A study of sense-making strategies and help-seeking behaviours associated with the use and provision of urgent care services

1. Aims and objectives

To identify sense-making strategies and help-seeking behaviours which explain the utilization of urgent care services to assist commissioners, healthcare professionals and service managers in their decision-making in a complex urgent care landscape.

1. To describe how patients, the public, providers (professionals and managers), and shapers (commissioners and policy makers) define and make sense of the urgent care landscape.
2. To explain how sense-making influences help-seeking strategies and patients’ choices in accessing and navigating available urgent (and emergency) care services
3. To analyse the ‘work’ (the ‘burden of treatment’) for patients involved in understanding, navigating and choosing to utilize urgent care
4. To explain urgent care utilization and identify modifiable factors in urgent care patient decision making

2. The changing landscape of urgent care in England

A recent report from the Keogh review has described urgent care as ‘for those people with urgent but non-life threatening needs’ with the goal of delivering ‘care in or as close to peoples’ homes as possible, minimising disruption and inconvenience for patients and their families’ (1). In England, urgent care includes a range of specific services for patients with a need (or perceived need) for care that is unscheduled, that is, healthcare that cannot be foreseen or planned before contact with a healthcare professional or service is made. Urgent care services include GP out-of-hours, minor injuries units, NHS walk-in centres and more recently, NHS 111. There is a recognised overlap between urgent and emergency care help-seeking so it is therefore important to consider urgent care in the wider context of an urgent and emergency care ‘system’ which includes ambulance services and hospital emergency departments (EDs).

There has been a growing pressure on EDs and 999 services (2) and research suggests that many patients that present to emergency care could be treated elsewhere, for example, in urgent care or in general practice. Between 12% (3) and 40% of emergency department attendances are described as ‘inappropriate’ (4), and some 40% of patients are discharged without treatment (2). Up to 50% of 999 calls requiring an ambulance to be dispatched could also be managed at the scene (2). In response to concerns about demand, the NHS has been encouraged to exploit ‘opportunities for bringing about a shift from hospital to home [by] greatly enhancing urgent care services provided outside of hospital’ (2). New and additional services, such as NHS Walk-in centres, extension of community pharmacist roles and the telephone-based NHS 111 service, have changed the landscape of urgent care, which previously was provided almost entirely within general practice. NHS 111 in particular was conceived to direct patients to the most appropriate service for their needs (5) and to overcome confusion about which service to contact by providing a centralised, accessible entry point

(6, 7). It was hoped that the addition of new services would reducing demand for emergency services but in the case of NHS 111 there is limited evidence that this has been achieved (8).

Guiding patients to 'get the right advice in the right place, first time' (7), reducing unnecessary emergency department attendances by providing more responsive urgent care services and providing better support for people to self-care has increasingly been the focus of national and local health policy (1, 2, 7). However, effective service provision requires a much deeper understanding of the factors that influence patients' help-seeking and choices. This project seeks to address the gaps in this evidence base to inform commissioners, providers and policy decision makers.

3. Review of the literature

Research that has examined the use of emergency services for 'non-urgent' or primary care reasons (9-13), suggests that there may be a mismatch between service provision and patterns of service use, and in turn, a potential disconnect between how patients/users define urgent care and how policy makers and service providers define it. Much of what we know about how patients and health professionals make sense of urgent and emergency care is derived from a sizable literature about the 'inappropriate' use of health services (3, 4, 14-17). This somewhat judgemental term is most commonly defined from the perspective of clinicians and service providers (18). There are inherent difficulties in defining what is inappropriate or unnecessary since service commissioners, policy makers, providers, clinicians and patients may hold different viewpoints.

Patients' decisions to access urgent and emergency care have been attributed to poorer access to primary care and preventative care (19-25) but it is clear that there are a range of processes that are likely to underlie attitudes and behaviours that influence help-seeking. Findings from the literature have suggested that health professionals and patients judge the severity and urgency of a condition differently (12, 26, 27). Furthermore healthcare professionals themselves do not always agree on what constitutes 'inappropriate' use (28-30). A recent qualitative study of ambulance service use suggests that many 999 calls are made on the basis of 'fundamental misconceptions about the types of treatment other urgent care avenues can provide' (11). However, whilst healthcare professionals may deem some service use as 'inappropriate', patients often have clear rationales for help seeking, even for symptoms that may be perceived as 'trivial' (9, 12, 31).

There are few studies that have directly compared patient and health service / professional conceptualizations of urgent or emergency (12, 32). One notable exception is a recent Australian study (32) which concluded that, although there was no significant difference between patients' perceptions of the urgency of their problem and the triage score allocated at the ED, health professionals and patients had different perspectives on what constitutes an emergency and when emergency health resources should be used. Health professionals based their assessment on knowledge and physiological measures whilst patients used 'socio-emotional' cues. A body of literature exists that has examined decision-making in relation to urgent care services, such as GP out-of-hours (31, 33-37), but there is little research about how patients understand and conceptualize urgent care. Furthermore, whilst we know that there is greater demand on urgent and emergency care from particular groups of patients, such as parents of young children (10, 13, 38, 39), those with long term conditions (40, 41), the elderly (42), and those from deprived populations (3) we do not know if specific populations differ in their conceptualization of ‘urgent’. Patients/the public, providers (professionals and managers), and shapers (commissioners and policy makers) may conceptualize urgent care differently. In this study, we will use a sense making perspective to describe, identify and explain differences in sense making. We will then examine how sense-making influences help-seeking strategies and patients’ choices in accessing and navigating available urgent (43) (see section 6).

Within the NHS, patients are required to distinguish between ‘routine’ (e.g. daytime general practice), ‘urgent’ (e.g. NHS 111, out-of-hours, walk-in centres) and ‘emergency’ (e.g. ED, 999) but it is not clear how patients, providers and policy makers differentially understand the alternative types of care, the services available and their expectations of them. This is important as these will influence whether or not people go on to use the services as providers might expect. Care that is categorised as urgent, emergency or unscheduled care are concepts used by policy-makers and service providers but it is unclear how meaningful these concepts are to patients when they are making decisions about what to do about a (real or perceived) healthcare need.

