of client contact. However, this negatively impacted on continuity of care.	Telephone interviews limits ability to clarify, probe and interpret body language.

9 Kaasalainen et al. (2014) Canada	To explore nurses' experiences of providing palliative care in rural areas with a particular focus on the impact of the physical residential setting.	District nurses (n=21) who provide EoL care in rural communities	Qualitative exploratory techniques. semi structured interviews	District nurses recruited from previous quantitative survey. Purposeful sampling. Telephone interviews thematically analysed. Interpretations shared with participants to ensure credibility	Rural district nurses face unique physical and emotional challenges to deliver EoL care. They frequently go beyond their role for the patient. The geographical distances meant support, supplies and patient contact time was restricted. Isolated patients made them more reliant on the district nurse and made poorer health choices of their own.	Single nursing site reduced transferability.
10 Reed et al. (2018) Australia	To create an initial understanding of how nurses practice EoL care in rural areas to provide a platform for further research that could inform practice	District nurses (n=7) who deliver EoL care in rural areas of Australia. Wide spread areas across all states.	Sequential mixed methods. Nurses wrote reflective accounts the follow up semi-structured interviews	Recruited district nurses purposefully selected from initial those who completed a wide spread Likert style questionnaire. Reflections used to guide semi-structured interviews. Thematic analysis.	District nurses reported knowing the rural area so knew what resources were available. They have a good social capital so can advocate successfully. There is an issue with boundary crossing and confidentiality as the nurse often knows the patient and their family socially. They justify this by demonstrating the likely improved health outcomes. DNs have the emotional intelligence to manage this.	Self-reporting and reflections rely on timely completion and memory. Small sample size
11 Farmer and Kilpatrick (2009) Scotland and Tasmania	Can front line HCPs stimulate changes in healthcare through entrepreneurial skills and could policy makers encourage HCPs into this role?	38 HCPs (Tasmania n=15, Scotland n=23) from rural areas. Primary healthcare services (GPs and DNs)	Mostly face-to-face (n=31) semi structured, 'exploratory' interviews. Otherwise telephone (n=7)	Participants recruited by advertisement, word of mouth and self-selection at research sites. Exploratory interviews were transcribed and thematically analysed	HCPs can built patient's social capital by identifying needs and then bridging and bonding to others. They feel obliged to become part of the community and use their own social capital to create opportunities for others. Some extreme examples where HCPs set up banks, shops, clubs for the communities. Large scale changes were mostly carried out by healthcare management and GPs whilst district nurses set up health clubs and health related activities.	Hard to generalize outside of the two countries. Self-selection biases.

12 Roden et al. (2016) Australia	To explore the strategies and sustainability of the health promotion (HP) role of the rural and urban DN	10 district nurses from varying settings (rural n=5, urban n=5) of New South Wales, Australia	Semi structured Interviews following up on Likert questionnaire on the self-efficacy and burden on HP	DNs approached to participate in quantitative study then purposeful selection for interviews. Transcriptions thematically analysed	There is a lack of multidisciplinary support for DNs in rural areas. Their commitment to the community means the district nurse feels responsible to undertake health promotion activities and find them to be successful because they are valued members of the community. Health promotion is usually sacrificed when rural healthcare pressures build.	Only in New South Wales. Small sample interviewed.
13 Reed et al. (2016) Australia	How do DNs successfully advocate for rural Australian EoL care goals?	DNs (n=7) from a nursing agency in rural Victoria, Australia	Pragmatism. Written reflective accounts and follow up semi-structured interviews.	Care agency DNs approached to take part voluntarily. Iterative analysis of reflective accounts. Semi structured interviews transcribed and thematically analysed	District nurses need to become generalists in the rural community as there is little/no specialist support. The district nurse can find support and resources due to their knowledge of the community. This requires flexible relationship boundaries as they often know the patient socially. The district nurse integrates into the patient's family network and build strong rapport. This creates a reciprocal and trusting relationship that can facilitate holistic care.	One practice setting limits transferability. Small sample
14 Wang, Y., et al. (2012) Norway	what was important to the service users of a new HaH service; to guide planning in the future	6 patients transferred to HaH service in Norway	9 patients recruited from concurrent quantitative study comparing inpatient to HaH experience	6 Patients were randomized to HaH treatment. Semi-structured interviews were transcribed and thematically analysed by a team of researchers	Participants discussed how they felt being treated at home compared to inpatient settings. Their social network was cited as a source of support during this time. Patients also discussed the relationship they shared with the district nurse and what work they undertook; which included some practical and emotional work alongside their healthcare role.	Small cohort, recruited from one inpatient setting limits transferability.

Translation and reconfiguration of the data is arguably the most subjective stage of the synthesis process (Lachal et al., 2017) and therefore, as with the other stages of this metasynthesis, findings and interpretations were discussed, revised and elaborated within the study team (Barry et al., 1999). Table 4 provides an overview of the synthesis process. In this synthesis, in order to translate the findings into one another and develop new meaning and understanding from the included themes, a line of argument synthesis was applied. This approach allowed data from primary studies that had different contexts, and theoretical and methodological approaches to be combined (Atkins et al., 2008) In doing so, new theories about the phenomena, the *third order* constructs, were developed (Atkins et al., 2008, Lachal et al., 2017). This was an iterative process of repeated reading that identified recurring and juxtaposing results that could be translated into one another and identify the novel themes (Noblit and Hare, 1988). Through this process the novel themes developed by the review team were; *Blurred boundaries between the types of work nurses in rural areas; Transactional and friend-like nurse-patient ties in rural localities; Negotiating professional responsibilities and network engagement;* and *Local embeddedness and shaping relations within local communities.* Table 4 provides an overview of the synthesis process.

3.4 Findings

3.4.1 The development of both transactional and friend-like nurse-patient ties in rural localities

Rural settings impact on the relationships between nurses and patients in several ways, and result in two key types of relationship styles with service users. The first are those that are transactional in nature, and develop as the result of relatively infrequent, discontinuous, and unreliable interactions between nurses and patients in community contexts (Devik et al., 2015). This is often due to nurses serving patients in isolated areas with poorly developed infrastructures and phone networks, long distances and travel times between patients, and high levels of staff turnover and rotation (especially where long distances need to be shared) (Kaasalainen et al., 2014, Terry et al., 2015, Roden et al., 2016). Within such contexts, patients have to *“take whoever, whether you like them or* *not"* (Findlay et al., 2017) meaning the building of trusting and therapeutic relationships between patients and nurses might become difficult (Grundberg et al., 2016, Terry et al., 2015). Patients cite that they "*never feel like discussing things with them [district nurses they see less frequently] in the same way*" (Findlay et al., 2017) which contributes to relations in rural areas which feel transactional, fleeting, and impersonal, although not necessarily ineffective (Wang et al., 2012).

However, the 1-to-1 contact in community settings and the interactional confidence that patients have due to being in their own homes where they "*know what is what" (Devik et al., 2015)*, also opens possibilities for development of close, highly personalised relationships between patients and nurses, which are valued by the patient (Findlay et al., 2017, Reed et al., 2016):

> "*We have a good connection. It means a lot to me. She is more than a nurse…she is a person"* (Devik et al., 2015).

Being open to the development of such *"comfortable" (Reed et al., 2016)* relations with patients fits with the perceptions of nurses of their professional role and they see it as an achievable aim and an effective way of supporting patients (Reed et al., 2018, Hunsberger et al., 2009). To accomplish this nurses may adopt certain interactional styles. For example, a *"relaxed conversation style"* (Griffiths et al., 2013) and make themselves personally accessible to the patient (Hunsberger et al., 2009) by, for example, giving out their personal number;

> *"your number is in the book, or you give them your personal number"* (Reed et al., 2018).

3.4.2 Engagement of the wider network in the delivery of good care

Where nurses develop close relationships with the patient, there is evidence to suggest that the nurse may be (or become) part of the social network, as well as interact with other individuals within the wider social network. In this way, they often utilise interactions with patients as an opportunity to identify emotional and practical needs being unmet by the rest of the patient's social network (Farmer and Kilpatrick, 2009, Roden et al., 2016, Reed et al., 2018, Reed et al., 2016, Gossett Zakrajsek et al., 2013, Wang et al., 2012), and commonly feeling obliged to offer support in these areas (Farmer and Kilpatrick, 2009, Gossett Zakrajsek et al., 2013). This support may include practical tasks such as stoking the fire, "Training the dog" (Reed et al., 2018), organising or providing transport (Farmer and Kilpatrick, 2009), organising financial support in the form of "getting benefits" (Griffiths et al., 2013, Farmer and Kilpatrick, 2009) and providing emotional support by spending time talking and discussing personal concerns (Griffiths et al., 2013, Grundberg et al., 2016). The rationale for undertaking practical roles might be in order to reduce negative events such as falls when less able patients attempt to do practical work independently; or even prevent self-neglect if patients cannot cook and wash clothing (Reed et al., 2016, Hunsberger et al., 2009). The emotional work undertaken by nurses during health visits may be used as a *"lever"* for further assessment (Griffiths et al., 2013) which not only reduces negative effects associated with loneliness, isolation and poor mental health, but also acts as a technique for identifying health needs (Grundberg et al., 2016, Griffiths et al., 2013). For example, district nurses would "*just, you know, chat about things in general…like a social visit…and sometimes by just doing that, little problems will come out"* (Griffiths et al., 2013).

When district nurses live and work in the same rural locality, there are often pre-existing relationships with the patient and/or other social network members (Findlay et al., 2017, Reed et al., 2018). For example one nurse said she was able to help a man to "*die at home with his three teenage sons – one of which I employed locally"* (Reed et al., 2018). This is beneficial as it helps to create an egalitarian relationship that is based on shared norms and values (Reed et al., 2018, Hunsberger et al., 2009). Moreover, the nurse may be well placed not only to successfully identify potential social networks of support (Kaasalainen et al., 2014) but also have the increased social capital within the community to enable its successful mobilisation (Farmer and Kilpatrick, 2009, Reed et al., 2016, Reed et al., 2018). The quote that *"People don't say no to a health care professional as readily"* (Farmer and Kilpatrick, 2009) epitomises this increased social capital and nurses are seen as the *"quarterback"* of the community (Kaasalainen et al., 2014); mobilising other professionals and healthcare services (Griffiths et al., 2013, Grundberg et al., 2016, Crotty et al., 2015b, Farmer and Kilpatrick, 2009). Nurses "*Bridge or bond [patients to others]*" (Farmer and Kilpatrick, 2009) such as churches, clubs or charities (Farmer and Kilpatrick, 2009, Grundberg et al., 2016) but also, in some cases, proactively create new social networks of support by establishing their own clubs, community projects or shops that offer an opportunity for interaction with others in the community (Farmer and Kilpatrick, 2009).

3.4.3 Blurring of professional boundaries in close community relationships

However, the development of complex nurse-patient relationships may result in some degree of crossing the boundary of one's professional role in order to fulfil key nursing responsibilities, especially in rural areas (Grundberg et al., 2016, Reed et al., 2016, Terry et al., 2015, Griffiths et al., 2013, Findlay et al., 2017, Wang et al., 2012, Reed et al., 2018):

> *"Individuals that carry out a formal service begin to undertake informal support roles" (Crotty et al., 2015).*

Nurses reported experiencing experience the pressure of expectations from patients to act as a substitute for the absent support from family, friends and peers; (Findlay et al., 2017) stating they "*get calls at home – A lot of calls!"* (Kaasalainen et al., 2014). Similarly, researchers highlighted that the familiarity patients had with nurses meant they found their *"privacy was invaded"* (Kaasalainen et al., 2014) when they were *"consulted about health issues in grocery stores or at sports events"* (Hunsberger et al., 2009). Such patient expectations are likely to be unrealistic given that rural factors outlined above restrict the time available to nurses to offer substantial emotional and practical support (Reed et al., 2016, Terry et al., 2015, Kaasalainen et al., 2014). This may leave nurses with difficult choices to make between disappointing raised patient expectations, fulfilling responsibilities to other patients, and the need to prioritise illness over all other types of work, such as domestic tasks or food shopping (Roden et al., 2016). Thus, close relationships between nurses and patients may be difficult to negotiate and manage (Hunsberger et al., 2009), adding substantial amount of relational work to the nurse workload, and raising issues of overburden or 'burnout', confidentiality, and meeting professional and legal responsibilities and standards (Reed et al., 2018, Devik et al., 2015).

Moreover, in rural community settings where social isolation can be common (Kaasalainen et al., 2014, Terry et al., 2015) some patients may act proactively use nurse visits as an opportunity for social contact (Grundberg et al., 2016), and in the absence of network support, patients may actively seek district nurses to provide emotional and other types of support (Crotty et al., 2015b, Devik et al., 2015):

> *"I see her if I come in here to say hello…I'm not actually allowed to consult with her because I'm not classed as homeless" (Crotty et al., 2015).*

However, when district nurses practice "*generosity exceeding what can be expected*" (Devik et al., 2015) relationships with patients strengthen and district nurses become more forthcoming with offering additional support and may come to be "*perceived by patients as a friend"* (Reed et al., 2016). It may also lead to reshaping existing relations between patients and members of their wider network. Relying on professionals for emotional and practical support can cause any available, existing support to dissipate leaving the patient vulnerable if formal support is discontinued (Findlay et al., 2017), while also putting additional pressure on nurses to further extending the depth and range of support they provide.

3.4.4 Issues accessing and navigating formal and informal support in the context of diminishing resources in rural areas

While building close nurse-patient relationships may sometimes be associated with higher personal job satisfaction (Reed et al., 2016, Hunsberger et al., 2009), the need to deal with complexity that such relations introduces associated negative experiences (Reed et al., 2018) maybe less acceptable to newly qualified nurses who *"may not be comfortable with all the different things [emotional and practical support] they had to do"*, according to their more experienced peers (Hunsberger et al., 2009). As with the community as a whole, smaller rural district nursing teams experience an increased sense of shared values and team spirit amongst themselves (Reed et al., 2016) and are able to create an *"extended family environment"* (Hunsberger et al., 2009) but there is a relative lack of specialist support available; which not only means nurses practice as generalists but also, that it restricts the services available that can be mobilised to support the patient (Reed et al., 2018, Reed et al., 2016, Roden et al., 2016, Kaasalainen et al., 2014, Hunsberger et al., 2009). Furthermore, the aging workforce in rural areas means that recruitment from outside the local area is increasingly common. This reduces the embeddedness and shared values of the nurse in *"both a geographical and social sense"* (Devik et al., 2015), limits the knowledge the nurse has of the community and therefore the influence they have to mobilise other forms of support (Hunsberger et al., 2009). Consequently, despite aiming to increase the social network of support through advocacy and mobilisation of others, in an attempt to improve efficiency or through an unawareness of the local community dynamics, district nurses unintentionally limit the patient's social capital if they are unable to participate in their usual social network interactions because of time-conflicting health interventions; arranged at a time to suit the professional (Findlay et al., 2017, Devik et al., 2015). For example, patients feel *"your life's not your own"* (Findlay et al., 2017) and that *"much time is spent waiting…there might be other things you would rather like to do"* (Devik et al., 2015). Patients with long term conditions and poor mental health have a more frequent use of paid and formal care use, and are therefore particularly vulnerable to this (Crotty et al., 2015b).

3.5 Discussion

This qualitative metasynthesis found that HCPs who work in rural areas are involved in wide ranging support for patients. This work goes beyond their professional specialty and experience and may include providing social and emotional support, help with daily tasks, and building links to local communities. Our findings indicate that taking on such a complex role is needed in order to provide effective and safe care for people living in rural areas. This review has found two dominant models in terms of how this is currently done in terms of developing relationships with patients and engaging with their wider networks of support: one model where nurse-patient relations are kept at an arms-length and another where nurses develop close relations with patients, which resemble friendships, with links extending to their wider networks including families, friends, and the localities where they live. These findings indicate that neither of these models is optimal for delivering patient-centred care in the community. In the case of the former, this is in part due to lack of understanding of the patient context, resources, and structure of support, with minimal or no knowledge and engagement of the wider social network members, and thus with likely negative implications for patient care and support tailored to individual needs. In the case of the latter, this is due to building expectations among patients and their network members that nurses might be able to address multiple gaps in the provision of health and social support arising from structural inequalities and the structure of people's networks. However, such relations are unrealistic and unsustainable over the longer term due to the risk of nurses becoming overburdened and because changes to healthcare service staff and provisions might make the nurse unreliable to patients; especially considering the uncertain finance, probable increase of complex community care and policy changes affecting healthcare, all of which reduces how effectively the nurse can deliver additional support.

Furthermore, as with other studies, this qualitative metasynthesis suggests that nurses developing an understanding of, and involvement with, patient's social networks does not automatically translate into positive outcomes for patients (Lucas, 2013, Rogers et al., 2014). For example, such close ties can have negative impact on the wider network of support by restricting engagement with existing network members and the building of new links. Therefore, our findings have suggested that nurse-patient relations in rural areas work best where nurses are seen as trusted acquaintances with a broad understanding of the social and emotional needs of patients and the financial and relational resources accessible to them. Such relationships are currently ad hoc, but they might develop, and become most effective in localities that nurses are familiar with and have greater social capital within the community because they live in the area or because they have been professionally involved with it over a longer period of time.

Table 5:
summary of synthesis process using second and third order processes

Number, Author, year, Country	Translatable concept	Summary of 2nd order interpretations by original author	Summary of 3rd order interpretations
Findlay et al. (2017) Scotland	Importance of a connection with family and friends when being treated at home.	Frustration and sadness at the lack of support was frequently cited, with contentment noted when friends and family were accessible. The timing of DN visits seem to restrict the ability to maintain existing relationships.	Some participants enjoyed the social aspects of the DN visits but due to timing most found them to be restricting and display ambivalence towards the service and the loneliness it brings. Ideally, individualizing services should reduce loneliness and improve associated mental and physiological health (e.g. frailty).
2 Crotty et al. (2015) South Australia	Spousal networks, the impact spouses/no spouse has on use of DN.	Spousal networks were denser and more likely to be maintained. Spouses interact with DNs and improve their significance within the SN. When there is no spouse, friends are more valuable; when there is no friendship support DNs fill friendship roles. LTCs alongside poor mental health makes maintaining networks difficult so transient SN members are frequently used.	The DN acts as a conduit to other services adding more 'weak', 'transient' relationships into the SN. This usually results in a network dominated by HCPs that is unlikely to provide long-term support and will be biomedically framed. This will likely lead to a lack of support with practical and emotional work; especially considering the mental health with long term condition cohort of this study.
3 Griffiths et al. (2013) England	Relationship between DN and patient during EoL care.	DNs give information, advice, education and instruction. DNs carry out this work in a relaxed manner that empowers the patients, becomes egalitarian and therefore therapeutic. The physical tasks and assessment are intertwined with the social aspects of their visits; often unnoticed by the patient. The frequency of the visits also correlated to an improved self-efficacy.	The DNs relaxed approach allows them to integrate into the patient's SN. The egalitarian relationship, not dissimilar to a friend, allows greater information sharing in both directions. The DN, once part of the SN adds new information and support, mobilise others into the SN and help with practical work that alleviates emotional stresses that impacts on their physical and mental health; thus benefiting the patient and their SN.
4 Grunberg et al. (2016) Sweden	Emotional support/work of the DN and how this helps identify needs and improve care.	DNs use informal dialogue to lift patients' mood and facilitate open discussion that helps identify further needs. This was deemed important to allow an integration into the SN meaning the DN had the role to mobilise others, advocate and meet their emotional	Despite the lack of resources DNs can utilize their relaxed approach, intertwined with planned visits, to provide emotional work; either by improving mood or identifying mental health concerns. Their role becomes similar to a friend by using general conversation and joking. They can

		needs. These skills are intrinsic with the DN often unaware they are detecting mental health needs. However, time and resources appear a barrier.	then integrate into the SN to meet emotional needs and to identify the correct people already in the SN to mobilise where needed.
5 Gossett-Zakrajsek et al. (2013) USA	The balance of formal and informal SN members during transitions from hospital to home.	Support, communication and reintegration are the three themes identified during transitions home. Successful transitions occur when there is synchronicity between formal and informal support that is planned with an appreciation for the changes occurred during time spent in hospital. There needs to be good communication between patient and informal and formal support.	A need for acute care creates changes to the patient's function and a break from their existing SN support. If there are weak ties these may disperse during inpatient stays. DNs should consider this, communicate with other SN members to overcome new shortcomings in the SN. The support provided of specialist community services at this time seems less likely to be accepted than the generalist DN support due to a stronger tie, frequency of interaction and therefore trust.
6 Devik et al. (2015) Norway	Values of patients on rural healthcare and how it affects the quality of care.	Patients have to adapt to the change in lifestyle when requiring DN input in rural areas due to the interventions being delayed, interrupting schedules and routines and being not readily available. Despite this being exacerbated by rurality patients prefer to remain here due to being a 'brick' in history and place giving them increased social capital and a sense of self, security and control.	The social capital retained by aging in place means patients can retain their existing ties to help meet health, emotional and practical work. DNs are less likely to become part of the patients SN due to their visits being infrequently, on a healthcare schedule and therefore difficult to mobilise by the patient. Patients prefer to navigate the community to find support but targeted those with knowledge of healthcare (e.g. retired nurses).
7 Hunsberger et al. (2009) Canada	Values of DNs on rural healthcare and how it affects care and themselves.	Rural healthcare can be rewarding and stressful. Often the initial attraction of open countryside become the stressor due to isolated practice. Acuity in these areas is increasing and experienced nurses are approaching retirement increasing demands on the services. More recently, only those already embedded in rural life appear to choose to work there. Urban policy and decision making frustrates rural healthcare and therefore rural specific training is needed.	The attraction of rural nursing is to help a community one is already embedded into. The shared community values helps integration into a SN to mobilise others. Willing DNs should nurture the attachment to the community to create stronger SN ties. However, the challenges of rural healthcare seem to outweigh the positives making recruitment a challenge. The blurring of boundaries between community member and DN cause confidentiality concerns and a burden on the DN who may be contacted out of hours or in public spaces.

8 Terry et al. (2015) Australia	The health and safety (HS) issues of rural healthcare and how it affects quality of care.	HS issues are complex and largely environmental. These include isolation, long distances, and poor infrastructure. DNs cite 'making do' and developing skills to overcome the HS issues. This includes rotating staff and dividing workload. Lack of funding, support, supervision and specific training exacerbate the problem and result in poor staff retention.	The needs of the DN and patient cannot be met in parallel. The HS issues in rural communities result in DNs create physical and emotion distress amongst DNs. The coping strategies used makes them less available to the patient, poor continuity of care and therefore a weaker tie is developed within the SN; encompassed by patients 'making do with who turns up' and 'not speaking to them in the same way'.
9 Kaasalainen et al. (2014) Canada	Physical and emotional challenges of EoL care in rural areas.	Rural nurses experience a unique challenge when delivering care to their patients; physically and emotionally. DNs have to overcome these challenges to support the patients with their increased risk of isolation and associated poorer health choices. Nurses often demonstrate extreme measures to go above and beyond for their patients.	Lack of resources force DNs to become generalists but this increases their frequency of interaction with the patient. They negotiate with the SN and community on behalf of the patient. They advocate and mobilise others into the network where possible which could burden the DN and confidentiality issues may arise when discussing the patient with the community. DNs nurture their tie with the SN by completing practical work like stoking the fire.
10 Reed et al. (2018) Australia	How local knowledge influences the way DNs care in rural areas.	DNs consider the values of patient and family to personalize care. Knowing the available resources in the rural area helps gather support for the patient. DNs have strong community relationships that empower them to advocate successfully. DNs possess the emotional intelligence to manage a personal and professional relationship and can justify it because of the likelihood of improved outcomes.	DNs face a challenge to meet patient's needs by nurturing a strong SN tie that could overburden them emotionally at EoL. If this is achieved they can successfully mobilise other members of the community and healthcare services. The challenges of burden, confidentiality and emotional distress are overcome by the DNs emotional intelligence.
11 Farmer and Kilpatrick (2009) Scotland and Tasmania	HCPs outside of their healthcare role creating opportunities for patients to increase their function and social capital. In rural areas.	The DN role in a rural community is both bonding and bridging with others. Nurses have been known to be embedded in the social fabric of the community and their remit extends to lift-giving, delivery and involvement in community facilities. They use their social capital in communities to implement change and establish entrepreneurial services (often outside of healthcare, such as establishing social clubs).	DNs use their position within the network to identify patient, SN and community needs. Especially true in rural areas where resources are limited, DNs go beyond their role and take it upon themselves to meet the needs. They also bridge and bond to other services (often out of reach to the rural patient) as a form of mobilizing others into the SN and improve the patient's social capital. Although not explicit in the data the improvement in social support and capital is likely to improve health; the DNs overarching goal.

12 Roden et al. (2016) Australia	DNs use their social capital for health promotion (HP). The pressures on rural DNs make this hard to sustain.	There is a lack of support and competing priorities for a rural DN. However, DNs had a more positive and committed outlook on HP, possibly because they knew and felt responsible for the community they served. Patients were more likely to follow the HP advice due to the respect they had for the DN. HP was often sacrificed when rural challenges (workforce, infrastructure, resources) limited their availability to patients causing stress and disengagement by the DN.	Effective HP requires committed DNs to be embedded into the community. This increases the tie strength between patient and DN and the patient is then more likely to follow advice. Relationships are mutual, open and conducive to honest reporting of health behaviors. Rurality acts as a facilitator to shared values, community engagement and therefore stronger tie but also restricts the time and resources available to deliver HP effectively. DNs may neglect HP as a result of rurality to treat the patient’s primary health need.
13 Reed et al. (2016) Australia	Rural DNs working and living in the same area and how this influences their role.	Successful EoL care requires DNs to be committed to the emotional work involved. Resonating with other studies, the knowledge of the people and resources available in the rural community was noted as valuable in advocating to the appropriate people. The DN needs to have a flexible relationship boundary with the patient create a reciprocal relationship for confident advocacy and emotional support.	EoL care increases the importance for DNs to become part of the SN of the patient and their family and should be encouraged. Increased tie strength and involvement in emotional work creates a reciprocal relationship and shared values that are conducive to good care. There is a risk of confidentiality breaches when advocating to other members of the rural community (e.g. priests). There is also a risk of emotional burden for the DN as they are likely to be unsupported in the rural setting.
14 Wang, Y., et al. (2012) Norway	Comparing experiences of being treated for acute illness at home or as an inpatient	A surprising finding was that participants at home felt safe despite the limited time with a HCP. This accredited to the ability to communicate via telephone at any time and also the personalized care plans. Being treated in their own home improved the relevance of the information and advice given; patients could relate it to their everyday life and therefore compliance increased. Nurses also had more time to spend 1-to-1.	Aging in place/ being ill in place allows information/health promotion to be more relevant to the patient and their SN and therefore accepted and implemented. They know “what-is-What” will increase long term self and collective efficacy. The acceptance is also due to the increased strength of the tie that is likely to be built between the nurse, patient and their family. This is because they are reliable, attentive, 1-to-1 and have the time to spend with the patient.