More recently, policy has focused on emphasizing minimising disruption and inconvenience for people using urgent care (1), partly achieved by providing care at ‘right time, first time’ and by providing better support for people to self-care (so that people who prefer can avoid the need to see a health professional). It is therefore timely to examine in detail the ‘work’ that patients are required to do to access and navigate the urgent care system. Studies suggest that patients may be unaware or confused about which service to use, and are often unsure about the appropriateness of their call to urgent (44) and emergency services (11), indicating that there may be burden for patients when deciding to seek help. Evidence suggests that some patients may choose emergency services over urgent care services because they perceive that the ED (45) or emergency ambulance services (11) are more responsive to their needs or are more convenient (19). Patients have reported ‘battling’ or ‘struggling’ to access urgent care services with additional difficulties in finding transport (11). A French study that has explored the use of EDs with ‘non urgent’ problems found that convenience was a major factor in choices between services, with perceptions that EDs provided access to technical facilities and the opportunity to receive care in a single location. Perceived availability of appropriate treatment / medication in a single location appears an attractive attribute for many patients (12, 20) in that the ED offers advantages as it ‘spare[s] patients the complexities of making several appointments in different places, and from being overwhelmed with organizational concerns’ (12). These studies indicate that there could be considerable work required by patients with urgent care needs to access, negotiate and participate in advice and treatment.

Concepts of ‘minimally disruptive medicine’ (46) and the ‘burden of treatment’ (i.e. the workload delegated to the patient by health professionals and services), can include accessing and organizing contacts and appointments, self-care and managing therapeutic regimens (47-50). Until now, these concepts have mostly been applied to patients with long-term conditions. However, we believe that these concepts provide a useful and novel framework for thinking about notions of patient ‘workload’ for those using urgent care when considering convenience and ‘minimal disruption’ (see section 6). It is not clear what role burden of treatment plays in patient (and health professional) decision making in urgent care, or whether the way in which urgent care is organised and delivered increases or reduces treatment burden for patients.

4. Need for the research

The research evidence to date contributes to understanding some of the ways that health professionals and patients conceptualize emergency and (to a lesser extent) urgent care, and some of the factors that influence the use of urgent care. However, there are issues that need further attention. Firstly, explanations are required to understand the potential mismatch in how definitions and meanings of urgent care differ between service users on the one hand and service providers and policy makers on the other, and whether differences can explain variations in perceptions of appropriateness about service use. Secondly, recent policy has suggested that there should be a focus on providing urgent care services that ‘minimise disruption and inconvenience’ for patients (1). In this new and complex urgent care landscape the ‘work’ that patients are required to do (burden of treatment) to make sense of, access, and navigate urgent care may be unclear. Further, we do not know if this in turn impacts on whether or how urgent care services are used. Perceptions of burden of treatment have implications for the decisions and the choices that patient make when using urgent care. A better understanding of this would inform how services might be tailored to the needs of particular user groups. Thirdly, whilst policy has increasingly focussed on supporting patients to self-care as a key part of urgent care, this may be challenging where patients lack capacity to cope or experience high burden of treatment.

Research is needed on to understand how urgent care is differentially defined and understood by different groups, and how this influences help-seeking behaviours and perceptions of ‘treatment burden’. A clear conceptual framework of sensemaking and help-seeking for NHS managers and commissioners will provide the foundation for informing health care planning. By identifying the modifiable factors that affect urgent care patient decision making, it allows the identification and implementation of future interventions. The proposal addresses current policy aims and will inform the goals set out in the most recent policy review of urgent and emergency care (1, 2), notably, the emphasis on self-care, right time right place, and minimising disruption and inconvenience for patients. However, there is also wider applicability in that the study will generate theory around understandings and behaviours that are theoretically generalizable in explaining patients’ understanding urgent care help-seeking, choices and service utilization in complex healthcare systems.

5. How does this project build on our previous work and other work?

This proposal extends our previous research HS&DR 10/1008/10, completed in 2012 (51) and 08/1819/217, completed in 2010 (52). The first of these examined the use of a single computer decision support system (CDSS) called NHS Pathways used in three different urgent and emergency care settings, focussing on how call handlers triaged and managed patients seeking 999 ambulance services and/or out-of-hours urgent care. NHS Pathways is the technology that underpins NHS 111 and one of the sites studied in this project was the first to use this technology in a single point of access service for urgent care. The second project expanded on this to examine work and workforce implications of NHS 111 and was able to look both at the telephone service itself, the technologies used and the wider network of urgent care provided in primary care. Both these studies have provided us with a deep and detailed understanding of the new NHS 111 services and insights into the provision of both urgent and emergency care in the English NHS. The questions to be addressed by the current proposal come directly out of this work, as we now seek to move beyond our organisational focus and explain how patients seek help and make choices in the increasingly complex landscape of service provision. This is the next vital step in building the evidence base necessary for effective service commissioning and provision. Our analysis of call-handling to urgent care single point of access and out-of-hours services, to 999 and NHS 111 suggests that there is confusion and variation in perspectives and experience of patients and the public about these services. For service providers this surfaces concern about ‘inappropriate’ service use and legitimacy and it also impacts on the workforce providing care - be it at the end of a phone, as a paramedic or in an urgent care service. Much of the existing research exploring patient help seeking predates the expansion in the range of urgent care services offered and all of it predates the introduction of NHS 111 recent changes in primary care configuration. The proposed project therefore fills a significant gap in the evidence base for urgent and emergency care.

This proposal draws on, and has strong links to May’s previous work including HS&DR 08/1602/135: *Understanding the implementation and integration of E-Health Services* (53). It draws on theoretical models of Minimally Disruptive Medicine/Burden of Treatment (46, 48, 50) and Normalization Processes in technology adoption and utilization (54) developed by May and colleagues from this HS&DR project and other work (55, 56). By analysing patients experiences of urgent care we seek to both understand the work required by patients to make sense of and navigate health care (i.e. the burden) and the ways in which service innovation and changes in provision (including the use of new technologies like NHS Pathways) have become routine and embedded (i.e. normalized) as strategies for managing health care needs. The research team is fortunate to be based in the NIHR CLARHC Wessex and the project has close links with the *Complexity and Patient Experience and Organisational Behaviour* programme of work within the CLAHRC (led by May) (57) which seeks to better understand interactions between health services and patients with long-term and life-limiting conditions in the context of cycles of hospital admission and readmission through unscheduled care. The proposed project will provide important empirical tests of the theoretical models adding value to this previous work, and extend knowledge of patient experiences to augment the current programme within the CLAHRC.

As well as building on previously funded research by members of the proposed team, this project also has significant links to other newly funded work including NIHR HS&DR 12/128/48 which is exploring the provision of 24/7 care (58), as well as recently completed NIHR HS&DR 10/1010/08 (51) which examined characteristics of emergency and urgent care system effects on unplanned admissions. Our proposal has been developed to augment these by developing explanations for patterns of utilization of urgent care.

6. Conceptual framework

The conceptual framework for the study is that service users, professionals and providers are working within a *system* of emergency and urgent care. Urgent care services are part of a complex landscape that includes GP out of hours, walk-in centres, and NHS 111, and has considerable overlap with EDs and 999 services (as well as wider links with other services such as general practice, pharmacies and social care). A better understanding is needed of how different groups understand and define urgent care, and how these definitions and understanding affects decision making, choices and the use of urgent care.

We believe that there may be differences in how the public, providers (professionals and managers), and shapers (commissioners and policy makers) define and make sense of the urgent care landscape. Sensemaking perspectives (43) will be employed to help us gain insight into contested definitions and meanings of urgent care and how this might influence peoples' attitudes and behaviours around service use (Objectives 1 and 2). When people make decisions about using particular health services, patients justify these to themselves and to the service they are using. The sensemaking perspective allows these processes to be examined in the context of beliefs, values, culture and language (43, 59). This perspective is particularly focused on the social construction (through individual and group narratives and processes) in collective sensemaking allowing us to identify if there are differences according to who is defining and making sense of urgent care and will allow us to consider patient, decision making help-seeking behaviour and choices beyond 'appropriate' or 'inappropriate' service use.

The proposal is also informed by burden of treatment theory, which will help us in thinking about the 'work' that people might experience in understanding, navigating and choosing to utilize urgent care (Objective 3). Burden of treatment has mostly been used in relation to people managing long term conditions (47, 48, 50). It specifically describes the 'workload of health care as well as its impact on patient functioning and well-being' (50). It proposes that the complex interaction of these demands might disrupt patient access, utilization and self-care where such workload exceeds the patient's capacity to cope (48, 49). Overload can lead to worsening of symptoms, reduced use of services or of the best service to suit their need, and a reduced ability to self-manage their illness(es). The potential workload involved in accessing and using urgent care services has not previously been considered in this way. Our proposal therefore provides a novel perspective for understanding patient decision making and behaviours concerning choice of services, and decisions about contacting urgent care.

7. Methods

This study is a mixed methods sequential design consisting of three sequential work packages (WP). The flow diagram (Appendix 1) illustrates how these fit together. The first work package (WP1) comprises a literature review and citizens' panels with service users and healthcare professionals to describe and explain how patients and the public, providers (professionals and managers), and shapers (commissioners and policy makers) define and make sense of the urgent care landscape (Objective 1). The second work package (WP2) comprises serial qualitative interviews to examine the role of sense making in patient help-seeking strategies accessing and navigating available urgent (and emergency) care services (Objectives 1 and 2) and to identify and describe the 'burden of treatment' for people navigating and using urgent care (Objective 3). Finally, in WP3 we will undertake an integrative analysis to construct a conceptual model of urgent care help-seeking behaviour that will explain urgent care utilization and identify modifiable factors that affect urgent care patient decision making (Objective 4).

Methods will be integrated primarily in two ways. First developmentally - the findings from one work package will inform the design and analysis of subsequent components. The literature review will inform the development of the citizens’ panel and the qualitative interviews. Secondly, as part of the integrative analysis, the results will be integrated by exploring convergence and contradiction in the results derived from different methods - a process of ‘crystallisation' to provide a more comprehensive account than offered by a single method (60).

7.1. Work package 1: Literature review and citizens’ panels. Describing and identifying public, providers policy makers definitions and sense making of urgent care (Objective 1)

This work package comprises a literature review, followed by two citizens’ panels. The literature review will generate meanings and definitions of urgent care from the multiple perspectives of policy makers, service providers and patients/the public. These meanings and definitions will then be debated in two citizens’ panels - one group of citizens (the public) and one group of health providers (professionals and commissioners). Sense making perspectives (43, 59) will be used to gain insight into contested definitions and meanings of urgent care, which are likely to have implications for peoples’ attitudes and behaviours associated with the use of urgent care services.

Literature review

A structured review of the published literature since 1990 will be undertaken. This will address the following question:

- How do service users (patients and public), providers (professionals and managers, and shapers (commissioners and policy makers) define and understand urgent care *differently*?

Relevant evidence will include policy documents as well as published empirical research. The scope of the research literature will include: (i) patient and professionals’ perceptions of urgency and the use of urgent and emergency services (ii) help-seeking in relation to urgent and unscheduled care services (including GP out-of-hours, urgent telephone based services such as NHS 111 and NHS Direct, walk-in centres) (iii) ‘non-urgent’ use of urgent and emergency services.

Policy documents and other grey literature will be examined to describe how policy makers have defined and conceptualized urgent care over the last 25 years. Key policy documents will include Department of Health, Scottish Government and other reports (e.g. National Audit Office, House of Commons Committees reports) that relate to the delivery of urgent or unscheduled care. Wider policy documents dealing with health care delivery will also be included where relevant (e.g. NHS Plan in England, White Papers). Reviewing this literature will be an important part of drawing out how different groups of stakeholders define and understand ‘urgency’ and ‘urgent care’.

A review team will be established at the start of the project to develop and then manage and conduct the review. This team will be further supported by the advisory panel which will include members of CCGs with particular expertise in urgent and emergency care provision, patient representatives and experts in research methods.

The review will include eight stages:

1. *Refining the review question*: The refinement of questions and concepts to be addressed in the review.
2. *Defining inclusion criteria and identifying research and policy evidence:* The review will consider policy documents and empirical research published since 1990 relating to urgent and emergency care (e.g. GP out-of-hours; NHS Direct; Walk-in centres; minor injuries units; EDs; ambulance services). During the 1990s there were numerous policy and service developments that radically changed the urgent and unscheduled care landscape. New services were launched (e.g. NHS Direct; minor injuries units) and changes occurred in the provision of existing services (e.g. the rise in popularity of GP cooperatives). Where documents and research identify key documents published prior 1990 these will also be considered for inclusion.
3. *Data Extraction:* Searching for empirical literature using electronic databases such as MedLine, CINAHL, Web of Knowledge.
4. *Quality assessment:* Empirical literature will be appraised against quality criteria.
5. *Primary documentary analysis of policy:* Policy documents will be subjected to primary documentary research to discern policy and service provider meanings of urgent and unscheduled care.
6. *Data synthesis:* Comparison of findings from the literature review with empirical data collected in the study; mapping of policy timelines about policy and service developments to examine how definitions and sense making have changed over a period of time.
7. *Consideration of findings for wider study*: The literature review findings will be used to complement and shape the focus of the study, and conduct subsequent data collection, including the citizens’ panels (WP1), and the interview study (WP2), where we can further explore the meanings and definitions of urgent care with empirical data collected from service users (WP2) and health care professionals / providers (citizens’ panels in WP1). From this work, we can refine the concept of urgent care.
8. *Dissemination:* See dissemination plans (section 10).