This may be because in such circumstances nurses are more likely to be familiar to patients, their family members and the wider local community either directly or indirectly through personal and professional reputation and support. These weak ties with patients paired with an understanding of local and individual structures of support, can allow nurses to help patients find, access and mobilise other network members in a way that is acceptable to them (Band et al., 2019, Vassilev et al., 2019) but also make them aware of new relationships and support that might be available, thus increasing the diversity of support and information (Pescosolido, 2006, Vassilev et al., 2014). Such relations with patients are likely to be sustainable over the longer term as, they are contextually sensitive, but also compared to strong ties, require lower levels of relational work (e.g. in negotiating acceptable engagement with other network members) and thus reduce the risk of burnout of nurses. Adapting the role of district nurses would allow them to improve collaborative work with people's informal network members while also delivering care that is better tailored to patient needs and context.

3.6 Implications for practice

Engagement with patient's social networks is likely to add value for patients living in rural areas and for community-based nursing teams. However, expectations for developing close relations with patients as a part of the nursing role should be seen as unrealistic considering the tensions between the growing complexity, demand and availability of services; but also due to additional tensions that such relations, and relational work (the interpersonal efforts that district nurses will invest in order to develop relationships between themselves and the patient (Locher and Watts, 2008)), are likely to create. Developing weak ties of trustworthiness and familiarity with patients is consistent with the nursing role and is likely to help with providing effective patient care. In developing such relations district nurses could focus on using health interactions to engage in conversations about family, friends and peers; and what they do or do not do to support the patient. Such knowledge, together with awareness of local resources and informal support, can allow nurses to help patients shape relations with their network members, access and negotiate relations within the community and healthcare services, mobilising other sources of support that can diversify the patient's existing network. This will add sustainability to the support; improve patient outcomes associated with improved health, practical and emotional support; and reduce the potential burden of responsibility on the healthcare service and professional. However, such relations between patient and nurses are currently only developed ad hoc. Making them sustainable in the context of increasing acuity and demand is likely to require putting in place support for professional development, and building resources and infrastructure enabling links between relevant professional and community resources and support (e.g. health trainers, social prescribers, befriending services).

3.7 Conclusions

This review used the systematic approach of a qualitative metasynthesis in order to gain insights into the effect of rurality on district nurse-patient relationships, where existing data had previously focused on the two themes in isolation. The focus of this review was to combine and address how the two factors influence, compliment or conflict with one another; and develop further understanding of what approaches patients and professionals should adopt in these contexts. Findings demonstrated that HCPs in rural areas cross boundaries, firstly, with the work they carry out, and secondly, form a professional relationship similar to friendship. There was also evidence of local embeddedness and nurses negotiating with the community in order to find support on the patient's behalf. The discussion demonstrated that nurse-patient-social network relationships can be unsustainable if they are burdensome or disruptive to existing social networks. Developing weak ties of familiarity with patients and building awareness of, and connection to, local structures of support is likely to offer a promising avenue for developing community based nursing support that is sustainable and tailored to patient needs. In this regard, this review contributes to the understanding of the key role that weak ties play in people's networks by exploring such ties in a different context and focused on healthcare professionals, but further research is needed, across varying community nursing services, in order to develop a clear understanding of the dynamics of such a role and relationships and the necessary conditions and resources that might be needed for their embeddedness into practice.

3.8 Limitations

This review included only qualitative studies. Although this method fills gaps in understanding and underlying mechanisms left by quantitative studies, qualitative synthesises cannot include the number of studies of a quantitative synthesis. Furthermore, as a review of a previously unexplored areas of rural healthcare paper, the outcomes identified are theoretical and may require empirical investigation to confirm.

3.9 Ethical statement

This is a qualitative metasynthesis of existing papers all of which had ethical approval.

3.10 Additional information

Conflicting interests

The authors declare that they have no conflicting interests.

Author contributions

JG designed the study under the guidance of IV and RB. JG carried out the literature searches and article selection which was reviewed by IV and RB until consensus was reached. JG wrote drafts of the manuscript of which each was reviewed by IV and RB. All authors read and approved the final manuscript, had full access to all of the data in this study and takes complete responsibility for the integrity of the data and the accuracy of the data analysis.

Data availability

The authors confirm that the data supporting the findings of this study are available within the article and its supplementary materials.

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4.0 Chapter 4: Empirical research: the design and practical implementation of primary research phases

Having conducted a metasynthesis, the review of the literature showed that, regarding community healthcare services, the majority of existing data focuses on district nurses. There are similarities and therefore some parallels can be made with HaH services that help place this project into a rural healthcare, community context. However, there are specificities to the HaH service, and therefore these findings strengthen the argument that more information is needed regarding HaH services. The metasynthesis has also shaped the next stage of this project by identifying the key aspects of the study setting and the participants who should be included, as well as the pertinent areas for quantitative (such as loneliness, collective efficacy and social network data) and qualitative (such as patient experience and the 'work' of HCPs) work where further exploration was needed.

This, in the context of the research aims, poses challenges for empirical researchers regarding the most appropriate methods most suited to answering them, within the scope of this project. The purpose of this chapter is to detail the considerations of the researcher and how these considerations shaped the final, ethically approved processes explained in this chapter. Specifically, a multi-phased, mixed method approach will be taken, and quantitative and qualitative findings will be integrated in order to develop a deeper understanding of the phenomena (Creswell and Clark, 2007, Shorten and Smith, 2017). Taking such an approach is suitable for a complex healthcare service (Mesel, 2013).

In summary, the primary phases of the research project contributed to the overall aim of the study by collecting primary data from a HaH setting. This involves using a multi-perspective, mixed methods approach to explore:

1. Staff experiences of HaH services and the role of patient personal networks.
2. The associations between patient characteristics (demographic, illness, self-efficacy), network member characteristics (socio-demographics, distance, type of relationship, frequency of contact), network structure characteristics (e.g. type of network, amount of support, collective efficacy, fragmentation), and key health related outcomes (e.g. loneliness, isolation, health related quality of life [HQoL])

3. How and why such associations may vary for patients at different stages of the illness trajectory.

Formal details about the procedures followed are within a protocol document written for ethical approval of the empirical study (appendix 1) and the following chapters will discuss the ongoing practice plan and rationale.

4.1 Study design

A three-stage mixed-methods approach has been used. This included:

1. Obtaining key health status indicators from patient medical records (e.g. comorbidities and current diagnosis).
2. Semi-structured interviews with HaH nursing and healthcare support workers were conducted. Interviews explored the HCP opinion and knowledge of the role of personal networks during HaH treatments.
3. Collecting quantitative data of HaH patients at two time points: Within one week of discharge and a 12-week follow up questionnaire.

4.2 Study setting

Previous chapters mentioned that HaH services are a cost-effective and patient accepted medical service where patients are treated at home (Leticia María Dopico, 2018). Although systematic reviews into these settings cannot confirm reduced costs, results concur that patient satisfaction is high with no negative impact on health outcomes (Gonçalves - Bradley et al., 2017). A HaH service that is part of a county hospital in a rural part of England is the research site for this study. This example receives patient referrals from various routes such as inpatient wards, outpatient clinics, GPs or community hubs (the latter two as part of admission avoidance) for medical intervention such intravenous antibiotics, observation or complex wound dressings/drain management (figure 2). The service also provides, medicines management support, anti-coagulation treatment, venepuncture and nutritional support.

Healthcare professionals travel from the hospital to provide the required treatment in the patient’s home. The multidisciplinary service has a maximum capacity of 17 virtual beds and a daily ‘virtual’ ward round allows doctors, nurses, allied health professionals (physiotherapists, occupational therapists, speech and language therapists and dieticians), microbiologists and pharmacists to discuss patient cases and update treatment plans. The length of admission varies depending on patient and medical need: from a single visit to multiple visits over 10 months.

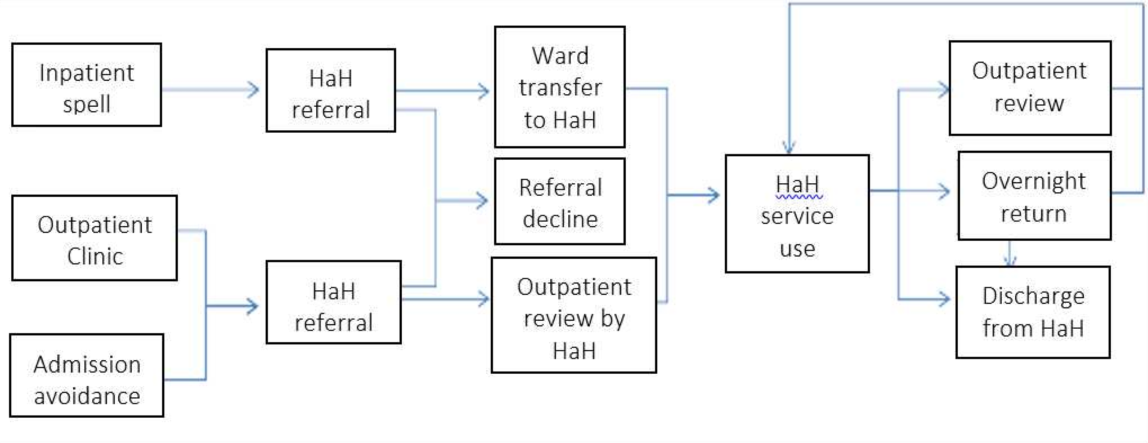

Figure 4: *The HaH service patient flow chart. The flow demonstrates the range of admission routes, the journey through the service, and the potential route to discharge or expected/unexpected re-admission.*

4.3 Participant identification

All patients referred via all admission routes to the HaH service were approached towards the end of medical treatment. Eligible, potential participants were approached, in person, by the researcher with an invitation letter and accompanying participant information sheet (PIS) and then followed up no sooner than 2 days later to give written consent (appendix 3). Following this, quantitative questionnaires (appendix 3) (available online or over the post depending on preference of participants) were sent with prepaid envelopes (where over the post).

Written informed consent was obtained for all patient participants. Those unable to give consent due to a lack of capacity (based on medical diagnosis and doctor assessment) were not included. This is due to ethical considerations as well as the inability to retain information and give accurate data required to meet the study aims and for the research team to work within the Mental Capacity Act (2005).

From a qualitative, HCP, perspective all staff nurses and healthcare support workers (the staff who are involved in delivering care and treatment on a daily basis) that actively give care and treatment to patients were approached to participate with a PIS, accompanying letter and written consent form (appendix 2).

4.4 sample size

Qualitative study:

The sample size of HCPs was determined by the number of staff willing to participate. At the time of recruitment, the service employed four registered nurses (excluding the PhD student researcher) and seven healthcare support workers, therefore a maximum of 11 HCPs could be approached. Participant characteristics can be seen within chapter 5.

Quantitative study:

Sample size for quantitative patient data collection was determined by admission rates to the HaH service and the response rate of those approached. It was estimated that during the planned 12 months of data collection around 100 patients might use the HaH service. All service users were invited to take part, however, due to interruptions caused by COVID-19, a total of 76 were included reflecting a response rate of 62%. Of the 76 participants completing the baseline questionnaire, 29% (n=22) did not return the follow-up questionnaire.

4.5 Approaches to data collection

4.5.1 Qualitative study

Interviews with healthcare professionals

Health care professionals were invited to take part in semi-structured, qualitative interviews. Interview schedules were used with the aim of exploring HaH staff perceptions of the service and the value they attribute to patients' SNs, how they engage with SN members and draw on the support they provide (see appendix 2).

4.5.2 Quantitative study

Exploring the literature on the topics of social networks, loneliness, QoL, self and collective efficacy and patient satisfaction identified multiple quantitative measures for each. After consultation between the research team and exploring feedback and guides to quantitative research (Valtorta et al., 2016) the following measures were used to explore statistical trends that could inform understanding of the role of SNs in supporting HaH service users:

- Socio-demographics
- The De Jong Gierveld 6 item scale for loneliness (Gierveld and Tilburg, 2006)
- Self-Efficacy for Managing Chronic Disease 6-item Scale (Lorig et al., 2001)
- CENS Collective efficacy (Band et al., 2019)
- World Health Organisation Quality of Life (WHOQOL-BREF) (World Health Organisation, 2014)
- Patient satisfaction survey (Department of Health, 2012)
- Personal network data name generator (member type, frequency of interaction, proximity) (Koetsenruijter et al., 2014, Vassilev et al., 2014)

The De Jong Gierveld 6 item scale for loneliness, Self-Efficacy for Managing Chronic Disease 6-item Scale, CENS Collective efficacy and WHOQOL-BREF measures are reapplied to the follow-up questionnaires given at 12 weeks post discharge. This would allow for outcomes to be projected based on trends in the data.

4.6 Data analysis plan

4.6.1 Qualitative analysis

Interviews with HCPs were digitally recorded, anonymised and transcribed verbatim. Although time consuming, all were transcribed by the PhD student researcher to create a greater understanding of the data set. Data were analysed using a thematic analysis approach (Braun and Clarke, 2006). In a relatively un-researched area of healthcare preconceived themes are unavailable to guide thematic analysis, therefore, an inductive approach was used to allow the data to determine new themes (Fereday and Muir-Cochrane, 2006). This means that concise and meaningful themes have been developed in a transparent and consistent manner by first familiarizing oneself with the data (in this case during self-transcription), reading and re-reading transcripts, looking for similarities and differences that become the basis for themes before finally defining and naming the themes. The process of analyses is presented here, in a chronological order (figure 5) but in reality, reverting to earlier phases is encouraged as codes may become apparent during later phases (Braun and Clarke, 2006). The qualitative analysis illuminated stakeholder perceptions and the meanings attributed to the successes and failures of the HaH service in relation to personal, social, and illness management needs. Furthermore, this stage of the analysis also helped interpret the findings from the quantitative analysis (Braun and Clarke, 2006).

4.6.2 Quantitative analysis

The quantitative data were organised using SPSS statistics V28. SPSS can be used to generate descriptive data (average patient age, size of patient network, satisfaction) and for the development of syntax that translate primary data into subscales scores and/or mean averages as prescribed by the authors of each measure. Primary SN data collected through a name generator can also be reconfigured to formulate new data for areas of potential interest (e.g. proximity of children, spousal networks, pets in network, mix of agents, amount of weak ties).

	Phase 1: familiarising with the data	Phase 2: Generate initial codes	Phase 3: Searching for themes	Phase 4: Reviewing themes	Phase 5: defining and naming themes	Phase 6: producing the report
Application to this research	JG to hand type transcripts of interviews	Highlighting points considered possible codes by the researcher. Different colours used to start grouping similar ideas	Re-focus the initial codes into groups. Visual tools such as tables will be used to manage data into groups	Refining phase 3 themes, possibly eliminating, dividing or adding new themes. Review the transcripts to retain meaning	Identify the essence of the theme and name it accordingly. A concise name for each theme to tell give the reader a sense of the theme. A detailed analysis of each theme will be required	Telling the complicated story of the social network analysis. Interesting, concise and coherent account of the data analysis and outcomes of it. Will include, but not simply list, extracts and quotes from transcripts where appropriate to add clarity.

Figure 5: *the processes of grouping verbatim transcripts into themes and analysing them in order to define new findings for production and dissemination.*

The study explored associations between individual level characteristics (x) (e.g. age, gender, socioeconomic status, health status, co-morbidities, length of admission, self-efficacy, loneliness), network structure characteristics (e.g. size of network, diversity of network, frequency of contact, collective efficacy), and WHOHQoL Q1 ("How would you rate your quality of life?") (y) and WHOQoL Q2 ("How would you rate your health?") as the main outcome measure (*z*). Intermediate correlations will also be explored (those stages between individual characteristics and HQOL) such as between SN characteristics and loneliness, collective efficacy and self-efficacy (*y*) before relating these to the primary outcome measure (WHOQoL Q1, Q2). This is done so that the greater understanding of the correlations between *x*&*y* and *y*&*z* can achieve a more detailed understanding of why *x=z.*

4.7 Empirical research plan summary

This chapter has demonstrated the planned and implemented stages of the empirical mixed-methods, multi-perspective project and why such an approach was chosen. Both methods of research have been undertaken in conjunction with one another. These are discussed in more depth in chapters 5 and 6.

5.0 Chapter 5: Paper two: Qualitative study: What is the work and the (in)formal workforce involved in supporting people using 'Hospital at Home' services?: A nurse perspective

This paper is the second of three papers forming the 'three paper thesis'. The qualitative study has been completed and submitted for peer review to the journal *Health and Social care in the Community.* The author has responded to reviewer comments and submitted the revised version of the paper, further referred to as Gillham et al. (2023).

5.1 Abstract

Pressure on healthcare systems to address growing population needs is forcing services to adapt, which includes supporting acute patients in the community. One emerging service in the United Kingdom that offers this level of treatment is 'Hospital at Home' (HaH). Self-management support is an area of particular importance in this context considering that acute care is provided in a community setting with limited input and monitoring by healthcare professionals. There is currently limited understanding about the full range of support needed by patients in such circumstances, and how providing treatment at home supports self-management and the engagement of network members. To explore this area, semi-structured interviews were conducted with the nurses (n=9) from a single HaH service to explore the patient's social network dynamics. Thematic analysis was used, and four themes were identified: prioritising illness work within a discourse of person-centred care; the work involved in the 'naturally' therapeutic environment of the home; partners as key members of the care team; limited awareness and engagement with (in)formal networks.

Findings demonstrate tensions between discourses where nurses idealise the value of the home and the provision of holistic service, while in practice prioritise illness (over relational, emotional practical) work, and delivering a service that is routinised, and time and cost efficient. There is recognition of the positive role of network members for self-management support, but awareness and engagement is limited to partners and the formal services that HaH staff are familiar with.

Developing a better understanding of the role of social networks in supporting people with acute need living at home, can help improve patient experiences and care, and HaH services, especially for people who are vulnerable, with complex needs, living alone, and with limited access to resources.

KEYWORDS: Hospital At Home, community nursing, social support networks, self-management, strong ties, weak ties, rural

What is known about this topic?

- New (and under researched) services such as 'HaH' are increasingly required to provide acute illness treatments in the community and reduce the burden on inpatient settings.
- A degree of self-management will be required for patients receiving 'HaH' treatment but knowledge of chronic illness shows that having support of a diverse SN facilitates this.
- Community healthcare professionals often go beyond their professional boundary to provide practical and emotional support.

What this paper adds?

- Nurses feel they provide patient-centred, individualised care but instead care provision is focussed on illness management and routinized.
- Nurses are heavily reliant on strong ties (in particular spouses) and other formal services to risk-manage and provide illness, emotional and practical work for patients.
- Improved understanding and engagement with members of people's wider network may help HaH staff to offer more appropriate and sustainable support for patients in different circumstances.

5.2 Introduction

The trend of aging and increasing populations has meant that maintaining the good health of all people has become increasingly difficult (World Health Organisation, 2006). In the United Kingdom longer life expectancy and a wider availability of treatments have been associated with higher demand for hospital beds and escalating costs of providing care and treatment (NHS England, 2019, Taylor and Bury, 2007). One way the National Health Service (NHS) has adapted to this demand has been by establishing out of hospital treatment services for acutely unwell patients. One such service is hospital at home (HaH).

5.2.1 Hospital at Home services

The introduction of the NHS ‘Long Term Plan in 2019 set out a £4.5bn budget rise for community services, which includes HaH services. HaH services typically provide short term, hospital level interventions in patients’ own homes as a means of avoiding admission or supporting an earlier discharge from hospital (UK Hospital at Home Society, 2021, NHS England, 2022). This includes administering treatments such as intravenous (IV) antibiotics and fluids to a patient group that has higher levels of acuity than those using other community based healthcare provisions such as district nursing services (NHS England, 2022, UK Hospital at Home Society, 2021) . To date, the focus of research into HaH services has centred on costs, health outcomes and patient satisfaction. These have indicated that HaH services are cost effective, and show no significant increase in morbidity or mortality whilst demonstrating a significantly higher level of patient satisfaction compared to inpatient settings (Shepperd et al., 2009, Pearson et al., 2013, Facultad and Lee, 2019, Caplan et al., 2017). However, there is currently limited understanding as to what aspects of the service patients value most and why, what is the nature of the work that is required to provide such support, and how is this work distributed between healthcare professionals (HCPs), patients, and members of their social networks (SNs).

5.2.2 Person-centred perspective on illness management

There is evidence that, for users of HaH services, complex illness work is closely intertwined with the emotional needs and practical everyday tasks that patients and people around them need to complete (Wang et al., 2012). The self-management support literature has demonstrated that illness management in everyday contexts is better understood as a collective rather than an individual process, and one that is most successfully undertaken within people's SNs (Vassilev et al., 2019, Foss et al., 2016). These can include a wide-ranging (formal and informal) workforce beyond HCPs (Vassilev et al., 2014, Kennedy et al., 2007). There is evidence that people who have access to diverse types of relationships including both 'strong', intimate ties (e.g. spouse, partner, children) and 'weak', more distant ties (e.g. acquaintances, HCPs and community group members) report better self-management and quality of support (Walker et al., 2018, Reeves et al., 2014). This is in part due to more adaptive support being provided, reduced risk of burnout, and the scope such networks have to link to other sources of support and information (Fiori et al., 2007, Fiori et al., 2006). There is evidence that the SN members play an important role in the self-management support of people with long-term conditions, but the relative importance of formal and informal network members, and the process of developing acceptable justifications for their involvement or not, are likely to differ where people are managing short-term acute illness.

5.2.3 Community-based support by healthcare professionals

Previous research has outlined some of the complexities in providing support in community settings where healthcare teams go beyond their professional speciality and attended patient's homes to stoke fires, walk dogs and spend time discussing personal issues of concern (Gillham et al., 2021, Griffiths et al., 2013). There is also evidence that the amount of non-illness work that community-based HCPs do varies, doing such work may trigger different processes, and may have positive and negative implications for professionals and service users (Cramm and Nieboer, 2017). For example, community-based HCPs can be effective in linking patients to new and reliable sources of emotional and practical support, while also not disrupting existing channels of informal support

(Vassilev et al., 2014, McGarry, 2009). Additionally, where professionals provide wide-ranging emotional, practical and relational support may lead to growing patient expectations and a sense of burden, especially when HCPs are unable to meet such expectations (Gillham et al., 2021).

Despite an emphasis on acute treatment being delivered outside of inpatient settings, there is currently limited understanding of the self-management support needs of people living at home during episodes of short-term, acute illness, and the relative importance, and the process of engaging formal and informal network members in providing such support. Developing such understanding can help improve patient experiences and HaH services. This study aimed to offer insights into this gap in knowledge by exploring the relational dynamics between HaH nurses, patients and members of their SNs (such as friends, family members, and neighbours). The paper takes a HaH nurse perspective and aims to address the following questions:

1. What is the nature of the illness, practical and emotional work involved in supporting people using 'HaH' services?
2. Who are the members of the formal and informal workforce involved in this work?
3. What are the tensions and complementarities in completing this work?

Addressing such questions, can help improve community based services, such as HaH, especially where greater support is needed for more vulnerable people with complex needs and limited access to support (Clarke et al., 2010).

5.3 Methods

5.3.1 Design

Qualitative interviews were conducted with HCPs working within a single NHS HaH site in the South-West of England. Patients are referred into the HaH service in order to prevent hospital admission or facilitate an early discharge. This service has the capacity to accommodate up to 15 patients. The lead author (JG) is employed as the deputy team lead within this service.

5.3.2 Sampling and recruitment

All registered staff nurses (n=4) and healthcare assistants (n=9) within the HaH service were approached to participate within the study. Written informed consent was obtained from all participants.

5.3.3 Data collection

All interviews were conducted face-to-face by the lead researcher in a neutral office within the HaH service. Semi-structured interviews were conducted between January 2021 and February 2022. Demographic (age, gender) data and employment information (job title, length of time working within service) was collected from each participant.

5.3.4 Data analysis

Interviews were recorded, anonymised and transcribed verbatim by the lead researcher. A proportion of the transcripts were then reviewed separately by each member of the research team with findings discussed until consensus was reached. The transcripts were analysed using iterative thematic analysis to find recurring trends that could come together into themes and sub-themes (Braun and Clarke, 2013). Focus within the transcripts was applied to the meaningful data relevant to relationships between nurse, patient and the SN of support; the 'work' undertaken by the healthcare professional and applied to the context of acute illness at home. At each stage of data coding and analysis, discussions were conducted within the research team to ensure consensus. An excerpt of the thematic analysis process can be seen in Table 6.

Quotation	Sub theme	Theme
I can't think of one that has come back with any negative feedback. It's always positive. (Participant 7)	Discourse/professional identity/ self-perceptions of service	Relationship with the patient and prioritising health work
We, I would say, have most of the things they could need (Participant 3)		
We're not just task driven (Participant 2)		
Sad to see us leave [when discharged] because we have a laugh. Especially those who don't have anyone (participant 1)	Developing an effective nurse-patient relationship and relational work	
just…umm…be just very friendly and open (participant 7)		
Chat about sport or family (Participant 2)		
at home they're more relaxed. They've got things that they can do, they can get on with things, even if it's just a jigsaw puzzle (Participant 7)	How being treated at home improves patient experience and nurse-patient dynamics	SN dynamics in the context of the home
Feel more relaxed at home (Participant 2)		
Some are engaged with their health but some are very passive (participant 3)	Breadth of patient as a barrier to providing emotional and practical work	
we've had people for a day and we've had patients for several months (Participant 7)		
the younger patient doesn't need a lot…you go in, give the antibiotics, have a chat and but there is other patients that probably would want more of your time. (Participant 4)		

Table 6: *An excerpt of a larger thematic analysis table demonstrating how data were utilised and organised to form subthemes and themes.*

5.4 Findings

In total, 9 participants were interviewed this included registered staff nurses (n=4) and healthcare assistants (n=5), and male (n=2) and female (n=7) participants. Participants had an age ranging from 32-57 (mean age = 46, SD= 8.21) and had worked in the service for a mean of 19 months (range = 4-30 months, mean length in months = 15.2, SD = 8.05). Interviews ranged from 40 to 100 minutes. The findings were summarised in four main themes. Extracts and quotations from the data are used to illustrate each theme, including any differences of perspective and nuances. As such, the extracts are representative of all the data.

5.4.1 Prioritising illness work within a discourse of person-centred care

Respondents had positive perceptions of the service (1-9); with participants claiming that *"I haven't had a patient who disliked the service"* (3) and *"we always get good feedback and a good response and they're [the patient] usually very happy to have us"* (6). This gives HaH staff a strong sense of professional identity associated with providing hospital level interventions at home (1,3-6,8), making *"people better"* (3) from a health perspective (3,7,8) whilst helping to *"save money for the NHS"* (4) by reducing the use of more expensive inpatient 'bed-days' (3,4,8) and facilitating "*people to be at home and be around loved ones"* (7).

The HaH staff thought that this positive patient perception of the service was in part due to the service being delivered in people's homes, rather than in hospital:

> *"You're coming into their home which is very different*
> *than going into their Hospital bed-space to deliver care"* (6)

This was because of the longer time HaH staff spend one-to-one with the patients during medical intervention (4-8) which allows nurses the *"time to converse"* (5) and build rapport with patients (1,2,3,5-9). *"Rapport building"* (1) is undertaken in a number of ways by the nurses; but most commonly through informal and unstructured discussions about people's life and concerns unrelated to their health or the specific health interventions and (1-7) and included *"having a good chat about anything really"* (1), *"having a laugh"* (1), talking about sport (2,3), hobbies (1,6,7), jobs (1,3,5,6) and families (3,6,8), food (8):

> *I find it's quite interesting to find out what they did for a living.*
> *You know to strike up a conversation"* (5)

Furthermore, participants refer to one-to-one nurse-patient interactions as an opportunity to build an egalitarian and reciprocal relationship through sharing experiences and personal stories (1,5-8). This is particularly pertinent in the patients' home where environmental cues such as pictures and artwork can be used as a tool for starting conversations (1,5). HaH staff *"sit and watch telly with them – like a game show and you do it together"* (1) and share personal information about themselves (1,5,7), their pets (1,7), past employment (6) and are generally *"friendly and open"* (7) to the point where one participant felt they:

> *"get to know them, and they know you. Then you*
> *do have that almost 'friendship' thing going on"* (7)

Developing relationships with patients is not only seen as an opportunity to provide a degree of emotional support; *"if you can get them laughing then that's really good medicine!"* (7), but also for creating *"a better picture of what this individual is going through"* (5) by asking *"how are you managing?"* (3) in reference to practical and emotional support. Patients are considered more likely to disclose information when they have a stronger relationship with the nurse (1,2,6,7). If additional practical work was identified then nurses, particularly healthcare assistants, would likely provide support *"off the hoof"* (1) in the short term (1,3,5,7,8), with tasks such as making hot drinks (1,2,5,7,8), *"A simple meal if they needed it. Some toast"* (5), *"feed[ing] the pets"* (7), *"basic shopping"* (5), *"toileting"* (9), or help *"getting into their pyjamas"* (7).

When considering that nurses *"get to know them [the patients] over time"* (1), the acceptability of providing emotional and practical support depends, in part, on the length and intensity of interaction with the service (1,6,7). For example, one participant explained that "*It can become much more comfortable [over time]…much more jovial"* (6), and that frequent users of the service have stronger relationships than others (3). Furthermore, length of time spent using the service and amount of contact during that time is a determining factor for relationship building (1-9); and considering that a medical diagnosis might necessitate HaH level interventions that range from one day to several months, and once-a-day to three-times-a-day (1-9), those whose medical need requires more interactions from the HaH nursing team are likely to see an increase in relationship strength with the nurse:

> *"if they're being seen three times a day you're going to build up*
> *quite a rapport with them"* (7)

However, the discourse about 'natural' and 'strong' nurse-patient tie appears to be a limited, infrequent, and unplanned by-product of a health-focussed service suggesting that there is a discrepancy between what HCPs think they can achieve and the reality in practice. For example, despite nurses claiming that best practice is to "*go in and do what you've got to do* [regarding additional practical and emotional work]" (3) and that they're *"not just task driven*" (2), the "chat" is superficial and kept within the time permitted for the health intervention (7,8): *"[have a] Friendly chat until it is time to leave"* (4). From this perspective the relationships are built as a means to "*pass the time, [and] the silence*" (4) during health interventions, rather than as an inherent part of offering a service that is holistic and patient centred. Therefore, the "*medical conversations take priority"* (3) and although informal discussions may help identify health problems which might otherwise go unrecognised (6) (such as patients "*eating the wrong foods"* (3) and ensuring that patients are *"drinking correctly and that their environment is safe"*(5)), the health focussed approach is used to limit the amount of additional work provided by nurses (4,6,7) meaning that *"it's not very often we [HCPs] do anything extra than delivering the antibiotics"* (6). This approach was optimal to some HaH staff because of the time specificity of planned health interventions such as intravenous medication, vital-sign observations and wound dressings (2-4,6-8). One participant stated it "*is important that the antibiotics are given on time"* (3) whilst another expanded: *"if they're having antibiotics three times a day then they have to have a certain gap between, so you have to go at six hours between*" (6). In contrast to the discourse of taking a holistic approach beyond illness work, there was also a perception that undertaking such work would be in tension with the need for clinical reliability within HaH services (3,4,5):

> *"I think if we started getting people out of bed and washing and dressing people then we're going to be late for the next visit and then that patient doesn't get their antibiotics"* (4).

Additionally, providing wider ranging support would also restrict the service's ability to assist as many people, with as wide a ranging conditions as possible (4,5):

> *"we would have to change the whole service and we wouldn't be able to take on as many patients if we were going to provide*

care as well" (4).

The low value and priority of emotional and practical support is also systematically embedded in the service where there is a strong drive towards minimising face-to-face interactions and time spent with patients where possible. Firstly, this is achieved through the use of technology; nurses are able to administer multiple doses of antibiotics across the day despite only visiting the patient once (1,3,4,7,8). Although some nurses argue that for some patients there is emotional value to this because there is "*less of a burden for them"* (1) if seen only once a day and *"gives them a bit more freedom…to enjoy their spare time walking, seeing family"* (1). Others suggested, "*I suppose it does free them up, but really it's for our time management"* (4). Secondly, the reduction in illness work is achieved through medically, illness focussed discharging (5,7): *"as soon as their infection markers are at a healthy level…that's when they go"* (5). This is in spite of nurses acknowledging that patients are often *"sad to see us leave"* (1), particularly those who lack social support (1,8) or "*don't see a lot of people and get used to you [the nurse] being there every day for their social interaction"* (4).

5.4.2 The work involved in the 'naturally' therapeutic environment of the home

HCPs believe that patients who use HaH services *"feel important"* (7) because they are being treated at home and that they share the nursing values of relieving pressure on NHS provision by *"freeing up a bed for a more acute patient and saving money"* (3). As such, HaH anticipate that patients will associate the service (and it's employees) with this positive experience (1-4,8). Experiences are further improved because patients are *"feeling at ease"* (3), are *"more relaxed at home"* (2) and are in their *"safe place"* (1,5). Home comforts such as a comfortable bed (1,3,4) and television (1,5,7) are widely cited as important factors to improving the experience of the patient (1-9); less interruption to sleep (3-5,8) and home cooking (3,4,6) adds to patients feeling *"comfortable in their own surroundings rather than being in a busy hospital"* (4).

The nurses feel that these factors contribute to more effective nurse patient relationships because the patient is more at ease in their own home which, in turn, facilitates a positive service experience. This is substantiated by the increased levels of *"engagement with their health"* (3) and empowerment in their treatment choices (2,3,5-8):

> *"It's more personal being in their house. There is, kind of, that working relationship with them [the patients] and [more] talk about their problems and worries"* (4)

Therefore, the main driver for what HaH nurses perceive as benefits of the service for patients appears to have little to do with the holistic work of the nurses and is mainly a by-product of patients being in their own home, which is perceived to be acting as a therapeutic environment. Respondents thought that by being treated at home, patients are able to maintain existing routines and "*just get on with things"* (7) in an environment that is more stable and consistent with their existing norms and values than inpatient settings (2,5,8): "*everything is around them that they have lived with all their lives…they have their loved ones with them"* (5) which may go some way to explaining why the healthcare professional may not go beyond the illness work. Nurses facilitate the patient's existing routine by providing a treatment service that *"isn't regimented"* (5) by the needs of a large hospital (such as limited options and access to food and drink (6,8)); and disruption when "*sleeping in bays of six"* (4)) and by encouraging independent choices such as *"eating and drinking what they [the patients] want"* (6) at a time that suits them (4,6,8) and *"going to bed when they want to, getting up when you want to"* (5). By doing this, nurses believe that this adaptive dynamic is inherent in the 'home environment' and that just being at home allows patients to benefit emotionally (4,6,8) but also improves health outcomes because of increased functioning whilst undertaking everyday tasks and the associated *"fitness, strength and stamina"* (4) that will be maintained as a result (4,6,7,8).

However, the nature of the work of HaH nurses is very diverse and difficult to standardise, as there are "*patients from the whole spectrum of nursing [who use HaH services]. There's surgical patients, there's medical patients; there's young patients from 19…right up to your 90s"* (4). This breadth of patient needs and contexts indicates that fitting even only the illness work required into a home context is not automatic. In contrast to the idealised narrative about comfort and benefits of the home environment, the accounts of the actual work completed indicate that there is need for a substantial amount of additional relational work on the part of both patients and HaH staff for the successful integration of care into the existing routines of patients. This additional work is made invisible and normalised as *"one shoe doesn't fit everybody*" (5). For example, HaH staff have to adapt type and quantity of additional work to each individual's attributes such as age (1-3) and level of illness acuity (3,4,7): "*There are a lot more unwell people but there are people who haven't felt unwell from the start"* (4). In the extremes, some patients continue to work during HaH admission (1-4) whilst others *"wouldn't be able to stand and cook a meal"* (6). Some patients require formal care (1,3,4,8) because they are "*older and less able and need help with personal needs and around their home"* (1) whilst others are able to undertake home improvement projects (5) and exercise (4).

There were clear counter examples to the discourse about the home as a naturally therapeutic and patient valued environment. Such cases were however narrated as being due to the personality traits of individual patients, rather than being an inherent part of the intrusion into people's private space (1,4,8). For example, patients may be *"stoic" and "closed off"* (8) and avoid asking for additional support or may simply "*cope better than others on their own, it depends on their personality"* (1) whilst others rely more heavily on the nurses for social support: "*We have a lot of people that don't really want to chat at all. And others that, when you're trying to leave, they're still chatting"* (4). This indicates the substantial amount of relational work required as nurses have to practice differently depending on contextual factors, individual needs and preferences, and assumed expectations (1-5,7,8):

> "*You wouldn't go into the house of someone who is young and independent and make them a cup of tea; it's not appropriate*" (2).

> *"With the younger patient, they don't need…want a lot. You go in, give the antibiotics, have a chat and go…but there are other patients that want more of your time"* (4).

A final consideration within this theme is how logistical and practical factors create challenges for establishing and maintaining relationships with patients. The most widely cited example of this is the long travel distances to some patients' homes (1-4,6,7) which restrict the ability to build a relationship because, for example, it reduces the number if nurse-patient interactions that individual might receive: *"if it's [the patient] far away then it limits the amount of visits a day"* (3) and *"We can go out to 30 miles from [hospital name], but they [the patient] would only get one visit"* (1). This may in turn increase the length of time it takes to build relationships and gather relevant health and social information about the patient (2,4,5). When considering that each interaction can take up to an hour (1-4,6) in addition to long travel distances this can cause restrictions in the number of patients that can access the HaH service (1,3,5):

> *"the amount of time you're going to spend…is going to be excessive and there may be other patients [that need the service]"* (5).

The longer travel distances from main healthcare hubs also limits the access to support available to the patients from other HCPs which means they have to *"trek into appointments"* (1) that replace medical reviews and diagnostic services that would be undertaken routinely whilst admitted to a hospital ward (3,6,7,8) which can cause the patient to feel *"[emotional] conflict between being happier at home to having to come back and forth [to hospital]"* (8).

Relationships between nurse and patient are also developed slowly because of staffing limitations (1,3) and the *"rotate[ing of] the runs"* (1) designed to reduce the burden on staff caused by driving too far in one day (5). One participant felt this causes anxiety among some patients: *"Some get anxious about who is coming in today"* (1). Rotating the attending nurse, designed to reduce the burden of long travel distances on one nurse, may inadvertently result in nurses being increasingly *"isolated and vulnerable"* (3) when facing challenges locating patients which they have never visited before (1,4,8) and when they *"don't know where you're going"(4),* especially in rural areas (1,2,4,7), *"in the middle of nowhere"* (2), late at night (2,4) and in bad weather (2,5) where telephone and GPS signal may be limited (5,7). Furthermore, some nurses suggested that some factors reduced their willingness to visit certain patients such as dangerous dogs that nurses *"had* *to make sure was shut out before we got there"* (7), "*police patrolling dangerous neighbourhoods"* (3) and the unclean or unhygienic conditions of some homes (1-3,5,7):

> *"Some [homes] are really filthy and you have to wipe your feet on the way out"* (7).

5.4.3 Partners as key members of the care team

HaH staff saw partners as playing an important role in supporting patients at home (1-9) and were aware that some partners were registered as long-term carers because of pre-existing health conditions (1,2,3,7). Our respondents thought *"it's easier if they have a husband or wife"* (3) because *"his wife does an awful lot for him"* (6) and that "*husbands or wives at home help to look after them [the patient]"* (1). There were cases where HaH staff thought that *"without the spouse it's difficult to see [the patient able to be] at home on his own"* (3). Partners undertake wide ranging work (1-9), which included practical work such as preparing meals (1-7), helping the patient to wash and dress (1,3,4), toileting (2,3,6), shopping (7) and domestic tasks such as cleaning, and walking and looking after pets (4,7). HaH staff thought that it was more acceptable for patients that practical everyday work was undertaken by a partner than provided by HCPs (1,3,5,7). This was in part because partners are able to *"maintain a routine that is important for them [the patient]"* due to the one-to-one nature of the relationship (1) and in part because of the concurrent emotional support that partners can provide, such as stimulating conversations (5,7) and increasing their self-worth (7):

> *"if you feel loved and wanted, you know, you're going to be a lot happier than if you're sat in a room on your own"* (7).

Partners were also involved with substantial amount of illness work such as dispensing medications (1,3,7), giving injections (3) and providing transport to medical appointments (4,5,8), keeping records of blood pressure and blood test results in order to inform other services (3) and "*she would get stuck in with the [wound] dressings because she had been doing it herself for a long time"* (1). In addition, most partners remain present during HaH staff interactions with patients (1,3) and use their in-depth knowledge of the patient to take on a care coordinator role within the service (1-4,9). This is achieved by *"advocating* *the patient's needs"* (2) to the healthcare professional, writing down and asking questions (1-4), raising concerns that the patient has not (4), providing contextual detail:

> *"without them [the partner] we would have had much less accurate information"* (3).

> *"she [wife] kept a food diary, without her we wouldn't have known"* (2).

While the home setting is narrated as 'natural' and easy for patients it was evident that this involved new types of work that had to be done not only by HaH nurses, but also by partners. Partners would spend time to prepare their home for the HaH staff; *"thinking the house needs to be perfect because they [the partner] think that's what we're [the HaH staff] looking at, criticising them"* (6) and that there are *"two strangers who you've never met in their home"* (5). HaH staff would aim to develop a collaborative relationship with partners, ensure their wellbeing (1,2,5,7) and, *"check out how they're doing"* (1):

> "[We need to]*check they're okay. Otherwise the whole thing [HaH treatment for the patient] would fall apart"* (2).

Furthermore, as with the patients, nurses use informal conversation (4,5,7,8) and *"chat"* (1,2,4,8) to *"converse with them [partners] on a level that isn't clinical"* (5). This is firstly done as a means to support the emotional wellbeing of the partner (1,2,9) but also to increase trust in the nurse and service (4-8). By doing so the likelihood of accurate information sharing is increased (5,8):

> *"That bond, that sort of personal way of conversing with someone, is what makes them want to be open with you…they might have something of value they want to share with me" (5).*

Over time, as the levels of familiarity and trust grow, the relational and presentational work that partners and HaH staff do may be reduced also making the overall support more efficient and adapted to partner's needs (3,4). For example, when there is such trust, partners see nursing visits *"as respite"* (3) or an opportunity for completing practical tasks such as *"go[ing] and do[ing] something in the garden, or go to the shop"* (4) knowing that their respective patient-partner is being treated.

5.4.4 Limited awareness and engagement with (in)formal networks

In contrast to discussions about the key role that partners play in supporting patients, respondents had a limited awareness of, and did not appear to place much value on, the support provided by other members of the patient networks. Where there was awareness of the wider network this tended to be from *"pictures of family"* and by *"looking around the home"* (1,5,7), and was limited to 'family': *"I'd probably say that's about it [for SN members]; normally just family"* (4) or *"They might not have any interaction, they might not have any close friends or relatives",* and even less so during the Covid-19 pandemic (1,3,4,7). "*Family support"* (2) provided by sons, daughters, grandchildren, parents (2,3,6) and other *"loved ones"* (5) was described with limited specificity (1,2,5,6,8) and was deemed *"helpful but not necessary"* (3).

The value of weaker ties such as neighbours (3,5,6,8), friends (1,3,5,6) and paid services (3) was acknowledged by nurses and was primarily linked to practical support (e.g. cleaning (3) and shopping (3)), while pets were seen as a providers of emotional support and companionship (1,7). However, support from such ties was poorly understood and considered inferior to support from partners (1,2,6,9), and interpreted primarily in terms of their value for HCPs:

> *"They [weak ties] just don't have the knowledge*
> *to support the patient as well [as partners]. They try to help*
> *but give less accurate information because they're*
> *not [always with the patient]"* (2)

The lack of understanding, awareness and value placed by nurses on the role of weak ties may be, in part, because most wider network members "*tend to stay out of the way [of nurses]"* (1) but also due to the ad-hoc exploration of, and engagement with, other network members. Weak ties are only encountered by chance (1,3,6,8) if *"work colleagues call[ed] whilst we were there"* (3), "*neighbours pop in"* (6) or "*We [nurses] pass them by chance"* (1). Although one participant does explicitly ask patients *"'Do you have a relative? Do you have a friend who gets your shopping?'"* (5), weak ties are more frequently explored through ad-hoc informal conversations with patients during health focussed interactions, as a way of being friendly and filling time (1,4,5,6):

> *"some of the [antibiotic] drips can take an hour so you've got a long time to go over general chit chat...what they're going to do today…what their children are doing today, what friends they've got"* (4).

When patients do not have a partner, are *"not in a relationship, family [are] very distant and so they're isolated"* (5), nurses tend to focus on helping with access to paid and formal services to fill gaps in support (1-9). For example: *"It's for us [the nurses] to recognise that by talking to them and go 'Okay. They would benefit from some outside support'"* (5). In such circumstances nurses tend to mobilise formal services on the patients' behalf (1-9): "*You know, get some, get social services support set up"* (5). Such support includes local care agencies that provide help with practical work such as personal hygiene and mobility needs (1-4,6,7), to prepare or deliver meals (1-3,6):

> "*if they weren't able to make a good meal then I'd talk about delivery of meals, of microwave meals. We can offer them a brochure for that"* (6).

Nurses might suggest patients have *"somebody to come in once a week and do the shopping*" (6) and may mobilise this support themselves by "*networking with somebody else, some other service, [such as the] Red Cross service to help with their shopping"* (5). Accessing and relying on formal services may be *"stressful, confusing and busy"* (1) for patients, it is unlikely to fulfil emotional work because *"you can't really ring the carers and say 'can you go and sit with them for a chat'"* (5), but by mobilising such support HaH staff are able to maintain a focus on the patients' health work (3,6,7):

> *"We can do 'care' but tend to refer on to others because of the time it takes and the urgency of the antibiotics"* (3).

Linking up with other services was not seen as easy or seamless for professionals either. Unlike engagement with informal support, it was more familiar to HaH staff and was considered an extension to their service. Although accessing some specialist consultant support is known to be difficult among the nursing team (3), such links were made because acting as a patient advocate was seen as part of the nursing role (1,4,7). For example, *"If there was another need, we would highlight it to the team leader"* (7) and that *"if I [a nurse] couldn't do it [resolve a health concern], I'll make sure I ask the right* *person"* (4). In doing so, HaH staff also utilise and build their professional networks (1,4). This is supported by the service's ability to advocate to other HCPs and specialist services such as dieticians (2,4), speech and language therapists (2), physiotherapists (1-3), occupational therapists (1,3,4) and tissue viability specialist nurses (2,3). Similarly, patients *"are still under the hospital doctor's care"* (4), the nurses have good links with medical teams (2,4,6) and are "*constantly in contact with [doctors], keeping them updated with information"* (6).

5.5 Discussion and implications

5.5.1 Discussion

This study took a SN approach in exploring professional perspectives on the nature of support needed by people using HaH services, the involvement of the formal and informal network members doing this work, and the mechanisms through which this work is done.

Findings demonstrate that the nature of the work required to support patients with acute illness living in community settings is complex and requires deeper understanding and engagement with personal and contextual factors (Gillham et al., 2021). However, while the provision of HaH care is narrated through discourses of person-centeredness and holistic care that can help address these complexities, the practice of HaH is dominated by the medical model focused on managing illness, reducing costs, being time efficient, whilst serving as broad a patient cohort as possible. Such a focus leaves substantial amounts of the emotional, practical, coordination and relational work needed by clients undone. While HaH staff are aware of these gaps in provision the financial and resource priorities within which they work offer limited scope for change in practice. The arising tensions in patient support are assumed to be self-resolved and framed within a discourse of the 'therapeutic environment of the home', which acts as a justification for the limited scope for practice change.

Another mechanism of addressing patient needs is through the engagement of network members in self-management support. Studies on self-management support have demonstrated the key role of social network members and the value of diverse types of relationships (including strong and weak ties) within networks in addressing the complex needs of people living with an illness in community settings (Walker et al., 2018, Rogers et al., 2014, Vassilev et al., 2013, Kennedy et al., 2016). However, our findings indicate that HaH staff have a limited understanding of the support networks of their clients, which is limited to partners and spouses. Additionally, the role of partners is not valued by HaH staff through their contribution to providing more holistic care but is primarily seen within the medical model i.e. providing information to improve diagnosis, medication understanding and adherence, interpretation and management of symptoms. Thus, partners are valued because they can act as a substitute for HaH nurses when they are not present and help with risk management, reducing time and costs, and doing more specialised illness work where there are clients with more complex needs. The reliance of HaH staff on spouses and partners may in part be due to the frequent contact and easy access during visits, proximity to patients, and their perceived reliability, access to resources, and knowledge of patient context and preferences (Vassilev et al., 2011, Cornford and Cornford, 1999, Cleak and Howe, 2004).

HaH staff place little value on members of people’s wider networks, especially weak ties such as neighbours, friends, colleagues, and community group members. These are only explored through ad-hoc “chat” and as a means of passing time during prolonged health interventions. Where nurses do coordinate weak ties, this tends to be for clients who live alone, who they link to other relevant health and social care services. This is in part due to their awareness of these services and their ability to mobilise support as a part of their professional role. Previous literature indicates that the assumption that all such work is done by partners for people who did not live alone may be incorrect (Walker et al., 2018, Vassilev et al., 2014, Rogers et al., 2014, Reeves et al., 2014, Rogers et al., 2011a).

In summary, although HaH services staff maybe aware of the important role that members of people’s wider networks paly in supporting patients, actual engagement with such support tends to be limited to spouses and partners, and primarily seen as a substitute for HCPs. The engagement of wider networks may help reduce burden on strong ties (where these are available) and healthcare professionals, improve self-management, patient access to sources of knowledge and support, and is likely to be especially important for people who live alone (Granovetter, 1983, Rogers et al., 2014).

5.5.2 Implications

HaH staff need to improve their awareness and understanding of the work done by patients and members of their wider networks. By changing practice to a way which recognises the contextual value of SN members and the importance of the work they do can lead to improved care and reduced cost for the health service

Improvement in this area appears potentially challenging in the context of a tension between the need of the HaH service to accommodate a broad patient group whilst providing standardized and reliable treatment; and one that is restricted by structured intervention timings and limited contact time with patients. However, even given these constraints our findings indicate that there may be underutilised resources within the current service. Specifically, HaH staff experience excess of time (when delivering interventions) which may offer a potential opportunity for embedding an intervention that can improve understanding and engagement with the networks and contextual resources of patients. Some such work is already done by HaH staff but this is only in an ad-hoc manner. For example, from a SN perspective, when assessing what support is available to patients, nurses could engage in a structured and meaningful conversation during excess time that explores the patient's SN and the role each member has within it (Vassilev et al., 2013, Kennedy et al., 2015). Developing such an approach might improve the service and would be in line with how the HaH staff professional role and identity. Further research from patient perspectives is likely to be complimentary to the findings of this study and contribute to developing a better understand of the full nature of the formal and informal workforce and the work done by the network members of HaH patients.

5.6 Conclusion

The changing landscape of healthcare services is causing increasingly acute illness to be treated in community settings. As a result, services such as HaH are increasingly common. These services appear to be able to treat wide-ranging conditions for patient living in very diverse circumstances, but this causes the nurses providing treatment a challenge when trying to balance the idealised, patient-centred service their professional identity favours, with the need to routinize service provisions and support as many patients as possible.

Developing a better understanding of and engagement with the social network members of HaH patients and the work they do, carries substantial potential in terms of accessing underutilised resources, improving patient support, and making the HaH service more efficient and person-centred.

5.7 Supporting Information

5.7.1 Acknowledgments

Our thanks to the University of Southampton whose support and funding of the PhD project of the lead researcher, JG has allowed this study to be possible. We would extend our thanks to the HaH site and the participants who gave up their time to be interviewed for the project.

5.7.2 Conflict of interest

The lead researcher practices clinically as a nurse within the HaH service which was the single site of this project. Maximum efforts were made to remain impartial and the iterative process of reviewing data by the whole research team has been used to reduce this limitation.

5.7.3 Author contributions

Data collection and transcription was undertaken by the lead researcher JG. JG reviewed and analysed all the data and IV and RB both reviewed a percentage of the data. JG led the production of the paper, and each draft of the paper was reviewed by IV and RB. All authors gave approval of the final draft.

5.7.4 Ethical considerations

Following ethical review, this project received a favourable opinion by the Frenchay REC on the 30th of October 2019. Written consent was gained by all participants prior to data collection.

6.0 Chapter 6: Quantitative study: Exploring the role of social networks, the quality of life and access to support of people using Hospital at Home services

6.1 Abstract

Background: Global aging and morbidity have contributed to higher levels of hospital admissions, and have demonstrated the limits of traditional models of care in addressing the problem. Hospital at Home (HaH) services offer a viable alternative whereby patients are treated in their own home, which requires care from healthcare professionals and self-management on the part of patients. Chronic illness research has demonstrated that self-management is a collective process that involves support from social network members (SN) to addressing the illness, practical and emotional needs of people. However, the role of social network members is not well understood in the context of people using HaH services.

Aim: To map the structure of SNs and the type of work network members undertake for HaH service users. In addition, this paper will explore the substitutability between network members with specific reference to the role of partners. Finally, this information will be used to predict the health Quality of Life (HQoL) of HaH service users.

Methods: All patients admitted to a single HaH service were invited to complete a questionnaire. Demographic, health, HQoL, psychosocial and SN data were collected (n=76). Follow up data were collected at 12-weeks.

Results: Findings indicate that a diverse group of patients are treated by the HaH service. Analysis of SN characteristics indicated that patients reported a wide range of network types that varied in terms of structure, dynamics and roles within the network, and that this was largely influenced by the presence of a partner. Where a partner was absent, there was some degree of substitutability with other network members contributing more, but this was insufficient to compensate for the absence of a partner. Regression analysis shows that self-reported health status and self-efficacy are key predictors of the HQoL of HaH service users.

Conclusions: Partners are crucial SN members for HaH patients for providing support but not having a partner does not restrict access to the service. Without partners, patients require a more diverse SN in order to receive adequate support. However, patients without partners had a smaller social network size on average, their other network members did more work when compared with people who had a partner but the overall level of work (illness, practical, emotional etc) was still lower thus people without a partner had a smaller network, less overall social network support form the network and they had lower perceived collective efficacy (which is unsurprising given the above). Weak ties function differently and have a less important role when compared to chronic illness support which is likely to be because they are unable to be mobilised more quickly as is required during HaH admission. HQoL is unrelated to any SN factors which suggests that the work of the SN is going unnoticed by participants. Further qualitative research may illuminate the role of SN support.