Citizens’ panels

Two citizens' panels (61) - one group of members of the public and one group of health providers / professionals - will be convened to debate and offer direction about how to define and conceptualize urgent health care. Citizens’ panels permit participants to ‘engage with evidence, deliberate and deliver recommendations on a range of complex and demanding topics’ (61). Each panel will take place over one day and between 10 and 15 participants will be recruited to each. Participants for the ‘public’ panel will be recruited, drawing on contacts and networks known to our local South Central RDS, to reflect the diversity of the community in the chosen study setting. They will act as independent citizens rather than experts or patient representatives. Healthcare professional and provider participants will be recruited from local healthcare settings.

For each panel, the day will include introducing participants to the aims of the panel and supporting introductory material will be given (this will include policy statements about urgent care, and findings generated from the literature review).

The panel will explore a set of questions which will be developed by reference to the literature review. The sorts of questions that the panel will debate include:

- How would you like to see urgent care described and defined?
- Are there circumstances in which urgent care services are particularly appropriate (or inappropriate)?
- What benefits and risks do you think that urgent care services have for i) patients ii) healthcare providers?
- What principles would you wish to see underpinning developments in the provision of urgent care services?

Additional structured elements will be introduced during the day to stimulate and guide discussion. These may include small group work and hypothetical scenarios derived from the literature review. The panels will explore examples of urgent care definitions, decision making and may also draw on web links, video and other visual resources as prompts.

Members of the research team will adopt a neutral role facilitating participation to ensure that discussion stays on-topic, and to derive recommendations and reach a consensus. We will be flexible about the timing of the public panel, possibly holding this on a weekend to ensure attendance from the widest range of participants possible (a range of ages, gender, education, socio-economic groups). The proceedings from the day will be recorded by contemporaneous notes by organisers and audio recordings, and additional data may include workbooks and flip charts used in the discussions. These data will be analysed qualitatively, using content and thematic approaches as appropriate. Outputs will include summaries of panel conclusions as well as analyses that will feed into our understandings of sense making and knowledge of services.

7.2. Work package 2: Serial qualitative interviews. Identifying and explaining patient help-seeking strategies, choices and workload in accessing and navigating available urgent care services (Objectives 1-3)

This work package will examine patients' decision making surrounding the use of urgent care services to provide unique and detailed insights about how patients make sense of the contemporary urgent care landscape, examine how they consider and make choices between services offered and analyse the work that they have to do to navigate and access urgent care. This work package will address Objectives 1-3. In order to obtain the rich description and understanding required, we propose to conduct qualitative semi structured interviews at two time points, with three carefully selected groups of service users that reflect a diversity and range of experiences of urgent care need.

We propose to conduct two interviews with each participant so that we can overcome some of the weaknesses associated with 'one shot' interview studies. The use of serial qualitative interviews (62) is a convenient and effective approach for building rapport and relationships between interviewee and interviewer to explore complex processes, and to generate the kinds of private accounts that may not be revealed in a single interview (63). Our focus on the complex interactions between sense making, understanding and navigation of the healthcare system, and choice /decision making necessitates this longitudinal approach. This design will also add a prospective dimension to the study, offering the respondents and researcher time and space to reflect on and revisit topics from the initial interview, and capture changes that occur between time points.

Study setting

Work package 2 (as well as the citizens’ panels in WP1) will centre on a geographical area served by a single NHS 111 provider (South Central). This area takes in four counties (Oxfordshire, Berkshire, Hampshire and Buckinghamshire) that are diverse in their geographic and demographic characteristics. By selecting an area covered by a single NHS 111 provider we have recognised, fixed geographical boundaries which also ‘make sense’ in the structure of the NHS service provision. Our familiarity with this setting and clear, established boundaries means that we have a good knowledge of the range of urgent and emergency care services available (GP out-of-hours services, walk-in centres, minor injuries units, community pharmacy and Emergency Departments). In addition, the area we propose to study is broadly coterminous with 17 Clinical Commissioning Groups (CCG) so we will be able to compare and contrast the ways these groups and processes have influenced service provision.

Whilst these counties are not the most socio-economically deprived when compared with other parts of the UK, this area includes pockets of deprivation and some Lower Super Output Areas are in the most deprived quintile nationally (e.g. parts of Portsmouth, Southampton, Reading, Milton Keynes). It also contains areas that are in the most affluent (e.g. Wokingham, New Forest, Aylesbury) categories. The area includes major cities (such as Portsmouth, Southampton, Oxford) and a good mix of accessible and more remote rural areas.

Sampling and recruitment

To ensure a broad range of participants in terms of socioeconomic and demographic characteristics, we will purposively sample from the three specific populations outlined below, who represent and display particular features of urgent care need and or use. The literature suggests that heavy users of urgent and emergency care include parents of young children (3), older patients (42), and those with chronic or multiple comorbidities (24, 40). Other groups that may be vulnerable and experience difficulties accessing service include particular ethnic groups and those with language and literacy challenges. There is some evidence that some ethnic groups are less likely to use urgent care and more likely to use emergency care (64), although this is contested (65).

We will make a final decision about the groups to be interviewed following the literature review and we will also review routinely collected data from urgent and emergency services to support the sampling decisions. At this stage, we believe that three groups of service users needed to reflect variation and diversity of sense making and experience surrounding urgent care. Two groups have been chosen to reflect populations with known high health care needs (patients with multiple co-morbidities and the oldest old). The third to represent a group that are known to be growing in the local context, who may be vulnerable in because of lack of familiarity with health services (66) and/or because of specific language/literacy barriers associated with not having English as a first language (East European migrants). We recognise that there may be some overlap between these three groups but the work package is designed to ensure maximum variation sampling across these three selected groups.

The proposed interviewees will include:

i) *Patients with multiple conditions:* this is a growing group of people requiring health care in the proposed setting and in the wider UK. The number of people with three or more long-term conditions is predicted to rise to 2.9 million by 2018 (67). This is a group that is poorly understood because so much research (particularly qualitative studies of patient experience) has focused on single diseases. It is a population that is identified with rising demand for emergency and urgent care (68).

ii) *Oldest old:* one of the most significant demographic changes experienced in the UK is the ageing population, and the associated increase in populations aged over 65 and over 85. The latter group, the oldest old are often physically and or cognitively frail and are known to have higher rates of attendance at emergency departments and to make greater use of urgent care services (69). We also know that the prevalence of long term conditions is increasing with the ageing population. Yet this is a group which is under researched and for whom we lack evidence about help seeking and decision making around health service use (70).

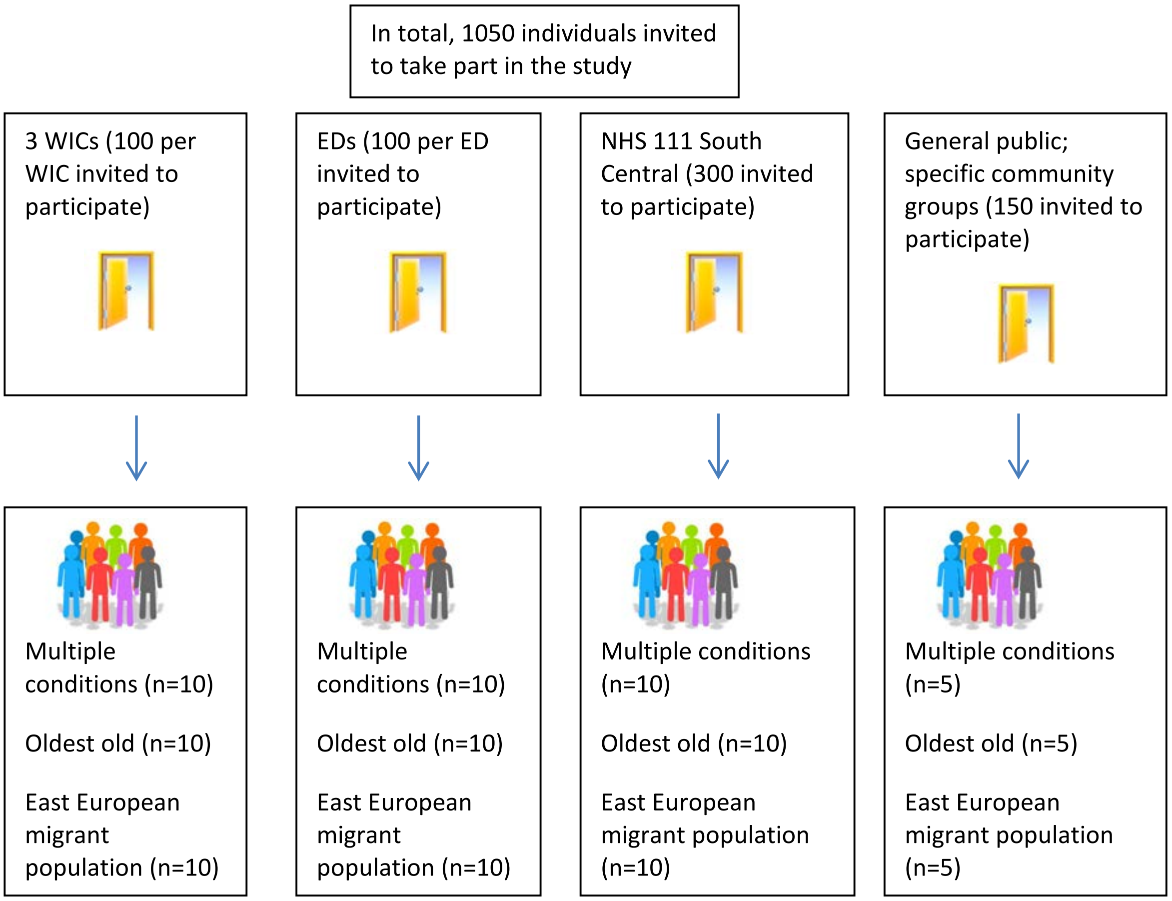
iii) *East European migrant population:* since the opening up of EU borders for migration in 2004 there have been some profound changes to the population of England, notably the major towns and cities in our chosen setting. In 2004 the Accession 8 (A8) countries - Poland, Slovakia, the Czech Republic, Slovenia, Hungary, Latvia, Lithuania and Estonia were granted rights of free movement across EU member states and some areas have been identified as having significant increases in migration in the years that followed notably by Polish nationals (it is estimated that 69% of migration from A8 into the UK has been from Poland). There have been relatively high rates of Polish and other A8 migration into the major towns and cities in our chosen setting, and interestingly some of the rural areas encompassed in our setting have experienced their first international migration from these East European Countries (71). This is a new population grouping and as a result we have little research evidence about their health needs, knowledge of, and use of urgent and emergency care (72, 73).

In qualitative interview studies it is always difficult to gauge in advance 'how many' is enough (74) when making sampling decisions. As with all qualitative research approaches the goal of sampling is not to enable statistical representativeness to all population groups but to provide the necessary detail and nuanced understanding of sense making and choices about urgent care and to capture the work associated navigating and accessing urgent care. From past experience we are aware that purposive samples allow us to access a range of different experiences and capture rich, detailed data about patient beliefs, attitudes and experiences, and reported behaviours. Recognising the need for some flexibility qualitative sampling the numbers below should be considered as close approximations (the totals may vary by ± 20).

To obtain an adequate final sample of completed serial qualitative interviews we aim to conduct a minimum of 160 interviews in total. We will recruit 35 people from each of the three population groups for the first interview (total 105). Allowing for attrition of up to one third in each group we will aim to interview at least 20 from each of the three groups for the second interview. This will provide a minimum core group of at least 60 people interviewed twice. The set of first interviews will also be substantial enough to enable rigorous comparative analyses.

To obtain our sample and ensure maximum variation we will purposively sample from service users of urgent and emergency health services (ED, WIC, NHS 111). We will widen the recruitment to target the general public and specific community groups (using a combination of community based advertising, direct invitation via CCG patient lists and snowball sampling) (Figure 1) as necessary to meet sample targets. Participants identified from NHS 111 callers will be drawn from the South Central area (counties of Hampshire, Berkshire, Oxfordshire, Buckinghamshire). We will work with three EDs and three WICs (across the South Central area) to identify attenders from the population groups to invite to take part in an interview. We aim to recruit approximately 10 participants from EDs, WICs, and NHS 111 for each of the three population groups. We estimate around five participants for each population group may be recruited by other means. Working on a conservative estimate of a 10% uptake rate of interview, we anticipate that we may need to approach around 1050 people to yield a total of 105 interviews.