Keywords: Hospital at Home, Social networks, Social Network Support, Self-Management support, Health Quality of Life, Patient Experience

6.2 Introduction

Demographic aging, financial challenges, and, more recently, the Covid-19 pandemic have put pressure on inpatient hospital bed availability (Nundy and Patel, 2020, Schultz et al., 2021) and has driven reform in healthcare in the United Kingdom (UK). This has included the increased application of out-of-hospital services such as 'Hospital at Home' (HaH) (NHS England, 2022). A key principle of HaH services is to provide alternative options for facility based treatments and diagnostics (such as administering intravenous (IV) antibiotics and fluids) in patients' own homes (Hostetter and Klein, 2020). This is seen as a process through which pressure on inpatient provision and costs to the NHS are reduced (UK Hospital at Home society, 2022).

To date, research into HaH services is mostly developed from professional and healthcare system perspectives (Leff et al., 2022). Although evaluations of HaH services from a patient (Nunan et al., 2020, Facultad and Lee, 2019) and healthcare professional (HCP)

(Schultz et al., 2021) perspective have largely been positive, the majority of research focusses on examining costs in relation to morbidity and mortality rates and comparing them to more traditional models of care such as being admitted to an inpatient ward for acute treatment (Caplan et al., 2017, Pearson et al., 2013, Shepperd et al., 2009, Shepperd et al., 2022). From a patient perspective, HaH is a viable alternative to in-hospital treatment as it is acceptable to patients (Leff et al., 2006, Facultad and Lee, 2019) and may reduce hospital related complications such as physical decline caused by reduced function and contracting further infection (Shepperd et al., 2022). Although previous research has helped in improving HaH services and can be used to guide their introduction in different localities, the emphasis on cost and health outcomes is insufficient to fully capture the full range of work and resources that are needed when care is provided in people's homes, the role of informal network members, and the set of outcomes most valued by service users. Such knowledge will offer complementary understanding of the support needed when providing acute care at home, which can help in the delivery of care that is better tailored to the values, concerns, priorities, and resources of service users, and guide the successful adoption and long-term sustainability of HaH services in different contexts. One way to developing such a complementary perspective on HaH services is to examine the relevant contexts, experiences, and outcomes from a patient and care giver perspective. Some of the gaps in HaH research are identified in a recent survey analysis which highlighted that areas of knowledge that need addressing through further research include: patient and caregiver (such as partner) involvement, the relationships between patient, healthcare staff and caregivers, and the roles of family members and caregivers (Leff et al., 2022). Taking a social network perspective offers promise in helping address some of these knowledge gaps.

The role of social networks

There is evidence that the management of illness in community settings is a collective, rather than an individual, process with members of people's social networks (SN) playing an important role (Vassilev et al., 2019, Foss et al., 2016). Within the context of living with a chronic illness, it is SNs that consist of wide-ranging, formal and informal, relationships beyond healthcare professionals (HCPs) and partners (including strong ties such as close family members and weak ties such friends, distant family members, neighbours, acquaintances, colleagues, community and hobby groups) that make a substantial contribution are most successful in supporting people to self-manage (Vassilev et al., 2014, Kennedy et al., 2007). This may in part be due to such networks providing support that is more adaptive to changing needs and circumstances, reducing the risk of burnout of partners and key caregivers, and increasing the scope of linking people to diverse sources of support, experiences, resources, and information (Rogers et al., 2014, Fiori et al., 2007, Fiori et al., 2006).

Within the context of HaH services, SN research and the understanding of the role of different network members is more limited than within chronic illness management (Augustine et al., 2021) and is primarily focussed on the support provided by the healthcare services and partners (Mäkelä et al., 2020). There is evidence that social support from informal network members with instrumental, emotional, and illness support can improve care and make HaH services more acceptable to patients (Augustine et al., 2021, Gillham et al., 2021). Having the support of friends and neighbours is particularly important for those who live alone (Chua et al., 2022). However, the nature of the work that such members of people's SNs undertake and under what circumstances they may be involved is less well understood. Specifically, self-management strategies, such as engaging and navigating the range of informal and formal relationships and resources, are likely to be more complex for acute illness compared to managing long-term conditions. This may be due to the complexities of the illness work involved (caused by hospital-level acuity) and the challenges of balancing it with the everyday emotional and practical needs (Wang et al., 2017) of users of HaH services and their carers, and the relational work needed to do that (Vassilev et al., 2019). Mapping the structure of the SNs of HaH users, and the work that the members of these networks do, can help improve our understanding of the contexts in which HaH services are delivered and how they might work for different populations. Improving our understanding of the contributions of different SN members (including neighbours, colleagues, professionals, friends, family members, partners and other informal caregivers), and the relational dynamics between patients, their informal network members, and the providers of formal healthcare services

(Leff et al., 2022) would also help improve our understanding about how acute illness is managed in everyday contexts and how this may shape the experiences, health, and quality of life of users of HaH services.

There is evidence that HaH services can be used to support a broad cohort of patients, with wide ranging demographic, health, and psychosocial factors (Leff et al., 2022, Shepperd et al., 2016). Each of these factors has the potential to affect outcomes for patients in a way that differs from other community health services (such as those that support people with chronic illness). The significant physical and psychological symptoms during acute illness at home could lead to experiences of isolation and loneliness (Kadowaki et al., 2014), while the self-efficacy of individuals (the individual’s belief that they have the specific capabilities to undertake certain actions that achieve the desired outcomes) (Bandura, 2005) and the collective efficacy of their networks (it’s capacity to provide acceptable support) (Bandura, 1986, Vassilev et al., 2019) might need to be mobilised over a short period of time but in order to complete substantial and high intensity workload. Mobilising network support for acute illness in community settings is likely to present unique challenges in negotiating and navigating network relationships, responsibilities, roles, identities, and access to resources (Barrett et al., 2016, Bryar and Griffiths, 2003). For example, in contrast to in-hospital care and self-management support for people with long-term conditions, users of HaH services may be more reliant on strong ties within their networks (e.g. partners or children) because they are less likely to be able to mobilise support from weak ties (e.g. acquaintances) over a short period of time, and only have limited access to support by healthcare professionals.

Potential impact of HaH on Health-Related Quality of Life

Given the complexity of self-management among the diverse population that is supported by HaH services then measuring and standardising experiential outcomes is needed to give insight into whether this is achievable and acceptable for patients. The existing literature discusses that HaH patients generally have a positive experience of using such services (Shepperd et al., 2022) and it is therefore a logical assumption that quality of life improves, or is at least maintained, as a result of avoiding admission to hospital through

HaH. Measuring quality of life during HaH admission could therefore function as a more in-depth and validated means to understanding how psychosocial and health factors align with individuals' needs and priorities during this time. Health related quality of Life (HQoL), defined as "*individuals' perceptions of their life in the context of the cultural and values system in which they live in relation to their goals, expectations, standards and concerns*" (World Health Organisation, 1996) is widely used to assess the broader successes of health services (Joshi et al., 2017, Jalali-Farahani et al., 2018, Kivits et al., 2013). Furthermore, the subjective measurement of one's HQoL is not only a reflection of health and disease symptoms but the way in which health affects the broader, multidimensional psychosocial aspects of life and vice-versa (Vahedi, 2010). From a SN perspective, HQoL is known to be associated with having good social support (Kivits et al., 2013) from, in particular, partners (Wiczinski et al., 2009). However, the effects of a sudden onset of increased illness work (as in acute illness) makes maintaining HQoL difficult for those who have SN support that are not used to providing it (Karlsen et al., 2016, Gonzalez - Saenz de Tejada, 2017). This may because patients have not developed the relational skills needed to navigate their SN for support with illness work, or that they choose not to disrupt the dynamics of the network by attempting to negotiate new roles for others (Manne et al., 2007). This situation is likely to occur among HaH patients during their sudden onset of acute illness and therefore it can be hypothesised that a range of individual, network, and structural level factors (e.g. health, demographic, socio-economic, and psychosocial characteristics, and access to formal and informal support) may all affect the HQoL of HaH service users. Therefore, these are key areas for assessment for successful application of a patient-centred service. By improving the understanding of how these factors are associated with service users' HQoL future attempts for development and improvement of HaH services will be more accurately guided.

Considering the above discussion around the important SN contexts of HaH patients and their HQoL, this paper aims to:

- To map the structure of, and the types of work done by, the social networks of people using HaH services;
- To explore if there is substitutability between network members in providing support;
- To understand whether SN structure and the work that SN members do affect the HQoL of patients receiving HaH care;
- To understand the role of partners in shaping the quality of life of people using HaH services
- To understand whether SN structure and the work that SN members do affect factors associated with HQoL such as the levels of coping and loneliness, socio-economic status, multi-morbidities of patients receiving HaH care; and
- Consider how this new knowledge may be used to improve the quality of life and the provision of support for people who use HaH services.

6.3 Methods

6.3.1 Ethical statement

All study participants gave informed, written consent to take part. This project received a favourable opinion by the Frenchay REC (19/SW/0207).

6.3.2 Study Design and sample characteristics

This study recruited patients recently discharged from a HaH service in the South-west of England. Patients using this service were either part of admission avoidance or facilitated early discharge from a single inpatient hospital, had to be admitted to the HaH service for 72 hours or longer to be eligible for inclusion, and were recruited via the lead researcher (JG), who is employed as the deputy team lead within this service.

Participants were recruited between January 2020 and May 2022 (n.b. data collection was paused during the COVID-19 pandemic between 9th March 2020 and 19th August 2020), and a total n=141 were approached to take part in this study)

Potential participants were initially approached face-to-face, during the final few days of their treatment, by JG, during a clinical intervention. Participants who declared verbal interest were given written information and consent form (n=76). Once written informed consent was received via a prepaid envelope, participants were sent their baseline questionnaire at discharge from the HaH service (the second follow-up questionnaire was sent to participants 12 weeks later). In total, n=54 completed the follow-up questionnaire; the reasons for not returning the follow-up questionnaire was not explored (n=22).

6.3.3 Measures

The first questionnaire (given at the point of discharge from the HaH service) was divided into several sections. The follow-up questionnaire contained the same measures.

Socio-demographic information

Section one collects patient demographics (date of birth, ethnicity, employment status and education level) and household data (household income and number of cohabitants).

In section two, participants would rate their experience of the HaH service; adapted from the *'friends and family'* test that is widely used across the NHS (NHS England, 2020). Section three, contains the first of four pre-existing, validated, Likert-style measures selected by the research team based on each's reliability, ability to answer the study aims and likelihood of participant participation due to length and comprehension of questions.

Social network characteristics

Participants were asked to list members of their SN of support and provide information about their relationship to them (e.g husband, wife, son, neighbour), frequency of contact (1=at least once a week, 2=at least once a month, 3=every couple of months, 4=less often), their geographical proximity to them (in miles) and to quantify the amount of health, emotional and practical 'work' they undertook for the participant by scoring each out of three (1=no help, 2=some help, 3=a lot of help). Participants were encouraged to list as many network members as they wanted, of any type of relationship (e.g. family, friends, colleagues, neighbours, pets) and were given an example to follow (Fiori et al., 2006, Fiori et al., 2007, Reeves et al., 2014). In order to describe SN structure and dynamics, each listed SN member would be coded into one of the seven categories based on their relationship to the participant (spouse/partner, immediate family [children, children-in-law, siblings, parents, grandparents and grandchildren], distant family [all other family not included under immediate family], friends [those listed specifically as a 'friend'], acquaintances [neighbours, colleagues and religious leaders], HCPs [nurses, doctors, occupational therapists, physiotherapists and paid carers] and pets [cats and dogs]).

Psychosocial measures

Self-efficacy was assessed using the Self-efficacy for Managing Chronic disease 6-item scale (Lorig et al., 2001) which asks participants to rate their confidence undertaking certain activities during HAH treatment. The Collective Efficacy Network Scale (CENS) (Band et al., 2019), a 12-item, 'Likert-style', measure was used to rate the collective efficacy of participants SN. Finally, the De Jong Gierveld Loneliness Scale (Gierveld and Tilburg, 2006) to explore participants loneliness during access to the service.

Outcome measures

The WHOHQoL-BREF (World Health Organisation, 2014) was selected as one of the best known instruments for capturing the subjective aspects of quality of life (Vahedi, 2010) and asks respondents to rate their quality of life (within four domains: physical, psychological social and environmental) during treatment for acute illness at home. Question one (How would you rate your Quality of life?) and two (How satisfied are you with your health?) of the WHOQoL do not fit into the above sub-themes and are widely used as primary outcomes measures.

Health data

Participants also consented for the researcher to access their medical notes to gain accurately reported accounts of their medical diagnosis and past medical history (PMH). To maximise consistency, this information was taken from the medical clerking from the time of admission to HaH.

6.3.4 Analysis

Firstly, all data analysis was undertaken in SPSS Statistics v28. The descriptive analysis was then undertaken in two parts. Firstly, participant characteristics and social network structure and dynamics of patients receiving HaH data were summarised. This, and the total number of comorbidities each participant had, admission length (in days) as well as demographic data, were analysed for frequency, averages and percentages (Table 1). Participants SNs could be categorised as with a partner or without a partner with percentages and frequencies of this and the amount of weak-tied network members (acquaintances and HCPs) and household members calculated. The SN member proximity to the participant data (in miles) was used to determine what percentage and likelihood of patient networks having proximal children (those living ⩽10miles). Similarly, the frequency of contact variable was also tallied and presented as percentages (Table 2).

Secondly, to ascertain the typical level of support provided by each relational type, the mean amount of illness, practical and emotional work provided to HaH patients by different members of the SN was calculated from the data. In order to explore how the presence of a spouse or partner influenced the work undertaken by the SN, comparisons were made between networks by calculating the mean work in each of the three domains provided by 1) network members from spousal networks including spouse/partners, 2) network members from spousal networks but excluding spouse/partners and 3) network members from non-spousal networks (Table 3).

Regression analysis method

Correlations between all dependent (WHOQoL Q1 and Q2) and independent variables including health data, validated measures and SN data; and all SN data, subscale data, health data and demographic data were first explored. For inclusion in a regression model a conservative p-value of <0.01 was set due to the multiple comparisons. Initially, all variables that significantly correlated with the dependent variables were included in a stepwise linear regression (at p<0.05) to explore characteristics of the patient and/or their SN that predicts HQoL at discharge and also at 12-weeks post discharge.

6.4 Results

6.4.1 Sample characteristics

A total of 76 participants completed the Hospital at Home questionnaire, reflecting a response rate of 62%. Of the 76 participants completing the baseline questionnaire, 29% (n=22) did not return the follow-up questionnaire.

Of the 76 participants, 74 were admitted for intravenous antibiotics (IVABs), one was given nebulisers, and one was treated with another form of intravenous medication. 64% were male (n=48) and their ages ranged from 20-95 years old (mean=68.3). 69.3% of participants were married (n=49) with a further 8.0% cohabiting (n=6). A total of 66.7% (n=50) of the participants lived in households of two residents; with 14.7% living alone (n=11). Length of admission ranged considerably from three days to 61 days, with an average time accessing the service of 21.5 days (SD=14.5). The number of comorbidities participants had also ranged from zero to eight (mean=2.97, SD=1.86).

6.4.2 Social Network Characteristics

The network characteristics of people using HaH Services

The 76 participants (Table 7) included in the study identified a total of 424 network members who contributed to illness, practical or emotional work during the HaH treatment with mean average network size of 5.6 individuals (SD=4.36, range=15). Table 8 outlines the SN data of the participants. The average household contained 2.21 people (SD=0.98) ranging from participants who lived alone to households of six. More than two-thirds of networks contained a spouse or partner (80.2%, n=61 which represented 14.0%

of the total network members (n=61). Close family members (n=130) formed the largest proportion of SN members (29.8%), followed by friends (22.2%, n=97). More distant relatives made up just 4.4% of the SN members (n=19), and pets the least included group (3.9%, n=17). Weak ties, such as acquaintances and neighbours accounted for 11.9% (n=52) and there were 43 HCPs (9.9%).

The network members that undertake the work of people who use HaH services

Participants generally reported high levels of interaction with their SN members. Participants had contact with almost two-thirds of their network members at least once a week (65.6%, n=278). Participants had contact with 17.4% of their network members (n=74 at least once a month, with 7.6% (n=32) every couple of months and 9.4% (n=40) less often. 34.2% (n=26) of the participants had at least one proximal child (children living ≤10miles) with the average network containing 0.5 proximal children (SD=84, range=4).

Table 7

Quantity and percentage of participant demographic and health data

PARTICIPANT CHARACTERISTIC		N (%)
Gender		
	Male	48 (63%)
	Female	28 (37%)
Ethnicity		
	White British	76 (100%)
	Non-white British	0 (0%)
Marital status		
	Married	55 (72.4%)
	Single	3 (3.9%)
	Widowed	6 (7.9 %)
	Divorced	5 (6.6%)
	Cohabiting	6 (7.9%)
	Missing data	1 (1.3%)
Employment status		
	Full-time	7 (9.3%)
	Part-time	3 (4.0%)
	Self-employed	6 (8.0%)
	Retired	57 (75.9%)
	Missing data	2 (2.8%)
Age (years)		
	Mean	68.6 (SD=14.60)
	Range	75
Number of comorbidities		
	Mean	2.97 (SD=1.86)
	Range	8
Length of admission (days)		
	Mean	21.5 (SD=14.15)
	Range	58

Table 8

Quantity and percentage of participant social network data

SOCIAL NETWORK CHARACTERISTICS		N (%)
Network size		
	Mean	5.60 (SD=4.36)
	Range	15
Household size		
	Mean	2.21 (SD=0.98)
	Range	5
Spousal/partner network		
	Yes	61 (80.2%)
	No	25 (19.8%)
Number of Weak ties		
	Mean	1.28 (SD=1.99)
	Range	12
Relationship type		
	Spouse/partner	61(14.0%)
	Immediate family	130 (29.8%)
	Distant family	19 (4.4%)
	Friends	97 (22.2%)
	Acquaintances	52 (11.9%)
	Healthcare professional	43 (9.86 %)
	Pet	17 (3.9%)
	unknown	17 (3.9%)
Frequency of contact with participant		
	At least once a week	278 (65.6%)
	At least once a month	74 (17.4%)
	Every couple of months	32 (7.6%)
	Less often	40 (9.4%)
Proximal children (within 10 miles)		
	Yes	26 (34.2%)
	No	50 (65.7%)
	Mean	0.5 (SD=8.40)
	Range	4

Table 9 compares the contributions to each of the three domains of work by each relationship type. Furthermore, Table 9 explores how the level of support and contributions by network members differs in networks *with* and *without* a partner. It is notable that there are wide-ranging relationship types involved in providing support to HaH service users. There are differences between how much support is available for different types of work. Participants report ease in accessing emotional support from their network (mean across all types of relationships = 2.33/3.00). Practical (1.80) and illness work (1.95) were less easily available. The amount of work varied significantly between types of relationships in each of the three domains (Table 3). Compared to other relationship types, partners were perceived to undertake the most work across all three domains (mean=2.77) with more practical (2.91) and emotional (2.75) support than any other type of relationship. HCPs provided highest level of illness work (2.76), with partners only slightly lower (2.64). No other relationship type provided a notably large or small amount of illness work quantified by a range of only 0.44 between the lowest supporting group, pets (1.38), and the highest supporting group, distant family (1.82).

Table 9

The work provided by different relational group and comparisons between networks with and without a partner

Type of work provided by each network member group	Total network members (all relational types) N (%)	Mean network level score of work provided (1=no help, 3=a lot of help)	Total network members from networks with a partner N (%)	Mean partner-network level work provided (1=no help, 3=a lot of help)	Total network members from networks without a partner N (%)	Mean non-partner network level work provided (1=no help, 3=a lot of help)
Illness work						
Spouse/partner	61 (14.6)	2.64	61 (17.4)	NA	NA	NA
Immediate family	130 (31.0)	1.80	106 (30.3)	1.43	24 (34.8)	2.17
Distant family	19 (4.5)	1.82	12 (3.4)	1.31	7 (10.1)	2.33
Friends	97 (23.2)	1.62	86 (26.6)	1.63	11 (15.9)	1.64
Acquaintances	52 (12.4)	1.60	37 (10.6)	1.18	15 (21.7)	2.02
Health care professionals	43 (10.3)	2.76	35 (10.0)	2.64	8 (11.6)	2.88
Pet	17 (4.1)	1.38	13 (3.7)	1.16	4 (5.8)	1.50
TOTAL	419		350		69	
AVERAGE	5.36	1.95	6.90	1.56	2.56	2.09
TOTAL AVERAGE WORK (n x average work)		10.45		10.76		5.35
Practical work						
Spouse/partner	49	2.91	49	NA	NA	NA
Immediate family	130	1.85	106	1.53	24	2.17
Distant family	19	1.89	12	1.28	7	2.50
Friends	97	1.60	86	1.56	11	1.27
Acquaintances	52	1.93	37	1.86	15	3.00
Health care professionals	43	1.29	35	1.58	8	1.00
Pet	17	1.11	13	1.05	4	1.00
TOTAL	407		338		69	
AVERAGE (mean)	5.36	1.80	6.90	1.48	2.56	1.65
TOTAL AVERAGE WORK (n x average work)		9.65		10.21		4.22
Emotional work						
Spouse/partner	49	2.75	NA	NA	NA	NA
Immediate family	130	2.37	106	2.53	24	2.21
Distant family	19	2.11	12	1.89	7	2.33
Friends	97	2.30	86	1.78	11	2.82
Acquaintances	52	1.72	37	2.30	15	1.14
Health care professionals	43	2.31	35	2.51	8	2.11
Pet	17	2.72	13	2.83	4	3.00
TOTAL	407		338		69	
AVERAGE (mean)	5.36	2.33	6.90	2.31	2.56	2.27
TOTAL AVERAGE WORK (n x average work)		12.48		15.93		5.81
Total	**5.36**	**2.02**	**6.90**	**1.78**	**2.56**	**2.00**

The group that provided the most/least support changed between illness, emotional and practical domains (Table 9). For example, although acquaintances offered little support with illness work (1.60) and emotional work (1.72), acquaintances were perceived to provide the second highest amount of practical support (1.93) behind spouse/partners. This fluctuating pattern between domains continued with pets who were, unsurprisingly, perceived to offer the lowest levels of illness (1.38) and practical work (1.11), but have value in the high amount of emotional support that they provide (2.72), almost equivalent to that of spouses and partners (2.75). Close family, distant family and friends remain fairly consistent with support across all three domains; ranking third to sixth in each domain out of the seven types of relationships. In summary, HCPs do the majority of the illness work but only marginally ahead of partners who do a lot of each type of work, meanwhile pets provide high levels of emotional support.

The substitutability of SN roles and how this is influenced by partners

On average, patients who did not have a partner reported smaller SNs (average n=2.56 members) compared to those who had a partner (n=6.86). The level of support provided by each type of relationship was higher in networks that did not have a partner (Table 9). This indicates that where there is no partner present, there is a degree of substitutability. The existing network members take on increased illness and practical work (compared with networks where there is a partner), however, no additional emotional work is undertaken in these cases. However, these higher contributions by network members of people who did not have a partner was not sufficiently high to compensate for the much smaller network size of these networks. Thus, the overall level of network support was substantially higher in networks with a partner for all types of work (as demonstrated by 'total average work' in table 3: illness, practical and emotional work provided by networks with partners was 10.76, 10.21, 15.93 respectively compared to an average of 5.35, 4.22 and 5.81 from those without). Friends constituted a much smaller proportion of the networks where there was no partner (15.9% without compared to 26.6% with) and their contribution was only higher in terms of emotional work, while their contribution to practical work was lower than in networks where there was a partner. The contribution of

HCPs was only higher for illness work provided in networks where there was no partner but was lower for emotional and practical work.

In the domains with the most variation in support from network members (illness and practical work), both immediate and distant family are perceived to fill the gap in support that might otherwise be provide by a spouse/partner represented by a large increase in work. Furthermore, the work of acquaintances (such as neighbours) increases from 1.86 to 3.00 for practical work when there was no partner and was also higher for illness work. The work provided by friends, pets and HCPs remain mostly static across both domains. Acquaintances and distant family members constituted a much higher percentage of the network members in networks where there was no partner (Acquaintances=10.9% without compared to 4.4% with a partner, distant family=10.1% without compared to 3.5% with a partner).

Overall, when analysing substitutability, these results indicate that other network members compensate for the absence of a spouse or partner to some extent. As demonstrated in Table 9, the average work provided (2.02) remains largely stable for a network without a spouse/partner (2.00) but the relationship type that increases or decreases support varies depending on the domain. However, when comparing the total average work of a network, when a spouse is *not* present the work of the remaining relational groups significantly reduces on average (5.13 compared to 10.86 when a partner is present).

6.4.3 Understanding health related quality of life

Variables associated with HQoL

HQoL was significantly associated with self-reported health status (p=<0.001), higher levels of self-efficacy (p=<0.001), Collective efficacy in the form of ‘network responsiveness’ (p=0.002) i.e. that the network is responsive, trustworthy and there to be called upon when needed (Band et al., 2019). SN variables including having a larger SN (p=0.008), more weak ties in the network (p=0.006) and/or a network that provided more illness work (p=0.009) correlated to a higher HQoL among the participants. The greater the amount of comorbidities the participants have, the lower their HQoL (p=0.006). Self-reported psychological (p=0.01) and environmental health (p=0.01) were also associated with overall HQoL. Table 10 details all significant correlations with HQoL and self-reported health status. Self-reported health status was significantly correlated with self-efficacy (p=<0.001), as is the number of comorbidities the participant had (p=<0.001). Psychological health is was also significantly associated with overall self-reported health (p=0.002).

Table 10

Correlations and P-values between the dependent variables and independent variables. Independent variables with no significant correlation with either dependent variable were not included in the table

Independent variables	Dependent variables	
	Overall HQoL (WHOQoL Q1)	Self-Perceived health status (WHOQoL Q2)
Overall HQoL (WHOQoL Q1)		0.610 (P=<0.001)
Self-perceived health status (WHOQoL Q2)	0.610 (P=<0.001)	
Physical health	0.224 (P=0.02)	0.296 (P=0.005)
Psychological health	0.370 (P=0.01)	0.327 (P=0.002)
Social health	-0.218 (P=0.03)	-0.200 (P=0.043)
Environmental Health	0.257 (P=0.01)	
Self efficacy	0.481 (P=<0.001)	0.504 (P=<0.001)
Network responsiveness	0.334 (P=0.002)	0.301 (P=0.004)
Emotional loneliness	-0.336 (P=0.017)	-0.242 (P=0.018)
Social network size	0.278 (P=0.008)	0.195 (P=0.046)
Mix of agents	0.210 (P=0.034)	0.237 (P=0.02)
Amount of weak ties	0.285 (P=0.006)	0.244 (P=0.017)
Total interaction with social network	0.239 (P=0.019)	
Illness work provided by social network	0.269 (P=0.009)	
Practical work provided by social network	0.207 (P=0.037)	
Total work score by social network	0.269 (P=0.009)	
Number of comorbidities	-0.311 (P=0.006)	-0.411 (P=<0.001)
Age	-0.267 (P=0.022)	

Participant age correlated negatively with the majority of SN variables i.e. older patients were likely to have a smaller SN (p=<0.001) and report less frequency of contact with SN members (p=<0.001) and live with fewer people (p=0.004). Older patient age correlated with more comorbidities (p<0.001), but with lower perceived SN support with illness work (p=<0.001), emotional work (p=0.004) and practical work (p=0.006). Larger, more diverse networks, and networks with partners were also associated with increased amounts of work across the three domains (p=<0.001) as well as an increase in frequency of contact with SN members (p=<0.001).

Predicting HQoL among HaH patients

A stepwise, linear regression was used to identify factors predictive of self-reported HQoL (WHOQoL Q1) (p<0.05). Of the 13 variables that were significantly correlated with HQoL, only two variables were found to significantly predict HQoL. These were self-reported health status and perceived self-efficacy. Step one included only WHOQoL Q2 which could predict HQoL with a significance of p=<0.001 and step two included Lorig mean score which, in isolation was not as significant at predicting HQoL (p=0.027) but when combined with WHOQoL Q2, would be more significant (p=<0.001). In summary, the analysis showed that better levels of health and higher levels of self-efficacy could reliably predict HQoL during HaH treatment (see Table 11).

Table 11

Regression output models

Model (included independent variables)	R	R Square	Adjusted R Square	Std. Error of the Estimate
Self-Perceived health status (WHOQoL Q2)	0.612	0.374	0.365	0.595
Self-Perceived health status (WHOQoL Q2) AND Self efficacy	0.648	0.419	0.402	0.578

6.5 Discussion

This paper aimed to understand the structure and function of the SNs of patients receiving HaH treatment, and the ways and extent to which they support patients receiving treatment. The findings presented here improve understanding of the processes that shape the experiences of people using HaH services (Facultad and Lee, 2019) by highlighting their access to support, who is providing it under different circumstances, and more broadly how is self-management support mobilised in the context of living with an acute illness at home.

6.5.1 SN support and the key role of strong ties in mobilising and sustaining it

The wide range of network members

Firstly, our findings indicate that there is a diverse range of strong (partners, close family) and weak ties (acquaintances, colleagues, neighbours, HCPs) that support patients with illness, emotional and practical work. The range of work each relationship type undertakes is varied, with some network members, such as acquaintances, more appropriately placed to provide practical work that is likely to be less personal and could be easily replicated in the future (such as collecting prescriptions, or food shopping). Others, such as HCPs, provide the more personal, private and specialised illness work. Furthermore, the amount of work provided by other relationships, e.g. distant family members, friends, seems to be adjusted in response to perceived need, due to having a partner or not, and size of the network. As with chronic illness this demonstrates that illness management is a collective process, rather than one undertaken by individuals or key carers in isolation (Rogers et al., 2014). However, the roles of different network members and the process of mobilising SN support appears to be different during acute, short-term treatment.

The key roles of partners

The diversity and type of the support provided by each relationship type seems to be shaped by the presence of a partner. Not only are partners important in terms of their own high level of individual work contribution across all three domains, but also the relational work they provide by mobilising and negotiating relations with other network members particularly friends and acquaintances. This may help explain the presence of a greater number of network members and higher level of overall support in these patients' networks, especially in relation to greater number of weak ties. Furthermore, partners may play an important role in improving the sustainability of wider network support by de-burdening other network members through negotiating acceptable support on behalf of the patient and distributing work across the network.

6.5.2 Substitutability of network members for people who do not have a partner

Our findings indicate that the network is, to some extent, able to adapt to context through a process of substitutability between network members. Consistent with existing literature (Walker et al., 2018, Rogers et al., 2014, Reeves et al., 2014), when there is no partner there is a greater reliance on close family, distant family members and on neighbours whose support is likely to be qualitatively different, and potentially less acceptable, for patients compared to partner support (Vassilev et al., 2013, Mäkelä et al., 2020). However, there are limits to substitutability within the networks. Thus, where there is no partner other network members make higher work contributions, yet this is insufficient to compensate for the much smaller network sizes of people with no partner. The overall network support for HaH patients without a partner is less than half compared to those where there is a partner. This is notably different for chronic illness where the differences in size between partner and non-partner networks are much smaller (Vassilev et al., 2013). This may be in part due to associated with the short term, rapidly changing nature of acute illness where participants have less time to develop and engage the networks of support they require, particularly with weak ties.

6.5.3 The role of weak ties

Neighbours as key weak ties

There is evidence that access to weaker ties such as community groups, acquaintances, neighbours and HCPs can play an important role within networks and improve the collective efficacy of networks (Band et al. 2019, Vassilev et al. 2019), and the level of acceptable support for patients (such as reducing pressure on stronger ties, increasing social capital, providing novel information and bridging or bonding to others) (Rogers et al., 2014, Brooks et al., 2012, Morgan and Thomas, 2009). One specificity of the networks of users of HaH services is that, compared to people with long-term conditions, the diversity of weak ties accessed is limited (for example, absence of hobby and community groups, small number of colleagues) and such ties are primarily neighbours (Vassilev et al., 2013). Neighbours have been shown to increase health related work to prevent health deterioration and in times of increased need (such as crisis or acute illness) (Zeng and Wu, 2022, Kim and Kawachi, 2017). In the context of HaH, service users' neighbours might play an important role because of their physical proximity, ease of access, the visibility of need for support (in contrast to colleagues and community group members, for example). However, adequate support that can achieve a sense of collective efficacy within the network relies on a willingness of the neighbours to undertake the work when needed (Sampson et al., 1997). This leaves HaH service users vulnerable to receiving inadequate levels of support when considering how access to a *range* of weak ties is known to improve the collective efficacy of networks (Vassilev et al., 2019).

The key but limited role of HCPs

As expected, HaH HCPs provided high level of illness work, which is within their professional role and is crucial to the health outcomes of HaH services. In addition, the emotional work provided by HCPs is relatively high in comparison to other types of relationships such as friends and acquaintances. Developing good emotional support is likely to occur in service users' own homes because relationships are more egalitarian, holistic and empowering for patients (Leff et al., 2006, Augustine et al., 2021, Gillham et al., 2023) and the one-to-one nature of interactions allows for rapport and the sharing of information to be more common between HCP and patient (Gillham et al., 2021).

The HCPs' work contribution appears to change depending on whether there is a partner in the network. When there is no partner, HCPs contribution to illness work is higher, albeit only slightly. Beyond illness work, HCPs can offer a degree of substitutability in the absence of partners and other wider network members. Other studies have found that HCPs perceive themselves to provide support that is wide-ranging, going well-beyond what is in their role, and that their contribution is higher for people who are in higher need and with limited informal support (Gillham et al., 2023). For example, HaH nurses see themselves as bridging the gap of patient access to support and link patients in need to other sources of healthcare support (Gillham et al., 2023). In contrast, and from the patient perspective taken within this study, participants rarely mentioned HCPs (beyond HaH staff) as sources of support. Additionally, the level of contribution by HCPs appears to be lower (not higher) with regards to providing support for the emotional and practical needs of people who do not have a partner. These are also people whose networks are substantially smaller thus receiving very low level of informal support. This may be due to the lack of confidence of nursing staff in providing emotional and psychological support and therefore choosing to avoid or risk ‘opening a can of worms’ they are unable to deal with (Griffiths et al., 2010, Griffiths, 2017). This may be particularly true when there are limited SN members to pick up the pieces. Nevertheless, this may indicate that HCPs may overestimate their capacity to assess the context and needs of patients, their ability to increase their own contribution, act as patient advocates and mobilise the additional support that might be needed.

6.5.4 Key predictors of the HQoL of HaH service users

As expected, HQoL of patients using HaH services can be predicted by disease severity and health status. These findings are mirrored for many health conditions (long or short term) and in many varying healthcare services (Pomeroy et al., 2020, Lionthina et al., 2020, Iriawan et al., 2021, Montagnese et al., 2020). Less predictably, self-efficacy, but not collective efficacy or SN characteristics, were among the key predictors of HQoL.

This was surprising considering that our findings also demonstrated that there was wide-ranging support received by HaH service users from different members of their SNs. There were multiple positive correlations between SN factors (such as size, partners, mix of agents and number of weak ties) and HQoL. However, while indicators of the level of support provided by network members (notably partners because of the large influence this group have on the SN dynamics), and SN characteristics (such as network size and frequency of contact) were associated with HQoL, they did not predict HQoL in the final model. The presence (or absence) of a partner was also not one of the key predictors of HQoL despite the wide-ranging contribution they make in terms of direct work and shaping the wider network dynamics. This may be suggested that the SN support patients are receiving is going unnoticed, taken for granted, or undervalued by them. Alternatively, the network is deliberately mobilised in such a way by patients considering that this is likely to be a short-term adjustment and therefore a long-term reorganisation which may disrupt existing relationships and SN member roles is being deliberately avoided.

While the self-efficacy of individuals and the collective efficacy of networks are interrelated, it may be the case that the capacity for network mobilisation over a short period of time is limited, while the support resulting from such mobilisation is less visible than individual capabilities to manage the illness. Previous research has found the important role of SN support and the collective efficacy of networks for the self-management and health outcomes of people living with long term conditions (Vassilev et al., 2016, Vassilev et al., 2019, Rogers et al., 2011b, Reeves et al., 2014, Vassilev et al., 2013). Further work needs to explore the role of social networks in relation to a range of health related outcomes for people with acute illness living at home (Mäkelä et al., 2020) considering that, in health, there are wider ranging social determinants of HQoL noted in chronic illness literature (such as bereavement, loss of physical function caused by poor health, and care-giver burnout) (Trikkalinou et al., 2017, Manavalan et al., 2017, Joshi et al., 2017, Fatima and Jibeen, 2019, Şahin et al., 2019).

6.6 Implications for practice and future research

Because health status and self-efficacy influence the HQoL of participants, it is important for HaH staff to consider this by assessing and preparing patients for use of the service and their ongoing needs after discharge. To prepare patients, staff should support the service user to develop the skills and tools required to self-manage and feel well enough to complete illness, emotional and practical work independently. Part of this assessment should consider the support provided by others (particularly weak ties when there is no partner) due to the way in which SN members are demonstrated within the data to provide wide ranging support for patients.

Further qualitative research from the perspective of HaH service users and informal network members would complement the findings of this study. This may help improve understanding as to the nature and quality of the work provided by SN members and the way patients navigate and negotiate the support they receive when living at home with an acute illness. This current study and further work on the role of the formal and informal workforce may make it possible to more accurately model the way SN factors affect HQoL among HaH patients. This could also be an aspect of assessment from a practical, HCP perspective.

6.7 Acknowledgments

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6.8 Author contributions

Designed: JG, IV, RB. Research performed: JG. Data analysed: JG, IV, RB. Interpretations of findings: JG, IV, RB. Manuscript drafted and finalised: JG, IV, RB

7.0 Chapter 7: Discussion and conclusion

7.1 Chapter introduction

This thesis sought to improve the understanding of the role of SNs in the context of a contemporary, increasingly prevalent and not sufficiently well understood HaH services. In recent years, empirical research (Saenger et al., 2020, Mas et al., 2016, Leff et al., 2022, Leff et al., 2006, Gossett Zakrajsek et al., 2013, Gonçalves - Bradley et al., 2017, Brody et al., 2019) and review papers (Shepperd et al., 2009, Caplan et al., 2017, Cordero-Guevara et al., 2022) of HaH services has increased and informed national guidelines in the UK (NHS England, 2022). Empirical studies have explored social support for patients to some extent, but have largely focused on the roles of primary care-givers and the burden it places upon them (Saenger et al., 2020, Mäkelä et al., 2020). The focus has not sufficiently addressed questions about accessing support within the context of the wider SNs of HaH service users. The work presented in this thesis contributes to the HaH evidence base by drawing on diverse literatures including self-management support, SNs, delivery of health services in rural areas, community based nursing and HaH services and has aimed to develop an understanding of the support needs and the access to formal and informal support of people who use HaH services.

The thesis started by outlining the increasing emphasis on NHS community services because of changing demographic and financial landscapes (Taylor and Bury, 2007). Such provision faces unique challenges, particularly the need for acute care provision in people's homes, and the mobilisation of individual and network resources to manage this in the context of everyday life. However, community based nursing and self-management approaches to patient care tend to overemphasise the role of individuals in managing their illness, and the interactions with and support from healthcare professionals, with limited focus on and understanding of the different types of illness and everyday work provided by members of people's informal networks (Vassilev et al., 2014). Taking a broader, whole network, approach to patient needs and support is especially important in the context of acute illness management in the community due to the need to mobilise a range of support quickly and maintain it over time. The literature of community based nursing also indicated that the delivery of HaH services in rural areas was likely to encounter specific challenges related to higher level of isolation, deprivation, aging workforces, and therefore poorer access to formal and informal resources of service users (Barrett et al., 2016, Kaasalainen et al., 2014, Hunsberger et al., 2009).

With the recognition of the likely increase of the provision of HaH services within the UK and internationally, this thesis sought to:

1. To develop understanding of the structural and relational processes operating at the interface of the HaH services and the way this affects the support, experiences, and health outcomes of patients.
2. To map the informal and formal workforce of HaH patients and the work that they do to provide support for HaH patients.
3. To further build upon existing literature which focusses on chronic illness to explore the SN dynamics of HaH patients and how these shape the outcomes of service users.
4. To identify candidate pathways to engaging SNs that can enhance the HaH service experience for patients, HCPs and the SN members.

Throughout this thesis, the implications of the findings of each paper are discussed within each of the individual chapters, therefore this chapter will reflect on the body of the work as a whole. This synthesis and triangulation of findings (Figure 6) will help develop recommendations for improvements in patient care and the delivery of HaH services. Firstly, the findings of each of the individual papers are summarised.

7.2 Summary of findings

7.2.1: Paper one: Rural influences on the social network dynamics of district nursing services: a qualitative meta-synthesis

This component of the thesis acknowledged the limited literature on SN contributions in the context of HaH services and therefore it aimed to build on existing knowledge on district nursing to draw similarities that could be used to inform HaH service provision and guide empirical work into HaH. This paper has been published in the journal *Health*

Science Reports (Gillham et al., 2021). The findings of this meta-synthesis suggested that four themes explain the SN dynamics of rural district nursing services.

Paper 1:
Literature review
key findings:

Transactional, friend like relationships develop in rural areas due to social capital and embeddedness of DNs and patients. There are logistical, financial and professional boundaries to successful SN support from DNs. Some of these factors are transferrable into HaH settings

Triangulated findings:

A lack of resources means HCP perceptions of patient-centredness do not correlate with patient findings that HCPs provide little support and patients rely on strong ties to maintain HQoL. Patients are vulnerable without partners and therefore HCPs should use health interactions and social capital to engage in SN conversations that can help them to undertake relational work on behalf of patients. This will benefit patients' HQoL, support nurses values and be acceptable to policy makers because it will not reduce service capacity.

Paper 2:
HCP perspectives
Key findings:

HCPs idealise a service that is holistic but in reality it is limited by the HaH model's health focus. As such HCPs rely on partners and other formal support. HCPs see the home as a naturally therapeutic location for treatment lwhich outweighs the challenges patients may face in managing their everyday work

Paper 3:
Patient surveys
Key findings:

HaH patients have diverse demographic and SN characteristics. Partners are Key SN members for and relational work. maintaining HQoL is difficult without a partner because networks are generally smaller. Neighbours offer practical work and HaH staff provide illness work but, this does not make up for the loss of support of a partner.

Figure 6: *The triangulation process revisited with findings from the three papers of this thesis. The central triangle presents the novel findings, which result from the synthesis of the key findings of each paper. The findings of each paper are colour coded to demonstrate how they are related to one another to form the 'triangulated findings'.*

The first theme was *the development of both transactional and friend-like nurse-patient ties in rural localities* and secondly, *engagement of the wider network in the delivery of good care*. The third and fourth theme discussed the *Blurring of professional boundaries in close community relationships* and the *issues accessing and navigating formal and informal support in the context of diminishing resources in rural areas* respectively (Gillham et al., 2021). As with existing research, these findings suggested that healthcare services in rural areas face unique challenges (such as long travel distances, isolated working, and an expectation that staff can practice as generalists) (Barrett et al., 2016) but was able to expand upon this by applying a SN focus to the synthesis by combining data that discusses the way such issues impact on the relationships between (and roles of) the patient, district nurses, the SN and the wider community. These findings suggested that there are possible limitations and challenges faced by district nurses with regards to engaging and integrating into SNs and which strategies are best used to overcome this. For example, results suggest that district nurses in rural localities overcome shortfalls in patients SN support by working beyond their professional specialties and experience to provide emotional support, help with daily tasks, and build links to communities themselves. There was also evidence that when nurses were embedded within rural localities (by living or working in the area for longer periods of time) they were more likely to develop 'friend-like' relationships with patients and were more likely to successfully negotiate with existing support networks and communities to find support for the patient. However, findings indicated that developing strong links with patients and members of their SN does not automatically translate into positive outcomes for patients or district nurses. Such close relations can be unsustainable, burdensome, and disruptive. By developing weaker ties with patients and building awareness of the structure of individual's networks and local sources of support would potentially offer more appropriate avenues for sustainable and tailored community-based nursing support.

This paper alone would be unable to answer the overarching thesis aims on HaH services; and whilst this paper focussed on district nurses and the SN dynamics of patients receiving district nursing care, these findings are important within the context of researching HaH services. There are similarities that can be drawn between the two community based services (i.e. working in isolation, supporting increasingly complex patient needs and a need to build relationships with other SN members). However, there also appear to be differences between the two. District nurses cite that longer term relationships, contextual understanding and increased social capital which is developed over time (due to chronic nature of many conditions) as a contributory factor in being able to provide patient acceptable support which may not occur in HaH services whereby HCP-patient interaction is short term. In contrast, HaH staff serve wider geographical distances which will reduce their knowledge of local contexts, formal and informal resources, and the trust they have within the communities.

Therefore, the results of this review added value to the overall aims of the thesis. Firstly, by highlighting the importance of SNs of support when self-managing health work in community settings. Secondly, the specific roles and techniques HCPs have in supporting patients were illuminated (such as mobilising community members to diversify the network, reduce pressure on HCPs, and provide additional work that reduces risks associated with self-management i.e falls and neglect). Finally, the paper emphasised the tensions between the pressures on HCPs to provide patient-centred support, the lack of professional support and a growing burden on them. These findings helped guide areas of exploration within the qualitative and quantitative parts of the study. These explored professional and patient perspectives on the structure and engagement of SN members and highlight the support needs of HaH patients and the process of mobilising formal and informal resources to provide it.

7.2.2 Paper two: What is the work and the (in)formal workforce involved in supporting people using 'Hospital at Home' services?: A nurse perspective

This manuscript is currently undergoing peer-review in the journal *Health and Social Care in the Community.* Although currently unpublished, to aid clarity in the discussion this paper will be referenced as Gillham et al. (2023) within this chapter.

Whilst existing literature acknowledges that HaH services have rarely been explored from a SN perspective (Leff et al., 2022) and has primarily focussed on health outcomes and finances (Shepperd et al., 2009, Shepperd et al., 2016, Pearson et al., 2013) the findings of the meta-synthesis in chapter three (Gillham et al., 2021) confirms the key findings of some more recent HaH based studies that social support is an important factor in experiences of service users in community settings (Augustine et al., 2021, Mäkelä et al., 2020). This qualitative study explored SN factors and processes from a nursing perspective (i.e. interviews with HaH nursing staff). Specifically, it aimed to understand how HaH HCPs, patients and their SN members navigate the support needed by service users, how they negotiate their roles (i.e. the SN dynamics), and what are the varying experiences in the context of HaH services.

The analysis of semi-structured interviews with HaH nursing staff identified four themes: prioritising illness work within a discourse of person-centred care; the work involved within the 'naturally' therapeutic environment of the home; partners as key members of the care team; limited awareness and engagement with (in)formal networks. Findings demonstrated a tension between discourses where nurses idealise the value of the home environment as therapeutic in its own right and the provision of holistic service, while in practice prioritising illness (over relational, emotional and practical) work. Nurses' focus is on delivering a service that could be routinised and time and cost-effective in order to support as many patients as possible to allow them to be treated at home and reduce pressure on hospital beds. However, their professional identity means they aspire to provide care that is both standardised and routine, but also more patient-centred than the current provision can facilitate. There is recognition of the positive role of network members for self-management support such as administering medication and preparing meals. However, awareness and engagement by nurses is limited to partners and the formal services that HaH staff are familiar with such as inpatient-based consultants and specialists. Furthermore, nurses felt that in the absence of a partner they increased their role of bridging and bonding the patient to others, provided more illness, emotional and practical support for patients, and put more effort into understanding their needs. This idealised self-perception is to some extent reflected in the perspectives adopted by other community based HCPs supporting people living with chronic illness (Walker et al., 2018, Vassilev et al., 2014, Rogers et al., 2014, Reeves et al., 2014, Rogers et al., 2011a, Wu and Sheng, 2019) and palliative care (Midlöv and Lindberg, 2020, Griffiths et al., 2013).

However, this paper offers only a nursing perspective on the role they and the wider SN have in supporting HaH patients. The findings of the quantitative paper, discussed below, are from a survey of HaH patients, and thus offer a complementary perspective on what support is available, how it is accessed by HaH patients, and what is its impact on patient outcomes The following section discusses this in more detail.

7.2.3 Paper three: Quantitative study: Exploring the role of social networks, the quality of life and access to support of people using Hospital at Home services

This final stage of the thesis is developed in preparation for submission to the journal *PLoS ONE*. To facilitate ease of reading and a succinct narrative, within the discussion of this thesis (chapter 7.3) the unpublished work is referenced as Gillham et al. (in preparation).

Traditional, medicalised models of care such as admission to a hospital ward where there is a high level of HCP input and limited engagement with informal support appear to be increasingly unsustainable because of the rising demands associated with larger and older populations and surges in admissions caused by crises, such as the recent Covid-19 pandemic (Schultz et al., 2021). Chapters 3 and 4 highlight that community services are being utilised as an alternative location to inpatient care but with limited understanding of the home, SN support, and local contexts and resources within which self-management takes place, and without adequate self-management support. HaH is seen as a viable alternative to inpatient models of care that can reduce hospital pressures (UK Hospital at Home Society, 2021) but the acceptability and effectiveness of such services will be improved by a better understanding of the factors that shape the quality of life of HaH service users. This paper explored how SN factors (such as size, mix of agents, weak ties and member roles) and other individual and contextual factors (e.g. demographic, psychosocial and health related) can affect the HQoL of HaH patients.

To do so, this paper used the quantitative method of conducting a survey using validated measures. The paper aimed to map the structure of the networks, the work done by its members and how this and other demographic and psychosocial factors could affect HQoL of patients. Furthermore, it aimed to detail the role of partners considering their prevalence in determining the role of HCPs (per (Gillham et al., 2023)) and use these findings to make recommendations for how to best support HaH patients.

The paper found that HaH services treat diverse patients with wide-ranging SN structures, with partners playing a key role. Although there is a degree of substitutability among network members, replacing the work of a partner means that individuals will need extra support through either mobilising what SN members already exist or with more 'formal' support in the short term. Weak ties, in particular HCPs, are unlikely to be an effective substitute for strong ties because they only appear to be able to provide one type of work i.e. HCPs provide illness work. An alternative perspective is that multiple weak ties may develop a collective efficacy and therefore be an appropriate substitute for partners depending on the need of the patient. For example, neighbours and HCPs separately complete practical and illness work respectively, but in combination, this could significantly reduce the gap in support. Self-reported health status and self-efficacy are the key predictors of HQoL. These findings complement the work presented in Chapter 5, Gillham et al. (2023), whereby partners are deemed to be highly important for supporting patients to self-manage their acute illness. However, there are also significant contrasts between the findings presented in each of the two papers. The HaH nurses acknowledge a potential deficit in support when there is no partner in the SN but they feel they themselves can offer a degree of substitutability for the work they provide. The data collated from the patient perspective suggests otherwise and is demonstrated by an insufficient increase in emotional and practical work by HCPs and the majority of other weak ties (with the exception of neighbours who increase practical work) when there is no partner. There is also no evidence of HaH staff are meaningfully bridging or bonding to other sources of support (formal or otherwise) as emphasised by the lack of inclusion by respondents of other formal services in their networks.

For patients who do not have a partner this means that they are potentially vulnerable to poor experiences and less positive outcomes when using HaH because of their significantly smaller network sizes and the lower total amount of support they are able to harness. This is different to chronic illness literature which shows weak ties to be more important when there is no partner (Rogers et al., 2014) and that networks are often larger where there is no partner (Reeves et al., 2014). Regression analysis shows that despite the correlations between SN factors and HQoL, the key predictors were self-reported health status and levels of self-efficacy. This raises questions of whether the work of partners and the wider network is going unnoticed by patients or whether there are other contextual and network processes related to accessing support and improving health and quality of life that need to be identified (such as patients choosing to avoid short term disruption of the dynamics of their SN in order to maintain its function in the longer term). Further qualitative research from a patient perspective would be needed to illuminate the meanings behind the findings and establish the role of SN support during HaH treatment.

7.3 Discussion

By taking a SN approach to the management of acute illness in a community setting and using mixed methods research techniques to explore the perspectives of professionals and patients, this thesis has illuminated the role that SN members play in supporting people using HaH services. It has also identified some of the tensions and complementarities between formal and informal support, and the difficulties inherent in providing treatment for acute illness in people's homes in the context of their everyday lives. The key findings of this thesis will be discussed in terms of three overarching contributions to the literature. Firstly, we will discuss '*Illuminating the contribution of social network members towards supporting people when using Hospital at Home services'*; secondly, '*Understanding the processes through which network support is mobilised when using HaH services';* and finally, '*Identifying the limitations of HaH services and the gaps in the care provided to community based patients with acute care needs'*.

7.3.1 Illuminating the contribution of social network members towards supporting people when using Hospital at Home services

Despite the increasing demand and pressures on formal healthcare services, particularly in response to the Covid-19 pandemic (Schultz et al., 2021), a thorough investment in holistic plans that clinicians will require to practice effectively (such as training in engagement with patients in the context of their home) and understand and mobilise SN support is still lacking. Services are often established rapidly in response to the changing socio-economic context or health policy and without appropriate support or understanding of the needs of the HaH service user (Leff et al., 2022). Research into HaH tends to focus more on quantifying key indicators such as mortality, morbidity and cost-effectiveness (Shepperd et al., 2009, Shepperd et al., 2016, Shepperd et al., 2022), and while this makes sense in order to provide evidence to support the decisional confidence to implement services, it gives little guidance to managers about the design and implementation of appropriately staffed, trained, and supported services. It also fails to acknowledge the best practices of district nursing and chronic illness services that educate nursing staff on how to best understand contextual factors that are important and meaningful to patients and support them in their own home whilst acutely unwell; and therefore, just transfer burden downwards to community based staff and patients and their SNs.