Figure 1. Sampling across settings



Qualitative interviews

The first interview will focus on patient sense-making to examine how patients conceptualise urgent care needs and their knowledge of urgent and emergency care service provision, and will explore how beliefs and understandings might influence decision making about help seeking (Objectives 1 and 2). The topic guide for these interviews will be informed by the literature review and the citizens' panels. The questions will include probing how interviewees distinguish between routine, urgent and emergency care needs and the range of services available, and examination of attitudes and beliefs about urgent care/services.

The second interview will examine in more detail patients' experiences of using urgent care services to interrogate and analyse ‘burden of treatment’ entailed when navigating and accessing care (Objective 3). The topic guide for these interviews will be informed by the burden of treatment model and will also draw on the analyses of interview 1 to examine the relationships between meanings, sense-making and experiences of help-seeking, examining the perceived ‘costs’ (or disadvantages) and benefits of using particular services. These interviews will also provide the groundwork for objective 4 by capturing the range of decisions and behaviours thus supporting the identification of potentially modifiable factors and inform the development of a conceptual model of behaviour (work package 3).

The interviews will be held 6 months apart to allow time for analysis of interview one so that this can inform the second interview. This will also allow the interviews, particularly the second one, to capture retrospective data for the preceding 6 months period, reducing recall bias. The interviews will be carried out by the researcher (or one of the research team) within the homes of the patients (or a public place of their choice). All the interviews will be digitally recorded and fully transcribed. Subject to patient consent we plan to archive anonymised transcripts for re-use in future secondary analyses.

Data analysis

We will use our well established data clinic approach (51, 52) to share and interpret data collectively, building emergent themes and developing narrative and interpretive summaries. Team members will initially read and open code a sample of transcripts. These early codes will be discussed and refined to form the basis for a coding scheme that will be used to code and manage the data within Atlas.Ti 6.2. Regular data clinics will be used to ensure collective input and discussion of emerging codes, themes of interest. We will utilise thematic comparative approaches to look across cases and to explore similarities and differences between the three population groups, paying close attention to contradictory cases. These analyses will be informed by conceptual ideas drawn from previous research and theorising, including work on health related sense-making, burden of treatment model. As the analysis develops we will refine themes by using matrix techniques to facilitate comparisons and interpretations. We will share emerging analysis with PPI and advisory group members in order to check and further develop our analyses and identify appropriate cases and narratives for the scenarios for work package 3.

7.3. Work package 3: Integrative analysis to build a conceptual model of urgent care utilization and patient decision making (Objective 4)

To meet Objective 4, we will undertake an integrative analysis of the data collected in WP1 and WP2 to build a conceptual model that explains the urgent care utilization from which we can then identify modifiable factors that affect urgent care patient decision making. Our starting point is that interaction with urgent care is not simply individual help-seeking behaviour but it is collective / group action, narratives and processes that are shaped by the perspectives and behaviours of multiple participants across the urgent and emergency care system.

First, we will undertake content analysis of findings (76) from the literature review, citizens' panels (WP1) and qualitative interviews (WP2) to develop codes that i) describe and explain different conceptualizations / definitions of urgent care; ii) identify, characterise and explain sense-making strategies that influence help-seeking choices and behaviours; iii) identify and characterise the 'work' (the 'burden of treatment') involved in understanding, navigating and choosing to utilize urgent care. Coding the data will be an iterative process and will involve independent coding by members of the team. These codes will be discussed within the data clinics to identify discrepancies, refine coding scheme and to reach a consensus. To support the process of analysis, interview transcripts, notes and transcripts from the citizens' panel will be imported into a qualitative analysis software package, Atlas.Ti 6.2 which will be primarily used to code data and facilitate data management and retrieval.

From these codes we will build taxonomies of factors that can be demonstrated to shape interaction choices and engagement behaviours.

Second, we will characterize these factors, showing how they are formed, how they are related to each other, and how they relate to the contexts in which they operate. Comparative approaches to these data will enable us to identify a set of factors common across contexts, and these will enable us to use techniques such as decision trees and logic models of interaction choices and engagement behaviours (77). We will also identify factors that are contingent or context specific, and integrate these into the model where they suggest robust underlying mechanisms that shape the potential for supportive interventions.

Third, we will assemble the products of integrative analysis as a set of empirically grounded but theoretically robust generative principles to direct and structure future policy and practice interventions, and to characterize the mechanisms and processes that such interventions would seek to restructure. The model will facilitate the identification of supportive interventions with the potential to be routinely incorporated in practice. To do this we will build on the development of an empirically grounded theoretical model relevant to the problem of making sense of, negotiating and navigating care. Work to develop Burden of Treatment Theory (46, 48-50) that identifies and explains aspects of patient behaviour in relation to self-management and self-care practices that participants to take on and perform multiple – often complex – tasks and that these tasks are negotiated, distributed, and delivered across social networks. This work provides a basic framework from which to develop a conceptual model of relational choices about engagement with urgent care.

Finally, we will characterise the causal and mediating mechanisms through which these factors shape individual and relational activities, and explain their operation. The model offers the opportunity to identify a set of modifiable factors – identify sense making and decision making that is common to all service users, as well as identifying contingent factors that are specific to each of the service user groups. We will then express these as a set of theoretical constructs mapped onto a conceptual model that shows the relationships between them and which suggests the pressure points at which transformative interventions can be aimed to support individuals and relational networks. We will operationalize these constructs through a set of linked formal hypotheses that will form the foundation of a translational framework on which intervention studies can be built.

8. Project management

JT (PI) will use 25% FTE to undertake day-to-day management of the project, and monitor project progress. This will include finance, ethics and governance for the research, leading the delivery of the research, liaising with collaborators, and managing the research assistant / fellow. JT will ensure that the final report is submitted to deadline and an interim report will follow WP1 of the study. The project team (the PI and co-applicants) will meet every two months to oversee the progress of the project against the timetable and help address any issues that arise over the course of the project. Meetings will usually be chaired by the PI (JT) and notes of the meeting will be recorded. The success of our previous HS&DR projects was facilitated by Southampton team members holding regular data clinic meetings. This approach will be used again in this project. JP will provide 15% FTE to supervise the citizens' panels (WP1), take a key role in analysis and dissemination, provide expertise in the psychological aspects and contribute to the integrative analysis and conceptual model. CP will provide 10% FTE to provide valuable advice about the literature review (WP1), and take a lead role in the analysis and reporting of qualitative data (WP2). As an experienced PI, CP will support JT in the day-to-day management of the project as necessary. CM will provide 2% FTE for 12 months and 5% FTE for 12 months and will contribute expertise on the theoretical concepts of sensemaking and burden of treatment, and will particularly be involved in the integrative analysis and the development of the conceptual model (WP3). CM has extensive experience of writing for social science and clinical audiences and will make a major contribution to dissemination of findings. AR will provide 2% FTE for 12 months and 5% FTE for 12 months and take a key role in WP2, providing expertise about illness behaviour and help-seeking. She has particular expertise in networks, relationships and illness work and the relationship of this to accessing health services. RC will provide 2.5% FTE to advise on clinical aspects of the project as they arise throughout the project. He will also advise on the service provider perspective of urgent and emergency care (contributing to WP1 and WP2 in particular). AL will provide 2.5% FTE and will bring specialist knowledge about NHS111 and urgent care delivery. A full time researcher (level 4, 100% FTE) will undertake much of the data collection, including undertaking a literature review, assisting in design of the qualitative interviews, undertaking interviews with participants, as managed by JT. A clerical assistant will provide 2.5%FTE to support administration and writing-up (provided by the Faculty of Health Sciences).