A patient and nursing focus on strong ties

Gillham et al. (2021) highlighted that drawing upon district nursing models in rural areas may provide insights into ways to improve experiences for HaH patients, for example, through improving nursing comprehension of the role of formal and informal support in the context of the everyday life. Specifically, engagement of SN members might help reduce workload for nurses whilst improving experiences for patients, but this may be more challenging for HaH nurses (compared to district nurses) who do not have the time (associated with patients' longer service use, as with district nurses) to develop the rapport and relationships. Broadly speaking, the benefit of engaging with SN members is supported by the findings within later stages of this thesis where the work provided by certain SN members (mostly partners and proximal children) is considered invaluable by staff (Gillham et. al. 2022). However, nurses limit their awareness to these groups perhaps because of the service's health-focussed structure and the lack of resources given to staff to explore SN structure and dynamics or because they can directly witness the positive impact they have on patient experiences. However, nurses aspire to deliver patient-centred treatments and should therefore be supported with the resources to develop skills not dissimilar to those of district nurses. For example, their awareness of local resources of support provides an opportunity to increase their bridging and linking social capital roles, i.e. their ability to connect patients to new sources of information and formal support with health work). By utilising SN mapping approaches, this thesis was able to demonstrate that patient's may be less inclined to explore and seek support from their SN members than HCPs. Two alternative explanations could be that patients are either taking the SN support for granted and deem their subjective sense of quality of life to be primarily shaped by their perceptions of their own abilities, efforts, and motivation in managing their illness (self-efficacy) (Gillham et al., in preparation) or that HQoL during acute illness is indeed driven by these factors because SN structures are unlikely to be reorganised for a short term, acute illness.

From either perspective, this is notably different from chronic illness management (whereby SN support from wide ranging network members is key to self-management) and district nursing services (whereby HCPs are proactive at engaging the wider community support and are well-placed to do that given their embeddedness in specific localities). Although HCPs tend to focus on promoting support from those who provide the tangible and visible work which is largely provided by strong ties such as partners (Gillham et al., 2023, Gillham et al., in preparation), they risk normalising sub-optimal care for people who do not have access to such support and where such support might be expected but in reality is unavailable or limited. Specifically, HCPs appear aware of how essential partner support is for providing everyday emotional and practical work, but they are less aware of the substantial amounts of the less tangible illness-based relational work partners do (e.g. coordinating care and advocating needs to HCPs). Furthermore, the nurse-partner focus is likely to manifest because the partner themselves value the support nurses provide them with (such as emotional support and health advice) (Gillham et al., 2023) which is known to be a reducer of stress for partners during onset of acute illness in community settings (Ramazanu and Griffiths, 2017).

However, HaH staff are less aware of the network processes through which support is mobilised in different circumstances, for example, when there is no partner per Gillham et al., (in preparation). Furthermore, the HaH nurses' give little focus to their anecdotal awareness of the complex role played by partners and also that of the wider SN (Gillham et al., 2023). This may be a reflection of the weaknesses inherent within the current service model developed from the perspective of policy makers (Leff et al., 2022) and therefore focusses on maximising service capacity and not on improving experiences of the patients who use HaH and HCPs providing the service. Therefore, this thesis has helped to demonstrate the lack of awareness, training and guidance for HCPs on engagement with key aspects of patient context, specifically, the importance of SN member support and how this is accessed. This may in part explain why nursing staff focus their attention almost exclusively on interactions with partners who are likely to be easily mobilised to provide support to patients in the short term (Mäkelä et al., 2020, Augustine et al., 2021, Cordero-Guevara et al., 2022). This reflection, that is derived from an integration of both datasets, suggests that those with limited access to informal support (especially if they do not have a partner) are going to be particularly vulnerable when using HaH services within the current model of implementation. Acute illness is, by definition, self-limiting, transient and short term (Jones et al., 2010), and therefore it can be logically suggested that during HaH service use, some patients would rather focus on the support of strong ties and not that of the wider network in order to avoid disrupting the support for periods outside of acute illness which will have been established over time and will be returned to after HaH admission. However, this only emphasises the substantial relational work that may need to be done within networks in order to get the necessary work done, and the gap in support where a partner or proximate child (the main candidates of doing this work) maybe unavailable.

Given the strong policy focus on self-management and the key findings of this thesis, i.e. how subjective perceptions of skill and motivation (self-efficacy) predict the perception of HQoL, there is reasonable concern that current HaH structure will not allow for assessment to resolve gaps in network provision. Even with assessment, these gaps may remain unnoticed because patients normalise SN support, especially from strong ties, and thus do not sufficiently appreciate their value, while also aiming to conform to normative expectations to be independent and not rely on others (Vassilev et al., 2017). Consequently, continuing to implement HaH services within the current model will favour those with an existing good level of informal support (e.g. a partner and other strong ties) and may lead to deepening the existing inequalities through insufficient support for people in higher need. For example, the support for those without a partner is, at present, being provided by HaH staff in a very limited and on an ‘ad-hoc’ basis. If such needs continue to be supported by HaH nurses then it is likely to remain unrecognised and unaddressed in the longer term and will lower patient outcomes and limit the successes of HaH services from the perspective of policy makers (because nurses may spend more time supporting patients with their everyday tasks thus limiting service capacity). However, if positive changes are made in order to provide patients and HaH staff with the tools and resources needed to identify and mobilise SN support (both informal and through formal services) this may, from a patient perspective, help reduce the amount of work that remains unmet; and allow HaH nursing staff to provide support that is better tailored, and reduce tensions between professional ideals of patient-centred care and workload pressures. This would be consistent with concepts surrounding social capital whereby HCPs might act as a bridge to accessing new sources of support (Mishra, 2020))and thus help people develop networks that are more diverse and better at providing sustainable support (Salehi et al., 2019, Ehsan et al., 2019). By considering these findings with a greater focus on social capital raises questions about the access of HaH patients to different types of relationships, how such support might be activated over the short-term engagement with the HaH service, and the knowledge and ability of HCPs to provide the needed support. Existing knowledge of bridging and bonding social capital suggests that HaH HCP's role will be limited to bridging to other weak ties, particularly to that of formal services (Rodgers et al., 2019). The pre-dominance in rural areas of networks with similar ties could act as a barrier to developing new and different types of connections and accepting support to accessing bridging social capital might be difficult and requiring justification (Jaye et al., 2023). In such a context patients may be choosing to avoid disruption and conflict within their existing network of support, particularly among strong ties (such as partners and close family members). HCPs may be able to play an important role in developing awareness of the value of diverse links, bridging social capital, and in offering support with accessing such support. Such a role is likely to extend the work of HAH staff, and initially increase the overall cost of service provision. However, if recognised and supported within the health service, it may have a positive impact on patient outcomes, while also improving job satisfaction and reducing burnout and staff turnover among HCPs, thus making the service more sustainable over the long-term.

Developing networks to include weak ties

At an individual patient level and in line with research on chronic illness management (Vassilev et al., 2013), the findings of Gillham et al. (in preparation) reveal that in instances where there is no partner, some patients may find it acceptable to obtain support with illness, emotional and practical tasks from a wider group of network members. However, the capacity of patients in need of such support to do the relational work required to mobilise others when needed is likely to be limited due to their acute health management needs and their perception that this episode of illness is primarily managed through their own ability to cope (their self-efficacy). The reason that the types of weak ties and the depth of their involvement varies between chronic and acute illness management might in part be due to the shorter term and more transient nature of support needed by people using HaH services.

In cases where there is no partner to support the patient (and indeed the nursing staff) during HaH service use, the amount of work provided by weak ties increases to a degree but not to the levels needed to make up for the typically smaller network sizes (Gillham et al. in preparation). A further issue from a patient perspective is that during HaH admission the weak ties that are present in the SN do not offer wide-ranging support, especially when there is no partner and is mostly focussed on practical work, which means patients experience difficulties in fulfilling their illness and emotional needs. Examples of practices that overcome such issues can be seen in community services such as district nursing whereby challenges are less likely to occur because HCPs have longer timeframes to build relationships which means HCPs are able to identify the gaps in support and understand individual patients' values that will allow for the most patient acceptable sources of support to be mobilised. Similarly, in the context of chronic illness management, patients have longer periods of time to navigate and negotiate relationships within their networks increase their social capital and develop more diverse networks, which are more sustainable over time (Holt-Lunstad et al., 2010, Reeves et al., 2014). However, the unplanned and sudden changes of health seen with HaH patients is not dissimilar to the initial onset of chronic illness where there is a significant loss of social contact which affects individuals' abilities to access the support they need (James et al., 2020) or result in a reduced social capital because of a loss in function and ability to interact with SN members (Salehi et al., 2019). The limited role played by weak ties among HaH patients may indicate that relations are more difficult to navigate during acute illness (possibly due to ill health and less time) and therefore those with prolonged use of HaH may find sustaining network support more difficult. HaH nurses can to an extent address such risks by improving their awareness of the key contextual factors identified in this research. This is especially relevant given that data showed that in some cases admission was up to 61 days with average admission length over three weeks.

This part of the discussion has highlighted that, as with chronic illness and district nursing services (Gillham et al., 2021), SN dynamics are complex for HaH patients and this is reflected in the varied way in which SNs can support HaH patients. There is an emphasis on the importance of HCPs undertaking an exploration of SNs in order to support the more vulnerable patients who are less likely to be able to manage the complexity of navigating SN of support for help with illness, emotional and practical work (i.e. those without a partner and those admitted for longer). HCPs may need to consider their role in exploring whether a patient is vulnerable to receiving insufficient levels of support and whether they are therefore required to structurally explore the informal support options with the patient and by mobilising other formal services in the absence of a partner as this seems to fit within their professional boundaries and service structure.

7.3.2 Understanding the processes through which network support is mobilised when using HaH services

Acute episodes of illness are traditionally treated in hospital settings such as wards where the support with practical and health tasks during ill health is provided by the HCPs (National Health Service, 2019b). Questions about the ability of inpatient wards to provide adequate emotional support remain and advocates of HaH services claim a better balance between the three types of support when using this type of healthcare service (UK Hospital at Home Society, 2021, Saenger et al., 2020, NHS England, 2022, Montalto, 1996).

Using social capital to identify and mobilise appropriate support

SN engagement does not manifest without a degree of effort from the individuals and those who undertake relational work on their behalf. Phase one, Gillham et al., (2021), focussed solely on how nurse-patient-network relations manifest in rural areas but was able to provide some insight into environmental and logistical factors; some of which could be transferrable to less geographically isolated areas and could be used to guide later phases. What was significant in the empirical stages of this research was the way in which patients and their partners have an increased social capital and ability to structure their SNs when treated at home despite acute illness (Gillham et al., 2023). This was viewed by nursing staff to benefit both patient experience and their psychosocial and health outcomes (Gillham et al., 2023). These findings are supported by existing research which shows that increased social capital is associated with positive experiences in the field of health (Yuasa et al., 2015, Pasha et al., 2021) and education (Hussin and Khan, 2017) literature.

Within this study, nursing staff were aware of the key role of social capital and “empowerment” of patients (Gillham et al., 2023). However, they appear to have limited awareness of how patients can increase their social capital, how this changes the way they can engage their SN (Gillham et al., in preparation) but also if and how HaH staff may also be able to do some of the relational work that is needed (Gillham et al., 2021). The latter could include coordinating access to other services as well as improving awareness and links with informal network members. HaH staff have less social capital than their district nursing colleagues who inherently become more embedded into the communities they serve over longer periods of interactions. Therefore, HaH nurses not only have a more limited awareness of SN support, but also a reduced social influence to mobilise support such as community groups and neighbours who are known to be key SN members in chronic illness. This lack of awareness means HaH nurses are right to be cautious in engaging informal support due to the uncertainty of its appropriateness which could put patients, and their own personal and professional ideals and standards (Nursing and Midwifery Council, 2018), at risk. HaH nurses (and therefore patients they treat) may benefit from exploring opportunities to increase their social capital within patients’ SN by, for example, making themselves known to family, friends and neighbours – but this needs to be balanced with other professional ideals, like confidentiality.

As a result, current practice means that HaH nurses are largely unaware of and do not engage with weak ties and relations beyond partners and key carers (Gillham et al., 2023). (Gillham et al., 2023) This is unlikely to change without appropriate and targeted interventions considering that community based nurses are known to avoid opportunities to explore this by avoiding difficult conversations around emotional needs because they believe they lack the skills needed to address such concerns (Griffiths et al., 2010, Griffiths, 2017). Therefore, more structured, policy driven changes will be needed to support nurses to change practices. However, the increasing pressures placed upon such services means that the emphasis will remain on increasing service capacity (NHS England, 2022, Brody et al., 2019) and will limit the likelihood that policy makers with address the capability of HCPs to formalise their ad-hoc processes to SN exploration. Consequently, any nurse and policy maker-accepted processes of SN exploration is likely to be a compromise which results in discussions around social support being undertaken within the context of the illness work they provide.

The varying levels of relational support during HaH service use

The mobilising, navigating and negotiating of support (the relational work) done within networks is central to everyday life but is even less visible than other types of work (emotional and practical). For HaH patients, partners are the key network members for doing such work (Gillham et al., in preparation). However, as with chronic illness management, where there are no partners other strong ties (such as children) will be needed to support patients to engage with wider and more sustainable support (Walker et al., 2018, Morris et al., 2016, Litwin, 2010, Vassilev et al., 2013) because HaH patients are unable to engage weak ties themselves. In the absence of adequate practical and emotional support from formal sources (such as HaH staff) and other informal strong ties, paired with the low levels of relational work done on behalf of patients by HaH staff, patients have an individual burden as they cannot distribute work though an adequately supportive network. This includes the relational work of mobilising and negotiating with friends, families and other wider members. Doing such work is known to be complex, it often remains undone, and thus many patients are likely to become isolated during ill health because of fear of burdening others and losing existing relationships (Walker et al., 2018, Locher and Watts, 2008). This may in part explain why neighbours play a more central role in supporting HaH patients than in chronic illness management. Also, patients cannot easily isolate themselves from this group as they are geographically close to one another and therefore the neighbours will be more visibly aware of the support that is needed (Cummins et al., 2005). Within the context of the Covid-19 pandemic, the key role played by neighbours may have been a side-effect of more significant and sustained over a longer period disruption to people's normal support systems (9.2% of participants were recruited pre-pandemic [n=7] and therefore the majority's SN could have been affected by the Covid-19 pandemic). Within this context, neighbours became more sensitive to the needs of vulnerable groups and may have increased the intensity of support (e.g. with shopping, food delivery and other practical work) than what they might provide outside of a crisis context (Felici, 2020, Jones et al., 2020, Tanner and Blagden, 2020). In the instance of HaH, neighbours provide similar types of support to during the pandemic by limiting themselves to practical support such as shopping.

This second aspect of the discussion highlights that the way in which patients receive the support they need is not routinized or automatic, is unique to their own situation, their background level of support and is reliant on their own social capital and the relational work and social capital of others. From a HaH perspective, nurses are well positioned to explore SN dynamics but have not been given the tools to do so and do not seek to increase their social capital with the patients' SN of support that they become a part of, to varying degrees, during HaH admission.

7.3.3 Identifying the limitations of HaH services and the gaps in the care provided to community based patients with acute care needs

Throughout the literature, there is evidence that enhancing the collective efficacy of people's support network can improve outcomes for patients (Cummins et al., 2005, Vassilev et al., 2019, Butel and Braun, 2019). However, this process is not automatic, and this thesis has demonstrated that this is especially true within HaH services for many nuanced reasons (such as contextual factors like rurality, self-limiting health conditions, varied admission lengths and diverse patient demographics). The data collection methods within this thesis has helped identify the different perspectives on SN contributions, navigation, and mobilisation but also how the healthcare-focussed perspective itself, can impact on these factors.

Professional and personal barriers to nurses providing wider ranging support for patients

In isolation, the nursing discourses suggest that the HaH service is one of patient-centeredness that demonstrates a willingness and ability to adapt to gaps in support left by, for example, the absence of a partner (Gillham et al., 2023). However, findings of Gillham et al., (in preparation) indicate that there may be gaps between discourse and practice, which will not be addressed if they remain unnoticed by nurses themselves. The tensions between discourse and what happens in reality may be due to the current service structures and the limited resources available (Cordero-Guevara et al., 2022), and also because nurses are divided between their professional aspirations of providing holistic support across all domains of work (illness, practical and emotional) and the context in which they work – i.e. a healthcare service that is being pressurised by fiscal challenges, aging populations and more complex health conditions (Cordero-Guevara et al., 2022). Therefore, it could be assumed that unless there is a shift in emphasis away from meeting admission targets towards greater value being placed on self-management support, then the gap is unlikely to be reduced.

The changes outlined above to parts of the HaH model would require deeper understanding of the limiting contexts than is currently applied by policy makers (NHS England and NHS improvement, 2022). For example, when reviewing the literature, the exhaustive list of rural factors that affect the SN practices of district nurses became clear but was only given a moderate focus (as a limiting factor) by HaH nursing staff. However, this does not mean that rural factors are not a limiter to SN engagement in HaH services but might highlights HaH nurses' limited awareness of how wider contextual factors can impact self-management and SN engagement. HaH nurses may be less aware and less able to overcome these issues compared to district nurses because they are not so embedded into the wider and personal communities of the patients they treat (Gillham et al., 2021). However, they acknowledge similar logistical challenges that district nurses experience as limiting factors to effective clinical practice (such as long travel distances, bad weather and poor patient living conditions) which can be considered equally restrictive to the quality and quantity of the support provided, particularly with practical and emotional work (Gillham et. al. 2022). However, nurses should be aware that there appears to be more significant, less visible contexts that are limiting their ability to practice in a more holistic manner. One suggestion from the novel contribution of the two empirical papers is that the users of HaH services are not only geographically and logistically varied (as with district nursing services) but also demographically varied (Gillham et al., in preparation) and therefore cause greater challenges for standardising the illness and relational work that might be needed, as well as the range of formal services that service users may need to be linked to. For example, where HaH services provide treatment for younger, independently functioning patients (who are more likely to experience better outcomes because of a reduced reliance on the support of others), nurses are able to establish relationships more readily (than with an older, frailer patient) (Gillham et al., 2023) despite the lesser need to do so for the purpose of exploring SNs and identifying gaps in support thus creating greater inequality. This can be drawn from SN literature which elucidates that people are more likely to build stronger links with others who have similar traits such as age (homophily) (Christakis and Fowler, 2009). However, this shows that from a nurse's perspective that their aspirations and what is most feasible within the constraints of HaH services are not always the same. That being the case, a degree of reflection is needed in order to recognise when and how best to build an equally effective rapport with those who are more reliant on the support of others but characteristically varied from themselves (typically older, frailer patients) (Gillham et al., 2023)).

Moreover, it is also likely that gaps in support for patients are hidden from HaH staff in the shorter-term admissions due to the ad-hoc network exploration approaches they adopt (Gillham et al., 2023). For example, although nurses are able to easily identify whether physical health and practical work is achieved among patients through observation during one or two interactions (Gillham et al., 2023), there is a risk that the hidden emotional needs, and the relational work required to meet them in the context of people's everyday life, may remain unnoticed and therefore unmet. In summary, there is a combination of contextual factors that may result in the need for complex work to be done by members of people's formal and informal network which HaH staff cannot undertake themselves, despite aspiring to do so, because they are operating within a healthcare focussed service. Therefore, nurses have two pathways to reduce the factors limiting experiences; firstly, they will need to standardise the assessment of patients' needs regardless of demographic, admission length and SN structure in order to identify needs and provide consistent emotional and practical support; and secondly, increase the awareness and value they place on other SN members to bolster the service in supporting patients where they cannot.

Addressing the lack of HaH nursing SN engagement practices

There is evidence in the wider literature on social support that engagement with, and mobilisation of patients' SN of support may offer a viable option to improve patient outcomes and capacity to self-manage (Walker et al., 2018, Vassilev et al., 2014, Kennedy et al., 2015, Vassilev et al., 2013). Within the context of HaH service users, mobilising SNs offers promise for broadening the scope of HaH services through more reliable and consistent practices. Although mobilising such support is complex and needs to be contextually sensitive (Pescosolido, 2006, Morris et al., 2016, Litwin, 2010) its potential is poorly understood and is largely overlooked by those implementing, managing and providing service in the current HaH format (Gillham et. al. 2022). In part, this might be due to HaH staff being currently poorly supported and underprepared to appropriately assess SN support despite broad awareness of potential benefits. However, through their ad-hoc explorations whilst "killing time" (Gillham et al., 2023), HaH nurses are to a degree aware of the shortcomings of some patients SN of support and therefore the risks of not applying this more holistic approach which results in their claims of bridging and bonding to others being ineffective and non-existent in reality. This discrepancy is demonstrated by the dearth of certain SN members being reported by patient participants (Gillham et al., in preparation) compared to those who were cited as being successfully mobilised by nursing staff (i.e. formal services) (Gillham et al., 2023).

If healthcare focussed models continue to favour formal services in isolation from informal support and the everyday life of patients such support maybe sub-optimal in terms of patient care and longer term service sustainability (Gillham et al., in preparation). Nurses might need to increase their social capital among formal provisions but also use this in order to better understand and engage with them. However, nurses should be aware that formal support is less empowering for patients and is rarely the most acceptable support for due to apprehension surrounding personal work being carried out by a ‘given’ SN member of which they have little jurisdiction (Pescosolido, 2006, Litwin, 2010). Therefore, from a healthcare service perspective, focusing on formal services may well be more easily standardized but this does not coincide with the HaH nurses’ professional identity and aspiration of providing individualized and patient-centred care (Gillham et al., 2023).

Therefore, a model that is built around patient-centeredness is optimal for patients as well as nurses but achieving this will require the latter to receive structural support at a policy level to overcome the logistical, resource related, and professional factors that are currently constraining SN exploration and engagement. Alternatively, policy makers and thus service providers might choose to focus on empowering patients to negotiate the most appropriate support themselves from their pre-existing pool of ‘chosen’ network members that will result in a provision of support that is acceptable to users and delivered in the context of the a lived experience and values that are shared with the patient (Litwin and Shiovitz-Ezra, 2011). One such chosen network member type, as discussed earlier, is neighbours who offer a *patient*-acceptable source of support but also a viable weak tie for *HaH nurses* to mobilise because they are geographically close to the patient and can therefore be addressed during planned healthcare focussed interactions (Gillham et al. (in preparation)) making it an acceptable solution for target-driven and healthcare focussed policies. Research supports this claim by showing that neighbours are likely to willingly provide short-term practical support (Ye and Chen, 2020); the type of support nurses are most keen to rapidly address compared to emotional work which is often avoided by nurses because it can vary a lot between patients, and has the potential to “open a can of worms" which attempting to support with would take them outside of their professional role (Griffiths, 2017)). However, the earlier discussion mentioned that sustaining weak tie support may be challenging to patients and therefore, it would be prudent for HaH nurses to broaden their awareness of other weak ties by increasing their awareness and social capital among community groups for those with longer term HaH service use given the known value of community groups in chronic illness management (Rogers et al., 2014).

In summary, the tensions between the breadth of patient and lack of standardization of SN exploration in practice presented in this chapter shows that it is likely that some patients will be disadvantaged by a lack of SN of support if they are unable to undertake relational work themselves (i.e. navigating existing support and mobilising it) during an acute illness. The current HaH service model limits the capability of the nurses and patients to assess the current support network for gaps and as such threatens the successes of such services. Firstly, this is an obvious concern for policy makers who advocate that more patients should be treated at home (National Health Service, 2019a, NHS England, 2022) but also for the professional values of nurses but importantly the HaH patients who would benefit from being treated at home providing they have adequate support across all domains of work (as cited by many of the nursing participants (Gillham et. al. 2022) and the positive quantitative responses to measures that explore HQoL, service experience and other psychosocial factors (Gillham et al., in preparation)). Nurses and patients should be provided with the best opportunities to source appropriate support from a range of chosen strong and weak ties before resorting to formal support.

7.4 Implications and future research

7.4.1 Implications for practice

The study has helped in demonstrating the key role of the informal workforce in supporting HaH service users, which is currently underutilised and therefore offers a potential resource for improving support for HaH staff. Such engagement is likely to require additional resources and interventions that are specifically focussed on assisting the network members who are being asked to bolster HaH services by providing support for patients. However, HaH staff will also need to reflect on their own practices that seem to favour those in least need of SN support but also be supported with training and resources to improve their capacity for understanding and engaging with people's SNs that they otherwise would not, thus also making the service more patient-centred. Although this may require additional relational work to be undertaken by HaH staff within an already pressurised system, this will likely improve patient care, identify the relevant SN based resources, and target their use where they are most required. Whilst each of the three research stages of this thesis discuss how the findings contribute to guiding future practice and further research this can be reviewed here and brought together as overarching guidance as follows.

The HaH nurses' discourse of patient centeredness is consistent with professional identity but in the context of limited resources and care not sufficiently sensitive to peoples' personal contexts, it may fail to identify and address the gap in provision, thus, potentially normalising sub-optimal care, especially for groups where additional needs are less visible. HaH staff may need more formal training to help improve understanding of, and engagement with, SNs. Some of the existing knowledge and interventions developed to support people living with chronic illness and within the context of other community-based services may help improve the HaH service. Gillham et al., (2021) emphasised the benefit of embeddedness and increasing social capital where possible as a means to overcome healthcare and logistical pressures. This will vary for HaH services depending on the contextual factors of each patient, which is known to be broad as per Gillham et al., (2023) and Gillham et al., (in preparation). However, HaH nurses have opportunities to build better rapport and increase their social capital; with weak ties and formal services which is currently overlooked as a potential means to improve the relational work they do. Therefore, nurses should consider a standardised way of achieving this that does not favour one context over another (such as rural vs urban). The experiences of Gillham et.al. (in preparation) suggests one method that could be adopted to achieve this is by undertaking a structured conversation which has been successfully applied in self-management support interventions (Vassilev et al., 2016, Vassilev et al., 2013) and would coincide with the nursing values of an informal, rapport building conversation implemented as part of planned health focussed interactions of patients using HaH services to avoid further disruption to time pressured service which will make it more acceptable to clinicians (Griffiths, 2017). This approach would require nurses to undertake a concentric circle network mapping exercise (Figure 7) (Antonucci et al., 2014) which could then be used to stimulate conversation to quantify SN member involvement and stimulate discussion that will lead to a greater understanding of the support received during HaH service and identify any gaps (Kennedy et al., 2016). This relatively simple and patient acceptable technique could be undertaken during planned health work from nursing staff and therefore overcome any concerns of burden on acutely unwell patients and already stretched community healthcare provision. Such knowledge might help nurses to more efficiently identify and engage with existing members of the SN and identify the gaps of support that can either be bridged by HaH nursing staff in the short term or by linking/bridging to other formal support services that has existing ties with HaH.

For the uptake of such changes to be embraced in practice then awareness of the importance of SNs in HaH services would need to be improved. Therefore, using the work within this thesis an educational and reflective exercise based on the known challenges faced in community settings as per Gillham et.al. (2021) and the known benefits of SN involvement from existing literature around chronic illness may be beneficial. This could also include discussion around the data from Gillham et.al. (2023) which highlights the range of network members that support patients and how illness, practical and emotional work each relational group typically takes. This will help nurses to gain the confidence to reduce their reliance upon strong ties and other formal services and increase their awareness of the value of weak ties such as neighbours and friends; and for longer term patients, explore alternative weak ties such as community groups which have been shown to beneficial to patients with chronic illness in providing peer support and sharing lived experiences (Rogers et al., 2014).