An advisory board will be set up to meet four times and will include staff users, key local and national stakeholders (e.g. CCG board members, strategic planning/policy, clinical, and managers), project representatives, and an external academic. The aim of the advisory group will be to review the strategic, analytic and practical issues emerging from the project.

A separate Patient and Public Involvement (PPI) advisory group will also be established as a separate group that will meet 5 times throughout the project, using our links with the South Central Research Design Service and a local community centre and to think about study design and about ways of disseminating the study findings (see section 11 for more detail).

9. Expertise and justification of support required

This study has an outstanding multi-disciplinary team from University of Southampton, University Hospital Southampton NHS and South Central Ambulance NHS Trusts. The team combines disciplinary expertise in sociology and psychology, and health services research with clinical and service delivery expertise. Applicants Dr Joanne Turnbull (JT), Professor Catherine Pope (CP), Dr Jane Prichard (JP), and Professor Carl May (CM) have previously collaborated on two successful HS&DR projects (delivered on time) which led to this follow-on proposal. Consequently the team have excellent shared understandings of the field of investigation, well tried mechanisms for interdisciplinary and cross-institutional working, and have many years’ experience in delivering large research projects. Time commitments have been calculated to deliver this study alongside other commitments. The contribution of each applicant has been carefully thought out to provide the requisite intellectual, practical, managerial and research skills.

JT is a health services researcher with a long-standing interest in urgent and unscheduled care, and extensive experience of applying mixed methods to the organisation and delivery of care. JT led the previous HS&DR project (10/1008/10). CP is a medical sociologist with extensive experience of qualitative methods and healthcare and an expert in qualitative evidence synthesis. JP, a psychologist, has expertise on quantitative methods, psychological theories applied to health, and expertise on trust and knowledge sharing. CM is a sociologist with a wealth of experience in theory development (e.g. explaining how innovations are routinely embedded in healthcare, how healthcare can burden patients). Professor Anne Rogers (AR) has an extensive history of primary care research, illness self-management and the role of social networks. Dr Robert Crouch (RC) is a highly experienced ED consultant nurse and clinical academic and brings clinical knowledge and an emergency care perspective. Mr Andrew Lennon (AL) brings specialist knowledge about NHS 111 and urgent care. RC and AL will provide crucial links to ED and the urgent care network.

We have consulted relevant stakeholders (e.g. NHS 111 service at South Central, Portsmouth CCG, Southampton ED) and secured their involvement in developing this proposal and agreement (in principle) to participate in this research.

10. Dissemination and Impact

10.1 Dissemination

Dissemination will seek to maximise the impact of findings to future planning and development of urgent care services. Outputs include:

(1) The project final report published in the NIHR HS&DR Journal.

(2) Project PowerPoint slides of the citizens’ jury reports and literature findings, for use by the research team and CCG managers to disseminate findings in a consistent format.

(3) Research and policy papers submitted to relevant journals to inform the research and policy community in the range of disciplinary and practice fields implicated in this research (e.g. BMC Health Services Research, Journal of Health Services Research, Social Science and Medicine, BMJ.)

Information about the project will be disseminated across its duration. Presentations will disseminate to the health research and provider communities at services research conferences (e.g. HSRN annual symposium; OBHC) and other appropriate health care and sociology conferences. Presentations at these events will commence early in the life cycle of the project, both to raise awareness about the project and also to collect feedback about the project methodology. Conference presentations about findings from WP1 (public, policy and service provider meanings and definitions of urgent care) of the project will be presented as this work is completed. This will enable more timely dissemination of project findings.

We will work closely with NIHR, our advisory and PPI groups to prepare findings (such as our interim report) that can be readily disseminated to target audiences of urgent care service providers, workforce planners, healthcare managers, and policy-makers. This will be facilitated by a project website and newsletters cascaded through CCG networks. We will also work with NHS England to disseminate findings nationally. Press releases through the University of Southampton (UoS) media centre will extend the reach of the findings to service users.

A project workshop will further disseminate findings. This workshop, undertaken at the end of year 2 and co-hosted by the University of Southampton and NHS Portsmouth CCG (Local lead on urgent care), will share findings with attendees (PPI members, project researchers, CCG members, and service providers) to identify untapped dissemination routes that will further the reach of research findings at both a local and national level.

10.2. Impact

The findings will facilitate researchers, healthcare professionals and policy makers to reach a shared conceptualization of urgent care so different groups are “speaking the same language”. This can positively impact on the delivery of urgent care by:

- Supporting the development of services that match service user and service provider expectations. For example, disparities between understandings of care can be reflected back to services to ask them to consider how they can manage expectations about what is 'appropriate'.

- Enabling subsequent development of targeted interventions to modify services and to design advertising/information campaigns/educational activities e.g. to assist access, navigation and choice of services
- Providing a structured framework of dimensions of patient sense-making strategies that influence help-seeking choices and behaviours that policy makers, commissioners and providers should take into account when making changes or introducing new interventions into complex systems of health care.
- Providing a holistic view of the urgent care system that can be used to modify access routes and provision to enhance patient experience (e.g. encourage patients to use NHS 111 in preference to EDs).
- Identifying evidence of things that do not work well, or do not work well for particular groups of service users which will inform how best to target services to particular groups.
- Speaking to current policy concerns. The Keogh report (1) has made proposals that include: i) Providing better support for people to self-care; ii) Helping people with urgent care needs to get the right advice in the right place, first time; iii) Providing highly responsive urgent care services so people no longer choose to queue in EDs, and iv) minimising disruption. Addressing these goals is only possible with a deeper understanding of the factors that influence help-seeking and choices.