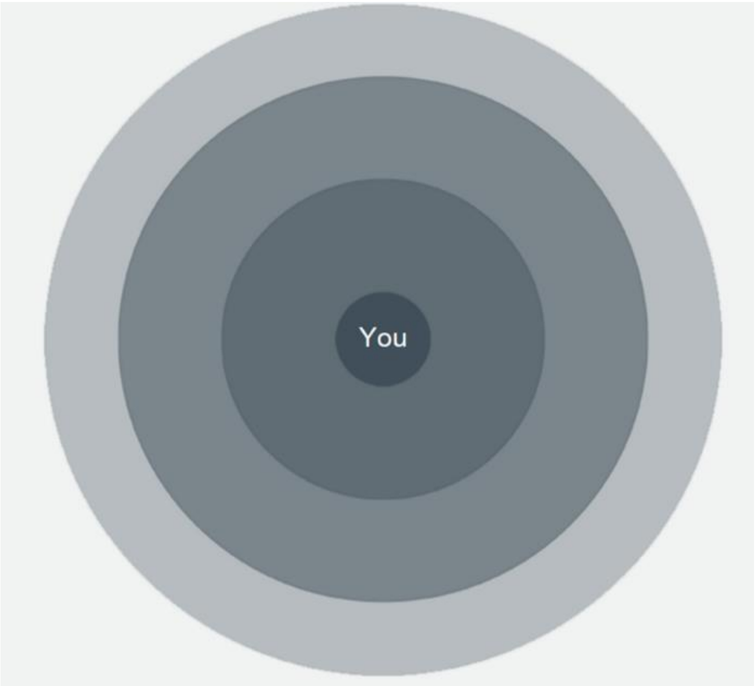

Figure 7: *Template of 'concentric circle' mapping exercise with the patient/participant central to the diagram. Those most important for providing SN support would be placed closest to them with the less influential SN members placed on the outer rings*

7.4.2 Future research

This thesis helps to extend the literature on community-based nursing by exploring more summative services such as district nurses from a SN perspective (Gillham et al., 2021) but also by expanding the literature of HaH services which has previously mainly focussed on comparing costs with health outcomes and admission lengths. This thesis offers a multi-perspective approach to understanding the phenomenon of HaH services and how SN dynamics are intertwined with the successes and failures of them and as such identifies a need for a more structured approach to understanding and engagement with people's SN. Further, more nuanced qualitative work from patient and carer perspectives (such as partners and neighbours) would help to further illuminate the meanings behind the findings of the third paper, Gillham et al., (in preparation), and add an alternative qualitative perspective which will improve the process of triangulating the findings per Gillham et al., (2023) (Goertz and Mahoney, 2012). Furthermore, there is a need for a more nuanced understanding of the limits of the HaH nurse role (i.e. limited capacity for engagement with SNs). This may include the development and evaluation of new interventions (such as the concentric circle mapping exercise (figure 7) (Antonucci et al., 2014) discussed in section 7.4.1), and qualitative exploration of the potential barriers to its implementation.

Finally, further quantitative exploration will illuminate potential limiting factors to positive patient experiences. This thesis has highlighted the way in which SN support is dependent on a variety of nuanced illness, demographic and psychosocial factors and therefore an equally nuanced exploration of the way each can affect one another is needed in order to identify other potential determinants of higher vulnerability for patients. For example, a separate study could be produced on the impact of gender, age, network size and/or marital status in relation to key predictors of experiences such as self-efficacy. The list of potential quantitative studies is exhaustive but focussing on what this thesis has identified to be a key predictor of positive outcomes (i.e. self-efficacy) as a dependant variable will add to the growing pool of knowledge that allows all stakeholders to best plan, implement and use HaH services.

7.5 limitations

Whilst the three papers in this thesis make an original contribution to the research literature, there are notable limitations. These are discussed within the included papers, but for clarity, they can be briefly returned to here.

7.5.1 Paper one: Rural influences on the social network dynamics of district nursing services: a qualitative meta-synthesis

Firstly, although similarities are drawn, the researched group (district nurses), can not be directly compared to HaH services and therefore differences may occur if a similar synthesis was undertaken among this service type. Moreover, as a meta-synthesis, this review included only qualitative studies which, although this fills gaps in understanding and underlying mechanisms left by quantitative studies, such methods of synthesis cannot include the number of studies of a quantitative synthesis. Furthermore, as a review of a previously unexplored areas the outcomes identified are theoretical and made of assumptions that will require empirical investigation to confirm. Such suggestions were made in previous chapters (7.4.2 Future research).

7.5.2 Paper two: What is the work and the (in)formal workforce involved in supporting people using 'Hospital at Home' services?: A nurse perspective

Here, a relatively small sample was taken from a single HaH service site. This restricts the generalisability of the findings. However, the larger cohort within paper three goes some way to overcoming this limitation. Furthermore, the lead researcher, as a practising clinician within the research site raises concerns about existing biases and implied knowledge from the participants, which may make data less explicitly detailed. However, the paper debates the benefits of being an 'insider' to the research and how this goes some way to facilitating a relaxed and open discussion during semi-structured interview and a lived experience that can be utilised to improve the analysis.

7.5.3 Paper three: Evaluating the personal, demographic, psychosocial and social network factors of Hospital at Home patients and how this contributes to quality of life during treatment.

Again, as a PhD, the scope of this project makes the sample size relatively small for a quantitative study. Although the response rate was high, the single recruitment site limits the transferability of the findings – especially considering that there is no universal or established way to operate a HaH service. Despite efforts that encourage openness and honest responses to quantitative question, the researcher was one of the participants' treating nurses which may have encouraged more positive feedback to service experience questions and the inclusion of HaH staff in SN of support. Future qualitative feedback would help to determine this.

Finally, COVID-19 pandemic had some bearing on the results of the quantitative data collection. Firstly, a minority of the participants (n=10) took part before the pandemic whilst the majority took part whilst social distancing measures were in place. This would likely impact on patients SN size and structure and as such the psychosocial measures that are included in the questionnaire. This limitation was acknowledged within the paper.

7.6 Conclusion

In the view that pressures are already increasing on HaH service provision and that they are likely to consider to do so in recognition of the changing global health and demographic factors (World Health Organisation, 2006). Existing exploratory research has already shown the value of SN support for improving people's ability to self-manage acute and chronic illness. Thereafter, SN interventions such as network mapping exercises have been demonstrated to be a beneficial method of improving patient health and experiences of managing illness as well as reducing the burden on healthcare services and strong ties in the context of chronic illness management. This emphasises the need for this method of exploration to be more readily applied to contemporary and potentially problematic services such as HaH to assess whether, and indeed how, such issues can be addressed to improve patient outcomes. Policy makers for such services are health focussed and advocate that HaH should support as wide-ranging a patient group as possible to maximise the benefit for inpatient pressures. Considering this, there is a likelihood that patients and their SNs are going to be geographically isolated and therefore rurality was a further theme that needed to be incorporated into any research.

This thesis (and the three papers within it) has used a mixed methods research approach from a critical realist perspective and made a novel contribution to the field of HaH services that can be used to reduce the imbalance between healthcare focussed demands and the need for application to be more patient-centred in order to improve health and experience outcomes. In part one, through illuminating existing SN dynamics at the heart of district nursing services that were largely hidden within exiting research that focussed on logistical challenges findings (such as the importance of social embeddedness and social capital of both patients and the HCPs for successful SN support to be developed) could be applied to empirical research of HaH services. The first of a two-part, mixed-methods, multi-perspective study sought nursing opinions on many aspects of HaH services (benefits, complications, patient experience and SN involvement). The findings illuminated that nurses have an awareness of the practical, emotional and illness work that is needed by patients but only use an informal and unstructured method of assessing SN dynamics. If a more thorough understanding were to be developed, then nurses would be able to utilise SN members more effectively to support the patient and reduce what is currently an ineffective approach of bridging to other formal sources of support. Current SN awareness among nursing staff is limited to spouses and other strong ties whereas part three of this study showed that there are, in fact, wider-ranging SN members who support patients in receipt of HaH care which is dependent on other factors such as the presence of a partner. For example, the data shows that the majority of patients had partner support but, in their absence, an increased amount of work is undertaken by weak ties such as neighbours; HaH staff are likely to be unaware of this. As such, nurses would be prudent to more closely explore weak ties in more detail in a structured and standardised manner that will improve experience outcomes, broaden the service provision and create a consistency for patients which nurses cite is currently not possible based on lack of support and logistical challenges.

In summary, HaH nurses are less embedded into the communities and SNs of the patients they serve than district nurses and therefore they should adopt more formal SN assessments to achieve the same outcomes district nurses benefit from due to their increased knowledge of the social contexts of patients which they develop over the longer periods of time they are afforded to build relationships. In HaH services, formal SN exploration should be in the form of a concentric circle mapping assessment that will be done during health interventions and therefore minimally disrupt the current health focussed provision. Training in SN assessment for nurses will be required and further qualitative research should focus on patient and carer perspectives in order to maximise the effectiveness of such practical approaches as well as measuring the proposed intervention in a quantitative study.

8.0 Reference list

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9.0 Appendices

9.1 Appendix 1: Ethical application protocol

Protocol

Study Title: Exploring the effects of social network dynamics on patients receiving 'hospital at home' care in a rural environment.

Researchers: Jack Gillham, Dr Ivaylo Vasillev, Dr Rebecca Band

Version Number	**Author**	**Date**
1.0	**Jack Gillham**	**21/11/2018**
2.0	**Jack Gillham**	**04/02/2019**
3.0	**Jack Gillham**	**16/07/2019**

1. Research team

Student researcher	Mr Jack Gillham Staff Nurse & PhD Student Acute hospital at Home Dorset County Hospital Williams avenue Dorchester Dorset DT1 2JY Telephone: 01305 254944 Email: jhg2g11@soton.ac.uk
Co-Investigators	(Chief investigator) Dr Ivaylo Vassilev – Principal research fellow University of Southampton Dr Rebecca Band – Senior research Fellow, University of Southampton

2. General information

2.1. Protocol authorisation

The protocol for this project will be primarily composed by PhD student researcher Jack Gillham under the supervision of chief investigator (CI) Dr Ivaylo Vassilev and Dr Rebecca Band. The protocol will be submitted and accepted as appropriate by the University of Southampton ethics committee and the NHS ethics committee.

2.2. Compliance

All aspects of this study will be undertaken in full compliance with the approved protocol, in keeping with Good Clinical Practice (GCP) guidelines and the General Data Protection Regulation (GDPR) (European Union, 2016).

2.3. Stakeholders

As a clinical/academic research fellowship, there is a dual investment. Firstly, the University of Southampton:

Faculty of Health Sciences

University of Southampton

University road

Southampton
SO167 1BJ

Telephone: 023 8059 5000

Secondly, the Dorset County Hospital Foundation Trust:

Dorset County Hospital

Williams avenue

Dorchester

Dorset

DT1 2JY

Telephone: 01305 251150

2.4. Funder

The Clinical/Doctoral Research Fellowship (CDRF) is jointly funded by The University of Southampton and the Dorset County Hospital (contact information as above).

3. Plain English Summary

In recent years NHS policy has emphasised the need to relocate care outside of hospitals and into community settings. For many health conditions there are financial benefits to this with no negative effect to medical outcomes. Treatment at home is shaped by the engagement with people's social networks. This may be through access to additional support, but there may also be a risk that patients might become isolated and lack the needed help with practical, everyday illness management tasks.

Initiatives such as Hospital at Home (HaH) support people with their health needs outside of hospitals. HaH staff may be well positioned to identify people who have insufficient social support or become lonely or isolated and therefore provide further support or opportunities for social interaction. Additionally, understanding the process of network engagement could help tailor and improve the support offered through the HaH service.

This study will use a mixed-methods approach to develop staff and patient understanding of the interactions between patient personal networks, the HaH service and patient outcomes during and after HaH treatment. This research will contribute to, and develop, the existing literature on the affect social networks have on health, loneliness, social isolation, coping and the process of activating and sustaining network support. In addition, these insights will be drawn on in order to improve the HaH service and patient care.

4. Background

As the strain and financial burden on the National Health Service (NHS) in the United Kingdom (UK) continues, the emphasis in government planning has been to prevent illness, manage long-term conditions (LTCs) and provide treatment in areas outside of hospitals in an attempt to decrease spending, improve outcomes and increase patient satisfaction. Within the *'Five Year Forward View'*, there is a strong emphasis on the NHS to treat patients outside of hospital settings whilst supporting people with complex health needs (England, 2014). However, home treatment could be considered to intensify underlying issues prevalent within community healthcare such as a high staff turnover, an expectation that healthcare professionals (HCPs) would become generalists despite a lack of education and support for that, poor supervision, and a dearth of services (Effken and Abbott, 2009). When treatment is provided through community based services, patients are also less likely to closely follow the medical guidelines than when treated in a hospital setting. In addition, the complexities of providing appropriate support are likely to be exacerbated for older populations with complex needs and limited financial resources, and living in rural areas characterised by large geographical distances, poor infrastructure and poor access to local hospitals, services (Allen, 2012; (Kennedy et al., 2015); (Todd, 2013). Therefore, access to, and engagement with, social networks is likely to play a key role in the recovery and well-being of patients who are offered medical treatment at home.

There is evidence that loneliness and isolation pose health risks equivalent to smoking and obesity, and are also associated with a host of poorer outcomes including cognitive decline, unhealthy lifestyle, depression, morbidity and mortality, admission to hospital, longer inpatient stays, delayed discharges (Niedzwiedz et al., 2016). Loneliness and isolation are particularly common among older people, with occurrence rates estimated to be at between 5% and 45% across Europe and the United States, and associated with, morbidity, reduced function, higher rates of healthcare services utilisation (Leigh-Hunt *et al.,* 2017). Within rural areas, 13% of older adults report feeling lonely and 49% report isolation from their family; citing widowhood, financial difficulties, area deprivation and physical health as causes (De Koning et al., 2016). Engagement of personal networks and a focus on what patients value can help improve their health and wellbeing while also reducing loneliness and isolation. There is evidence that network members play a key role in providing emotional, illness and practical support, such as administering medication, arranging appointments, help with shopping, cleaning, personal care, coping when anxious or down (Morris et al., 2016). However, the effectiveness of personal communities in supporting patients is dependent not just on their availability, but also on their capacity to do the right thing, at the right time, in a way acceptable to patients (i.e. their collective efficacy) (Vassilev, 2014). Thus, for some people existing commitments to family members, friends, colleagues, local communities may take precedence over concerns about their own health. In such cases, especially where patients may also have limited access to financial resources, HCPs or other community based network members or groups may become key sources of support. People who are primarily reliant on support from HCPs or weak (not family and friends) ties are likely to face challenges with accessing support for practical everyday tasks, such as shopping or cleaning. Such networks may also put additional and unrealistic expectations on HCP and other weak ties for social and emotional support (Crotty et al., 2015a). What is clear is that personal networks are a broad continuum that requires significant navigation and negotiation by the person at the centre and by members of their personal community (Kennedy et al., 2015). There is evidence that it is diverse networks that include a wide range of relationships, especially weak ties (such as groups, activities, neighbours, acquaintances) that are the most likely to provide effective support acceptable to patients (Vassilev et al., 2013, Kang and Ellis‐Hill, 2015).

HaH is an effective, cost-effective, and acceptable to patients service where the medical needs of patients (e.g. urinary or respiratory tract infections) are treated at home (Leticia María Dopico, 2018) (see section 7.1 for more detail). However, there is at present a knowledge gap about the impact of social networks on the processes surrounding the delivery, effectiveness, and acceptability of such innovative services. A better understanding of the processes associated with navigating social networks, negotiating accessible support, and how these change over time and in different contexts can help improving the HaH service.

5. Aims and objectives

The aims of the current study are therefore:

5. To develop understanding of the processes operating at the interface of the HaH services and social networks in co-shaping the support, experiences, and health outcomes of patients.
6. To identify candidate pathways to engaging social networks that can enhance the HaH service.

This will involve using a mixed-methods approach in order to explore:

4. Patient and staff experiences of HaH services and the role of patient personal networks.
5. The meanings patients attribute to network engagement in managing their health and network change over time.
6. The associations between patient characteristics (demographic, illness, self-efficacy), network member characteristics (socio-demographics, distance, type of relationship, frequency of contact), network structure characteristics (e.g. type of network, amount of support, collective efficacy, fragmentation), and key health related outcomes (e.g. loneliness, isolation, health related quality of life)
7. How and why such associations may vary for patients at different stages of the illness trajectory, and for those living in rural and urban areas.

6. Study design

A four-stage mixed-methods approach will be used. This will include:

4. Obtaining key health status indicators from patient medical records (e.g. comorbidities and current diagnosis).
5. Collecting quantitative data of HaH patients at two time points: Within one week of discharge and a 12 week follow up.
6. Conducting semi-structured interviews with a sub-set of patients taking part in the study. Up to 30 patients will be interviewed within 2 weeks after completing the follow up questionnaire. This will involve mapping of their personal communities in order to explore the role and engagement of networks during HaH treatment, and how treatment at home (HaH) has affected this.
7. Semi-structured interviews with HaH registered staff nurses and healthcare support workers will be conducted at two time points: at the beginning and at the end of the project. At the start of the research project, interviews will explore the HCP opinion and knowledge of personal networks and their interactions with the service. The second set of interviews with HCP will be conducted after all patient data has been collected in order to explore the role of network support in purposively selected case studies, to explore the specific impact and interactions with HaH care provision in order to explore how to improve the service and guide research in the future.

7. Participant identification and recruitment

7.1 Clinical setting/ Hospital at Home description

The Dorset County Hospital's (DCH) HaH service (established in 2015) will be the subject of this research. The service receives patient referrals from various routes such as inpatient wards, outpatient clinics, GPs or community hubs (the latter two as part of admission avoidance). Patients are referred with a medical need, such as a respiratory tract infection or infected surgical wound typically needing intravenous antibiotics, observation and complex wound dressings/drain management. The service also provides, medicines management support, anti-coagulation treatment, venepuncture, nutritional support.

Healthcare professionals travel from the hospital to provide the required care in the patient's home (within a 30 minute drive). The multidisciplinary service has a maximum capacity of 12 virtual beds and a daily 'virtual' ward round allows doctors, nurses, allied health professionals (physiotherapists, occupational therapists, speech and language therapists and dieticians), microbiologists and pharmacists to discuss patient cases and update treatment plans. The length of admission varies depending on patient and medical need: from a single visit to multiple visits over 10 months.

7.2 Participant identification

All patients referred via all admission routes to the HaH service will be approached towards the end of their medical treatment for inclusion within this study. Eligible, potential participants will be approached with an invite letter and accompanying participant information sheet (PIS) (appendix 2) by the PhD student researcher. Patients will be followed up by the PhD student researcher no sooner than 2 days after receiving the PIS. Following quantitative questionnaires up to 30 participants will be invited to take part in semi-structured, face to face interviews. Participants will be purposively selected to gain a diverse sample in terms of socio-demographic characteristics, diagnosis, network structure, admission routes, and health outcomes.

Written informed consent will be obtained for all patient participants. Those unable to give consent due to a lack of capacity (based on medical diagnosis and doctor assessment) will not be included. This is due to the inability to retain information and give accurate data required to meet the study aims and for the research team to work within the Mental Capacity Act (2005). Patients who lack capacity are very rarely treated by the HaH service and this will therefore not effect recruitment.

All staff nurses and healthcare support workers (the staff who are involved in care and treatment on a daily basis) that actively give care and treatment to patients will be approached to participate.

7.3 Inclusion criteria

- Patients admitted to HaH service
- Estimated discharge date of greater than three days from admission

- Willing to participate/provide informed consent.
- All HaH staff who deliver care and treatment to patients.

7.4 Exclusion criteria

- Patients under the age of 18.
- Patients with an estimated discharge date less than 72hours from admission.
- Patients who lack capacity to give consent
- Patients or Staff unwilling to participate or consent.
- HaH staff who do not actively deliver care or treatment for patients (e.g. administrators)
- HaH temporary/bank/agency staff.

7.5 Participant flow through the study

Patient participants will be approached face-to-face by the CI about the research and given the Patient participant information letter during an early nursing intervention. During a later nursing intervention the PhD student researcher will approach the participant to ask whether they wish to take part, and consent if they agree. Consent forms will include space for participant contact details to arrange follow-up interview if required.

Patients who consent to participate will be asked to complete the baseline questionnaire within 7 days of discharge from the HaH service (returned via a pre-paid envelope). A follow-up questionnaire will be completed 12 weeks after the date of discharge from HaH and returned via post (pre-paid envelope).

Up to 30 patients will be interviewed face to face no longer than two weeks after completing the follow-up questionnaire. During the interviews the PhD student researchers will guide participants through the process of mapping their personal network using the concentric circle technique. This will initiate discussion around the role of the network and experience of the service including reflection on the network dynamics during treatment and changes occurring during and after treatment from HaH staff.

In circumstances where the participant’s health deteriorates and they are admitted/readmitted to a hospital ward, data collection will continue after discharge from hospital, or discharge from

HaH if the patient returns to use this service. This will allow for investigation into how engagement with personal network and HaH staff are shaped during unforeseen changes in circumstances

All HCPs will be approached and consented for two semi-structured interviews, one at the start of the research, before patient participation begins, and a second after all patient data is collected.

7.6 Discontinuation and withdrawal

Both patient and HCP participants can choose to discontinue at any time without giving a reason. In this case, existing, anonymised data will be included in analysis but no further data will be collected.

Participants can withdraw from the study and request all their data is removed/ not included in analysis.

If capacity deteriorates during the research at this point consent cannot be given and the participant will be withdrawn from the study. Any data collected to this point will be anonymised and included in analysis.

8.0 Sample Size

HCP sample will be determined by the number of staff willing to participate. The service currently employs 3 registered nurses (excluding the PhD student researcher) and 7 healthcare support workers, therefore a maximum of 10 HCPs will be interviewed.

Sample size for quantitative patient data will be determined by admission rates to the HaH service at the DCH. It is estimated that during the planned 12 months of data collection 100 patients will use the HaH service. As many of the patients willing to participate and fitting the inclusion criteria will be included in the study.

For qualitative interviews, patient participants will be included until data saturation has been reached. It is estimated that this will result in interviews being conducted with up to 30 participants.

8.0 Measures

8.1 Patient Health Records

With consent from participants, data will be gathered from medical notes to obtain the following information:

- Current medical diagnosis/condition
- Past medical history

Data will be gathered from medical clerking of the current admission to DCH or HaH to ensure up-to-date, reliable data and avoid data being incorrectly explained if participants are asked directly.

8.2 Quantitative Questionnaire Measures

The questionnaires given to the patient at the point of, or shortly after discharge from the HaH service will contain the following validated measurement tools:

- Demographic questions
- SF12 subjective health measure
- The De Jong Gierveld 6 item scale for loneliness (De Jong Gierveld and Van Tilburg, 2006)
- Self-Efficacy for Managing Chronic Disease 6-item Scale (Lorig et al., 2001)
- CENS Collective efficacy measure
- World Health Organisation Quality of Life (WHOQOL-BREF) measure (World Health Organisation, 2014)
- Patient satisfaction survey
- Personal network data (member type, frequency of interaction, proximity)

The SF12 subjective health, The De Jong Gierveld 6 item scale for loneliness, Self-Efficacy for Managing Chronic Disease 6-item Scale, CENS Collective efficacy and WHOQOL-BREF measures will be reapplied 12 weeks post discharge. This will allow outcomes can be projected based on trends in the data and inferences can be made.

8.3 Qualitative study methods

All willing HaH staff will be consented for two semi structured interviews, following an interview schedule. An initial interview will broadly discuss the service and their feelings and awareness of the impact of patients' personal networks on outcomes during treatment and ongoing after discharge. The second interview will take place after all data has been collected from patients (including quantitative measures and qualitative interviews). The cases and results will be discussed from a HaH staff perspective to consider their feelings and awareness at the time of the results and how they feel it may impact on future practice of the service.

Patient participants will consent to be contacted either via telephone or face-to-face during a nursing intervention by the CI to arrange a suitable time for the face-to-face, semi-structured interview to be completed within 2 weeks following their second interview. The interviews will start with the completion of a network mapping exercise in conjunction with the researcher. Network member occurrence and prevalence within this map can be used quantitatively but will primarily be used to initiate discussion (Kennedy *et al.,* 2015). Discussion will focus on how personal networks and HaH services and its staff have integrated into, and mobilised within, the patients' personal networks during treatment.

All interviews will be audio-recorded and transcribed verbatim. The transcripts will be anonymised with all patient identification information removed. Interviews will ordinarily be conducted 1-to-1 without a family member or friend present. However, in circumstances where the participant requests this, it will be acknowledged in the analysis.

Patient participants will be purposefully selected for interview by the research team to obtain a sample containing a range of demographics and quantitative outcomes (such as loneliness or poor efficacy). Interviews will continue until data saturation. It is anticipated that up to 30 people will be recruited. The interviews will explore changes to social networks during HaH treatment, engagement with and experiences of the HaH service, types of work (health, emotional, task) done by different network members and HaH staff during and after treatment, gaps in network support and strategies used to address these gaps.

8.4 Duration of study participation

Patient participants: Considering the questionnaires are required to be completed at discharge of HaH treatment, the follow up questionnaire 12 weeks after baseline, and a face-to-face interview up to 2 weeks after receiving the follow up questionnaire, the length of participation is expected to last for about 14 weeks.

HaH staff participants: HaH staff will be interviewed before and after all patient data collection. Data collection of patients is estimated to take one year and therefore staff participation should take no longer than 14 months.

Overall, data collection for the study is expected to last 12-18 months.

9. Data analysis

9.1 Quantitative Analysis

Data will be analysed and displayed in appropriate descriptive and graphical form. We will explore associations between individual level characterisitics (e.g. age, gender, socioeconomic status, health status, co-morbidities, length of admission, self-efficacy, loneliness), network structure characteristics (e.g. size of network, diversity of network, frequency of contact, collective efficacy), and HQOL, and satisfaction with HaH services.

9.2 Qualitative Analysis

Qualitative interviews will be digitally recorded, anonymised and transcribed. Although time consuming, some will be transcribed by the PhD student researcher to create a greater understanding of the data set. Data will be analysed using thematic analysis approach. This is a flexible approach (Braun and Clarke 2006) (figure 3) that allows the development of concise and meaningful themes in a transparent and consistent manner. The qualitative analysis will illuminate patient and stakeholder perceptions and the meanings they attribute to the successes and failures of the HaH service in relation to personal, social, and illness management needs. This stage of the analysis will also help interpreting the findings from the quantitative analysis. Figure 3 represents the process in a chronological order. In reality, reverting to earlier phases is encouraged as codes may become apparent during later phases (Braun and Clarke, 2006)

Thematic Analysis						
	Phase 1: familiarising with the data	Phase 2: Generate initial codes	Phase 3: Searching for themes	Phase 4: Reviewing themes	Phase 5: defining and naming themes	Phase 6: producing the report
Application to this research	CI to hand type transcripts of interviews	Highlighting points considered possible codes by the researcher. Different colours used to start grouping similar ideas	Re-focus the initial codes into groups. Visual tools such as tables will be used to manage data into groups	Refining phase 3 themes, possibly eliminating, dividing or adding new themes. Review the transcripts to retain meaning	Identify the essence of the theme and name it accordingly. A concise name for each theme to tell give the reader a sense of the theme. A detailed analysis of each theme will be required	Telling the complicated story of the social network analysis. Interesting, concise and coherent account of the data analysis and outcomes of it. Will include, but not simply list, extracts and quotes from transcripts where appropriate to add clarity.

10. Ethical considerations

Patient participants, acutely unwell and potentially lonely and/or isolated, may be considered vulnerable and therefore careful ethical considerations must be made. The ethical principles in healthcare, social care and health and social research, known as principalism (Parahoo, 2014), will be applied as follows:

- Autonomy: Participants will be given the best available information on the study, outlining key benefits to practice, pertinence to health policy and potential risks to their emotional wellbeing. This knowledge means participants can give informed consent. The right to discontinue/withdraw without reproach will be clearly explained to the participant.

  Contact details of the research team will be within the PIS should the participant have any questions.

- Beneficence: By participating in the study, those included will add to the pool of knowledge around the benefits of HaH services. This has the potential to improve the NHS service which they and others may access in the future. The participant will receive increased interactions with healthcare professionals during the research period which may benefit their mental health.

- Non-maleficence: The time given by participants to the study (completing two questionnaires and a semi-structured interview) should total no longer than three hours across a 12 week period. Therefore, the risk of over burdening is low. Patient and public involvement (PPI) during planning will be used to confirm this by piloting the study with Patient Research Ambassadors (PRA).

  Should a participant undertaking the study feel upset when talking about their personal networks of support and potential feelings of social isolation, there would be an opportunity to move onto a different question, take a break in the intervention/interview or the intervention/interview could be terminated at any time.

  During the study, face-to-face interaction with the researcher is minimal, therefore a risk of psychological damage caused by a loss of this social interaction is considered low. Finally, the research will run concurrent to the participants' treatment with the HaH service. Their medical needs will come above that of the research.

  Anonymising all data will protect the participant from any reproach (from health services or personal network members) as a result of their responses to both qualitative and quantitative questions.

- Justice: Not all participants of the quantitative stage will take part in qualitative interviews. The decision to include some and not others will be in order to obtain a breadth of data and whether data saturation is yet reached. Once participants are made aware they are not for interview, they are given the opportunity to participate if they actively wished to be involved in interviews. All decisions will be communicated to the participant. (Beauchamp and Childress, 2009)

11. Data protection and storage

Data will be collected, anonymised and stored in compliance with the General Data Protection Regulations (GDPR) (European Union, 2016).

Anonymised questionnaires and interview transcripts will be stored in a locked filing cabinet at Dorset County Hospital. Audio recordings will be kept on University of Southampton encrypted devices and servers.

Both electronic and paper data will be kept secure for 10 years after the research has concluded.

12. Research governance

This study will be conducted in accordance with the Research Governance Framework for Health and Social Care. Regular updates, meetings and communication via email and telephone with experienced research supervisors will ensure the quality of the research is to a high standard, in-line with the expectations for PhD projects at the University of Southampton.

13. Patient public involvement

Patient and public involvement representatives were recruited from DCH's network of Patient Research Ambassadors (PRAs).

All of the PRAs were approached and given the opportunity to join the research. Two PRAs have committed to regular meetings with the PhD student researcher to give a public perspective (e.g. on the research design, ethical issues of burden, and use of language on questionnaires to increase participant understanding).

It is anticipated that the PRAs will view the anonymised transcripts and assist with the data analysis which may give insights overlooked by the research team.

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Southampton

9.2 Appendix 2: Healthcare professional participant documents

Staff participant information letter

You are invited to take part in:

The ‘Hospital at Home’ social network study

Study title: Exploring the effects of social network dynamics on patients receiving ‘Hospital at Home’ care in a rural environment.

1. Summary of the study:

This is a student PhD project conducted by Staff Nurse Jack Gillham under the supervision of Principle research fellow Dr Ivaylo Vassilev and senior research fellow Dr Rebecca Band. This project is about the Hospital at Home service you work in. It focuses on how the service works, who makes it work for you and what can be done to improve it in the future.

2. What will happen if you choose to take part?

- You will take part in an interview to discuss how you feel about the service and how you think it works for patients.
- If you still work for the service, you will be asked to do another, similar interview after the research with patients is completed. This will look at more specific cases to get your opinion and views on this.

3. What is the study about?

We want to get more information about how the Hospital at Home service works well or not so well for people. By doing this, in the future we hope to be able to identify people who are unlikely to have a positive experience with the service and therefore put things in place that can improve it for them.

We want to know who helps make the service work. This could be yourself, patient's family and friends and/or the hospital staff.

Understanding more about these things can help to improve the service in the future.

4. Why have I been asked to take part?

We are asking every nurse and healthcare assistant employed by the 'Hospital at Home' service at the Dorset County Hospital to take part.

5. What would happen next if I agree to take part?

- You will be given time to consider before being asked to give written consent by the researcher, who is also a staff nurse from the 'Hospital at Home' team.
- Once this is done you will arrange a suitable time and place to complete the first interview.

6. Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

7. Can I change my mind?

You have the right to change your mind and discontinue or withdraw at any time without giving a reason and without your ongoing and future employment being affected.

If you discontinue you will not take any further part in the study but agree that all your information can be included in the study. If you withdraw from the study, only the information about you that has been made anonymous will be used and only for the purposes of achieving the objectives of the study only.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

8. How will my information be stored and who can see it?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Interviews will be audio recorded and then transcribed. Interview transcripts will be stored in a locked filing cabinet and digital information will be stored on encrypted devices in locked offices. Your data will be anonymised and assigned a pseudonym. Audio recordings will be deleted once anonymised and transcribed.

All anonymised data is required to be kept for 10 years once the research has been completed but will remain anonymised throughout.

9. What else?

- The results of the study will be written up and published. The results will also be discussed at conferences. These will never include the names of people who have taken part, only code names or numbers. You can have a results summary if you wish.
- The study has been approved by the University of Southampton ethics committee and an NHS Research Ethics Committee
- This project is GDPR compliant. The University of Southampton is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that

we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished.

- Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
- The University of Southampton will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Southampton and regulatory organisations may look at your research records to check the accuracy of the research study.
- The only people in the University of Southampton who will have access to information that identifies you will be people who need to contact you to or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.
- If for any other reason you cannot continue your data will be treated as if you have chosen to withdraw from the study.

10. Concerns and complaints

If you have a concern or complaint about the study, please contact the Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk). The University of Southampton has insurance in place to cover its legal liabilities in respect of this study.

Staff participant consent form

Study title: Exploring the effects of social network dynamics on patients receiving 'hospital at home' care in a rural environment.

Researcher name: Jack Gillham
ERGO number: 46874
Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet Version 2.3 25/10/2019 and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw (at any time) for any reason without my participation rights being affected.	
I understand that my personal information collected about me such as my name or where I live will not be shared beyond the study team.	
I understand that should I discontinue or withdraw from the study then the information collected about me up to this point may still be used for the purposes of achieving the objectives of the study only, as per the Participant information sheet Version 2.3 25/10/2019	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used).	
I understand that taking part in the study involves audio recording which will be transcribed and then destroyed for the purposes set out in the participation information sheet.	

Name of participant (print name)………………………………………………………………………………
Signature of participant……………………………………………………………………………………….
Date……………………………………………………………………………………….

Name of researcher (print name)………………………………………………………………………………
Signature of researcher ……………………………………………………………………………………….
Date………………………………………………………………………………………………………

Staff participant Interview schedule

Opening (Establish Rapport) (5 mins)

My name is Jack. As a fellow member of staff from the hospital at home service we've probably already met.

We've met today in a different role to get information about your time working for the service. Try to forget that I work for the service and give me your best and most honest (whether that's positive or negative) answers to help improve the service for future users.

You don't have to answer any questions you don't want to. Ask to stop at any time if you wish.

The interview usually takes 30-60 minutes – is this ok? Thankyou

Check understanding, read the PIS and consent form signed. Remind them it is being recorded.

Body of Interview 1. (Roles and responsibilities) (15 mins)

This part of the interview is about you, your role and the service as a whole. Is this ok?

What is your role in the service?

- What do you do for the service users?
- Anything else you do for them?...consider things beyond the tasks expected of you

What are your thoughts on the service as a whole?

- Strengths and weaknesses?
- Do you think there are challenges to treating patients at home compared to hospital? (Time, physical obstacles, rurality, resources etc.)

What is your understanding on the involvement of the people around the patient during HaH treatment?

  - What do the people do for the patients? How do you know this?
  - What is their involvement with HaH? How do you know this?

  - Does the involvement change over time when HaH are involved…is it different at the start and end of treatment? What makes you think/know this?
  - Is there a difference/affect/relevance depending on who it is? E.g. a neighbour compared to a spouse

[Transition] Great! That's the end of the questions on your role and the role of the service. Is there anything else you would like to add?

Body of interview 2. (Service user experience) (15 mins)

[Check happy to continue]

This section is going to ask you about the experiences of the patients.

Generally, how do you think the service is for patients?

- Is feedback positive or negative? *[explore pros and cons]*
- Considering the pros and cons discussed, what could be done to improve the service?

What do you know and think about the involvement of the people around the patient's (their social network) during their time with the service?

- Do some not have enough support? What happens then? Do staff end up filling gaps in roles that may be filled by friends and family?
- How do patients manage tasks at home?

You said HaH staff help with *[comment from earlier]*. What about when the HaH service ends? Who would help with this then?

- What else do you know and think about happens after HaH involvement ends regarding the patient's ability to cope? And with their ongoing health needs?
- How does discharging them make you feel? Positive and negatives?

[transition] Thankyou! That is the end of this section of the interview. Is there anything else you can think of that might be important regarding the time of discharge and afterwards for patients?

Close (5 mins)

We are reaching the end of the interview now. Is there anything else you'd like to add about your role in the HaH service? What could be done to improve it? Or how it affects patients during and after?

Thank-you so much for taking part, as you know I am involved in a PhD research project and the information you have been given will be really helpful in achieving the aims of it.

As you may remember from the PIS there will be another interview in the future to discuss findings from the patient interviews and I look forward to doing that with you then. I will contact you nearer the time.

9.3 Appendix 3: Patient participant documents

Patient Participant Information Sheet

Study Title: Exploring the effects of social network dynamics on patients receiving 'Hospital at Home' care in a rural environment.

Researcher: Jack Gillham

ERGO number: 26874

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This is a student PhD project conducted by Staff Nurse Jack Gillham under the supervision of principal research fellow Dr Ivaylo Vassilev and senior research fellow Rebecca Band. This project is about the Hospital at Home service you have recently used. It focuses on how the service works, who makes it work for you and what can be done to improve it for future patients.

Why have I been asked to participate?

We are asking everyone being treated by the 'Hospital at Home' service at the Dorset County Hospital to take part.

What will happen to me if I take part?

You will be given time to consider before being asked to give written consent by the researcher, who is also a staff nurse from the ‘Hospital at Home’ team.

Once this is done you will be given the first of two questionnaires to complete on your own. These can be completed online (link below) or on paper and returned in the FREEPOST envelope provided. It is your choice whether you choose to complete online or via post. If you choose the online option the researcher will give you the link to the website. The questionnaire should take about 30 minutes to complete.

The online questionnaire can be found at: https://www.isurvey.soton.ac.uk/37641

You may not hear anything from the research team until you are prompted via your preferred contact route to complete the second questionnaire 12 weeks later. You will be sent this in the post or informed of the web address. This will have lots of, but not all of, the same questions as the first. Again, this can be returned in an pre-addressed FREEPOST envelope if you opt for the postal option. You are welcome to change from online to paper (or vice-versa) if you wish. This questionnaire should also take about 30 minutes to complete.

Finally, you may be approached to take part in an interview with the researcher. This will be an informal discussion about the answers to the questionnaire, how you cope at home with or without support from family and friends, and your experience with the Hospital at Home service. This will take about an hour. This can take place face-to-face or via the telephone depending on your preference.

Are there any benefits in my taking part?

There may not appear to be any immediate benefits to taking part. However, taking part in this research will help gather information on the Hospital at Home service which can help to improve it, and others like it, and therefore improve any future care and treatment you or your family may receive from it.

Are there any risks involved?

The questions within the research ask you about the relationships you have with friends and family, and how they help you cope with your health. You may find talking about this emotional. During interviews, please to tell the researcher if you are feeling distressed and wish to pause, stop or withdraw from the study.

The study will take up to 2 hours (2x 30 minute questionnaires, 1x 1 hour interview) of your time.

What data will be collected?

All data will be collected by the PhD student researcher and Hospital at Home staff nurse, Jack Gillham

The researcher will look at the doctor's records from your current admission to Hospital at Home service to obtain your current medical diagnosis and any other ongoing health problems.

You will be asked to complete two very similar questionnaires. The first when you are discharged, and the second 12 weeks later. The questionnaires will ask you about how you having been coping at home, what help you have received and from whom, and what effect this has had on your health.

If you are approached to take part in an interview, the researcher will ask you questions about your time with, and since discharge from, the Hospital at Home service to get more detail about the answers to your questionnaires. This will focus on your ability to cope with or without support from family, friends and healthcare staff. The interviews will be audio recorded, transcribed word-for-word, anonymised so you cannot be identified and then the audio recordings will be deleted.

The University of Southampton will use your name and contact details, may contact you about the research study, will make sure that relevant information about the study is recorded for your care, and will oversee the quality of the study. Individuals from the University of Southampton and regulatory organisations may look at your research records to check the accuracy of the research study.

The only people in the University of Southampton who will have access to information that identifies you will be people who need to contact you to or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

The questionnaires will be stored in a locked filing cabinet and digital information will be stored on encrypted devices in locked offices. Your data will be anonymised and assigned a pseudonym. Audio recordings will be deleted once transcribed.

All anonymised data is required to be kept for 10 years once the research has been completed but will remain anonymised throughout.

The initial questionnaire will ask for contact details for the purpose of arranging interview. This will be stored securely and not shared with any other parties.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

You have the right to change your mind and withdraw or discontinue at any time without giving a reason and without your participant rights or ongoing and future care being affected. The contact details for the research team can be found at the bottom of this letter.

If you discontinue you will not take any further part in the study but agree that all your information can be included in the study. If you withdraw from the study, only the information about you that has been made anonymous will be used and only for the purposes of achieving the objectives of the study only.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

If you can no longer take part due to health needs and/or cannot give consent to continue your data will be treated as if you have chosen to withdraw.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The results of the study will be written up and may be published. The results may also be discussed at conferences. These will never include the names of people who have taken part, only code names or numbers. You can have a results summary if you wish.

Where can I get more information?

More information can be obtained from any members of the research team.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Jack Gillham (Staff nurse and PhD student researcher)

Email: jhg2g11@soton.ac.uk

Telephone: 01305254944

Dr Ivaylo Vassilev (Chief investigator, principal research fellow and Academic Supervisor to Jack Gillham)

Email: I.I.Vassilev@soton.ac.uk

Dr Rebecca Band (Senior research fellow and Academic Supervisor to Jack Gillham)

Email: R.J.Band@soton.ac.uk

As the sponsor for the PhD project, The University of Southampton can be contacted:

Email: rgoinfo@soton.ac.uk

Telephone: 02380595058

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, ‘Personal data’ means any information that relates to and is capable of identifying a living individual. The University’s data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

The University of Southampton is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you until the research has finished. The unidentifiable data will be kept for 10 years

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you until the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.

Thank you for taking the time to read the information sheet and considering taking part in the research. We will contact you to find out if you would like to take part soon.

UNIVERSITY OF
Southampton

Patient participant consent form

Study title: Exploring the effects of social network dynamics on patients receiving ‘hospital at home’ care in a rural environment.

Researcher name: Jack Gillham

ERGO number:46874

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (09/06/2020 [Version 2.3]) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw (at any time) for any reason without my participation rights being affected.	
I understand that my medical records will be used only to gain information on my current medical diagnosis and other, pre-existing health conditions	
I understand that my personal information collected about me such as my name or where I live will not be shared beyond the study team.	
I understand that should I discontinue or withdraw from the study then the anonymised information collected about me up to this point may still be used only for the purposes of achieving the objectives of the study as per the Participant information sheet (09/06/2020 [Version 2.3])	
I have been informed that it is my choice to complete questionnaires either online or via post (Please indicate choice below) Online ☐ Postal ☐	
I agree to be contacted to be re-consented to take part and for interview by the researcher	

Name of participant (print name)……………………………………………………………………………

Signature of participant………………………………………………………………………………….

Date……………………………………………………………………………………….

Name of researcher (print name)……………………………………………………………………………

Signature of researcher ………………………………………………………………………………….

Date……….

I may be contacted by:

Telephone ☐

Email ☐

Both ☐

Email address ……………………………………………………………….

Telephone number ……………………………………………………………….

Address ………………………………………………………………….

……………………………………………………………..

………………………………………………………………….

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UNIVERSITY OF Southampton

Patient Participant Questionnaire

Hospital at Home Research Project

Thank-you for agreeing to take part in this project that can help to improve the service for users in the future.

Your participation will improve the understanding of how the service works for people, who helps make it work and what the limitations are.

The questionnaire has 6 sections; About you, your abilities to cope with or without support and information about you the people who help you.

How to complete the questionnaire:

- Please read the instructions and questions carefully.
- Fill in the answer which best describes how you feel
- Most questions will ask you to tick a box or circle a number.
- Please try to answer all the questions. If you do not wish to answer the question, please leave this blank.
- Do not spend too long on each question the first answer which comes to you is probably the best one.
- If there are no right or wrong answers. If you are unsure about how to answer a question please put the best answer you can.
- You may wish to take breaks whilst completing the questionnaire.
- The information you provide will remain strictly confidential and will not affect your future treatment.
- Please return your completed questionnaire in the FREEPOST envelope provided.

Section 1: About you

First of all we would like to get some information about you to help us understand your background and how this may have impacted on how the Hospital at Home service has worked for you

Please complete the form below with details about you and your household. Please leave any questions blank that you prefer not to answer.

Full name ……………………………………………

Date of Birth ……………………………………………

Gender ……………………………………………

Ethnicity ……………………………………………

Marital status	Single	☐
	Married/ civil-partnership	☐
	Divorced/ separated	☐
	Widowed	☐
	Co-habiting	☐
Educational level	Primary School	☐
	Secondary School (up to 16)	☐
	College/sixth form	☐
	University	☐

Employment status (please tick)

Full time employment ☐
Part-time employment ☐
Self-employed ☐
Unemployed ☐
Student ☐
Retired ☐
Other (please state) ☐
………………………………………………

Household members (including yourself)

1 ☐
2 ☐
3 ☐
4 ☐
5+ ☐

Section 2: Satisfaction

This section asks you how satisfied you were with the treatment and service you received from the Hospital at Home department.

1. **With 0 being very dissatisfied and 10 being extremely satisfied, how would you rate your experience with the hospital at home team?** Please circle one

Extremely dissatisfied **Extremely satisfied**

1 2 3 4 5 6 7 8 9 10

2. **If they needed hospital treatment, how likely would you be to recommend the Hospital at Home service to friends or family?**

Very unlikely	☐
Unlikely	☐
Neither likely or unlikely	☐
Likely	☐
Very likely	☐

Section 3: Quality of Life

This section asks how you feel about your quality of life including health and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns.

We ask that you think about your life during Hospital at Home treatment. Please circle the most appropriate answer.

During/since Hospital at Home treatment:

1. How would you rate your quality of life?
   Very good   Good   neither good or bad   Bad   Very bad
2. How satisfied are you with your health?
   Very Satisfied   Satisfied   neither satisfied or   dissatisfied   Very
   dissatisfied
   dissatisfied
3. To what extent do you feel that physical pain prevents you from doing what you need to do?
   Not at all   a little   a moderate amount   very much   extremely
4. How much do you need any medical treatment to function in your daily life?
   Not at all   a little   a moderate amount   very much   extremely
5. How much do you enjoy life?
   Not at all   a little   a moderate amount   very much   extremely
6. To what extent do you feel your life to be meaningful?
   Not at all   a little   a moderate amount   very much   extremely
7. How well are you able to concentrate?
   Not at all   a little   a moderate amount   very much   extremely

8. How safe do you feel in your daily life?
   Not at all a little a moderate amount very much extremely

9. How healthy is your physical environment?
   Not at all a little a moderate amount very much extremely

10. Do you have enough energy for everyday life?
    Not at all a little a moderate amount mostly completely

11. Are you able to accept your bodily appearance?
    Not at all a little a moderate amount very much extremely

12. Have you enough money to meet your needs?
    Not at all a little a moderate amount very much extremely

13. How available to you is the information that you need in your day-to-day life?
    Not at all a little a moderate amount very much extremely

14. To what extent do you have the opportunity for leisure activities?
    Not at all a little a moderate amount very much extremely

15. How well are you able to get around?
    Very poor poor Neither poor or well well very well

16. How satisfied are you with your sleep?
    Very Satisfied Satisfied neither satisfied or dissatisfied dissatisfied Very dissatisfied

17. How satisfied are you with your ability to perform your daily living activities?
    Very Satisfied Satisfied neither satisfied or dissatisfied dissatisfied Very dissatisfied

18. How satisfied are you with your capacity for work?
    Very Satisfied Satisfied neither satisfied or dissatisfied dissatisfied very dissatisfied

19. How satisfied are you with yourself?

Very Satisfied	Satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied

20. How satisfied are you with your personal relationships?

Very Satisfied	Satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied

21. How satisfied are you with your sex life?

Very Satisfied	Satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied

22. How satisfied are you with the support you get from your friends?

Very satisfied	Satisfied	neither satisfied or dissatisfied	dissatisfied	very dissatisfied

23. How satisfied are you with the conditions of your living place?

Very Satisfied	Satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied

24. How satisfied are you with your access to health services?

Very Satisfied	Satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied

25. How satisfied are you with your mode of transportation?

Very Satisfied	Satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied

26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?

Very rarely	rarely	neither often or rarely	often	Very often

Section 4: Self efficacy

In this section, we would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly during Hospital at Home treatment. Please circle the correct number.

1. How confident do you feel that you can keep the fatigue caused by your disease from interfering with the things you want to do?

Not at all confident very confident

1 2 3 4 5 6 7 8 9 10

2. How confident do you feel that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

Not at all confident very confident

1 2 3 4 5 6 7 8 9 10

3. How confident do you feel that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

Not at all confident very confident

1 2 3 4 5 6 7 8 9 10

4. How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

Not at all confident very
confident

1 2 3 4 5 6 7 8 9 10

5. How confident do you feel that you can achieve the different tasks and activities needed to manage your health condition to reduce your need to see a doctor?

Not at all confident very
confident

1 2 3 4 5 6 7 8 9 10

6. How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

Not at all confident very
confident

1 2 3 4 5 6 7 8 9 10

Section 5: Collective efficacy

We would like you to think about the people around you that are important in helping you manage your everyday needs during treatment by the Hospital at Home team. This could include family members, friends, neighbours, colleagues, members of hobby and interest groups, health professionals (including Hospital at Home staff) and acquaintances.

Please answer each question by circling the answer (1, totally agree – 5, totally disagree) which you think is closest to your experiences over the last year. Don't spend too long thinking about each question; your first reaction to each item will probably be most accurate. If there is anything unclear or you would like to comment on a particular question, please feel free to make a note in the space below each question.

1. **With my health in mind, there are people around me who know how to support me**

   1 2 3 4 5

2. **I do not ask for practical help from the people around me even when I need it**

   1 2 3 4 5

3. **There are people around me who fully understand what I can and cannot do**

   1 2 3 4 5

4. **Most of the people around me are able to see when I need help**

   1 2 3 4 5

5. **I find it difficult to accept that I may need help from others**

   1 2 3 4 5

6. **People around me help me to maintain a healthy lifestyle**

   1 2 3 4 5

7. **In critical situations, I can rely on the people around me for help**

1 2 3 4 5

8. **People around me try to find solutions to the problems I am facing**

1 2 3 4 5

9. **People around me will work together if they think that I need help**

1 2 3 4 5

10. **I don’t expect support from people around me because they have problems of their own**

1 2 3 4 5

11. **I do not ask for emotional help from the people around me even when I need it**

1 2 3 4 5

12. **People around me are able to adapt when my needs change**

1 2 3 4 5

Section 6: Loneliness

This section also asks you to think about your social relationships whilst admitted to the Hospital at Home service. Think about all aspects of your life not only your health needs.

Please tick the appropriate box.

Question	Yes	More or less	No
1. I experience a general sense of emptiness			
2. There are plenty of people I can rely on when I have problems			
3. There are many people I can trust completely			
4. I miss having people around me			
5. There are enough people I feel close to			
6. I often feel rejected			

Section 7: Your social network

This section asks you to list all the people who have support you whilst you have been treated by the Hospital at Home service.

This can include anyone from friends, family and neighbours to healthcare staff, pets and members of social groups or teams.

We would like to know their gender, relationship to you, how often you see them and how far away they live from you.

Network member number	**Member name** (initials)	**Gender** (1 male, 2 female)	**Relationship** (e.g. daughter, cousin, GP, friend, pet)	**How often do you see them?** 1= at least once a week 2= at least once a month 3= every couple of months 4= less often	**How close do they live to you?** Approx. in miles
example	PG	1	neighbour	[✓ 1] 2 3 4	0 miles
1				1 2 3 4	
2				1 2 3 4	
3				1 2 3 4	
4				1 2 3 4	
5				1 2 3 4	
6				1 2 3 4	
7				1 2 3 4	
8				1 2 3 4	
9				1 2 3 4	
10				1 2 3 4	
11				1 2 3 4	
12				1 2 3 4	
13				1 2 3 4	
14				1 2 3 4	
15				1 2 3 4	
16				1 2 3 4	
17				1 2 3 4	
18				1 2 3 4	
19				1 2 3 4	
20				1 2 3 4	

In relation to the network members you have just listed in the table above, we would now like to know what they have helped you with and how much. Think about this is relation to the time you have been treated by the Hospital at Home service.

There are three groups:

1) health related support
2) help with practical tasks and chores
3) emotional support

	Rate the level in which each network member helps you with: **(1= No help, 2= Some help, 3= A lot of help)**		
Network member **(numbered from previous page)**	**Information or tasks relating to your health**	**Practical tasks** **(e.g. shopping, cleaning)**	**Emotional support** **(e.g. company, talking about worries)**
example	**1 [✓ 2] 3**	**[✓ 1] 2 3**	**1 [✓ 2] 3**
1	**1 2 3**	**1 2 3**	**1 2 3**
2	**1 2 3**	**1 2 3**	**1 2 3**
3	**1 2 3**	**1 2 3**	**1 2 3**
4	**1 2 3**	**1 2 3**	**1 2 3**
5	**1 2 3**	**1 2 3**	**1 2 3**
6	**1 2 3**	**1 2 3**	**1 2 3**
7	**1 2 3**	**1 2 3**	**1 2 3**
8	**1 2 3**	**1 2 3**	**1 2 3**
9	**1 2 3**	**1 2 3**	**1 2 3**
10	**1 2 3**	**1 2 3**	**1 2 3**
11	**1 2 3**	**1 2 3**	**1 2 3**
12	**1 2 3**	**1 2 3**	**1 2 3**
13	**1 2 3**	**1 2 3**	**1 2 3**
14	**1 2 3**	**1 2 3**	**1 2 3**
15	**1 2 3**	**1 2 3**	**1 2 3**
16	**1 2 3**	**1 2 3**	**1 2 3**
17	**1 2 3**	**1 2 3**	**1 2 3**
18	**1 2 3**	**1 2 3**	**1 2 3**
19	**1 2 3**	**1 2 3**	**1 2 3**
20	**1 2 3**	**1 2 3**	**1 2 3**

Thank-you for taking time to complete the questionnaire. The information you have shared will be very helpful to help answer the questionnaires that can be used to improve the service for the future.

Please return in the FREEPOST envelope provided.