The work also has wider applicability in generating theory that is theoretically generalizable in explaining patients' understanding, help-seeking, choices and use in complex healthcare systems. The study provides a foundation for operationalizing different ways of conceptualizing urgent care and provides the groundwork for testing empirically testing the model in future research.

With the current close attention to urgent care services, it is essential that dissemination of project findings is timely and targeted to those stakeholders most in need of this evidence. The dissemination strategy described in 'the plans for dissemination' has therefore been designed to maximise reach to these stakeholders through engagement with CCGs and NHS England as crucial conduits of knowledge dispersion within the NHS, and to do so from early in the project to maximise impact.

The final report published on the NIHR Journals Library Website, journal and conference papers, newsletters and the project website will all be utilised to ensure that the work is widely available to service managers, service users, health services researchers, and policy developers. Use of the University of Southampton Eprints repository will further ensure free open access to findings so promoting utilization.

Involvement with our PPI group, advisory members and service users at the project workshop will develop further dissemination approaches that are meaningful to all stakeholders so maximising their influence. The workshop will further be used to identify local solutions to urgent care problems so promoting direct impact of the project findings and to identify future research priorities.

11. User involvement

In preparing the application we sought the advice and assistance of South Central Research Design Service. A poster was designed to advertise 2 meetings (circulated to local GP practices, supermarkets, community centres) to seek peoples' views about research needed in urgent care; perceptions of urgent care / NHS 111; and on the outline of proposal. It proved difficult to convene a meeting to suit all participants, so we met with interested individuals separately. Consultation has taken place in relation to:

Identifying and prioritising the research focus. Conversations with PPI individuals suggested that the subject area is one of importance to the public. It also evidenced their confusion about the concepts used by the NHS around urgent and emergency care and where to go for different care needs. It also revealed a lack of understanding about newer urgent care services such as NHS 111.

Designing and Managing the research protocol to strengthen the quality of the research and ensure methods are acceptable to the participants. We used individuals’ comments to revise our lay summary. Individuals commented on participant recruitment in the emergency department and the need to approach this sensitively.

PPI involvement will continue collaboratively during the project by engaging users in the development of participant information sheets, and consideration of ethical issues. PPI members will also have the opportunity to consider the findings and help interpret these, as well as involvement in planning dissemination.

A small group of PPI participants will be convened; some have already collaborated on this proposal. We will work with South Central RDS and our contacts with a local community centre to identify other potential participants (up to 5). PPI members will form a separate PPI group which is a deliberate decision on the part of the research team. The main reason for establishing a separate group is to provide time and a comfortable environment in which PPI members felt fully able to engage and contribute to the research design, interpretation of findings and dissemination. Our experiences from previous projects, where we have involved PPI representatives only as part of an advisory board, is that the ‘PPI voice’ can ‘get a bit lost’ amongst academic, health service managers, and clinical members. However, it is important that there is a mechanism for PPI to directly feed into the main research management process. One of the ways we will facilitate this is asking 1-2 PPI members to be part of the advisory board panel. PPI members will also be invited to collaborate with the researchers, CCG members and service providers at a workshop to develop plans for dissemination of research findings and identification of local solutions to addressing urgent care use.

Dissemination: PPI members will collaborate with the researchers, CCG members, and service providers at a workshop to develop plans for dissemination of research findings and identification of local solutions to addressing urgent care use. This will also involve reflection on what the project has achieved, and consideration of what more needs doing which may identify future research priorities. PPI members will be updated with project progress (e.g. newsletters; website). PPI activity will be planned to minimise inconvenience; expenses will be reimbursed. Activities will be facilitated by the research team. PPI members will be consulted about training needs to enable participation (e.g. group work, research methods) and provided by the research team if required.

12. Ethical and research governance considerations

NHS ethical review will be required for the citizens’ panels (WP1), and qualitative interviews (WP2). The first major activity in the project is a literature review which will not require ethical review. Therefore the REC application will be made in the first 1-4 months of the study, alongside the literature review. R&D / Site Specific Information approval will be submitted to relevant organisations covering NHS 111, the EDs and WICs involved in participant recruitment. This will require several R&D applications across several trusts – something that we have experience of managing in our previous projects.

The main ethical issues of the study relate to informed consent and data protection/confidentiality for participants in the study. We will work with NHS service providers to identify and be sensitive to patients and people who may be vulnerable (for example, where patients may have died).

Individual written consent will be obtained for interviews and the recording. Participants will be able to ask any questions they have about the study and to withdraw from the study. It is important that patients do not feel pressurised to participate. It will be explained that participation is voluntary and that no detriment will occur to patient care as a result of their decision to participate or not. No identifiable information will be stored that relate to the citizens’ panels or interview transcripts. Data files will contain only their participant identification number. Files will be stored on a password protected computer. All electronic data will be held on password protected University computers. Non−digital documents will be kept in a locked cabinet at the University of Southampton. Only the named research team members will have access to these data. JT will act as custodian of the data.

All projects are registered with the University of Southampton Research Governance Office (RGO), who ensure that research does not commence until necessary approvals are in place. Their role is to review research protocols and assess:

- Compliance with legislative frameworks (e.g. Data Protection Act, GCP Directive)
- Compliance with guidelines that inform best research practice
- NHS Research Governance Framework
- Compliance with University policies

Following assessment of the protocol the RGO will:

- Register research projects on the University database
- Arrange research sponsorship and insurance
- Offer advice and guidance to ensure appropriate approvals are obtained from all the regulatory authorities before the research commences
- Monitor ongoing research; assist in investigations in case of complaint

The researcher, PI (and other co-applicants if necessary) will apply for renewal of research passports and Disclosure & Barring Service checks before research commences.

13. Plan of investigation and timetable

The project includes three work packages, which are planned sequentially as they will draw on data generated from earlier work packages. The team will undertake some initial work so that the study can commence in May 2015, including initial meetings and/or contact with local NHS providers; invite and brief advisory / reference group members; and setting up a patient and public involvement group. The chart below sets out a monthly timetable. Team meetings / data clinics will take place every two months for the duration of the project. Briefly:

- Months 1-3: liaison with sites, initial visits; prepare ethical approval and governance; team meetings; first PPI meeting; WP1 plan the literature review.
- Months 4-6: WP1 conducting literature review; WP1 prepare and convene citizens' panels
- Months 7-9: WP1 writing up literature review; analysis of citizens' panels; team meeting; 2nd PPI meeting; plan WP2 design / scope of qualitative interviews
- Months 10-12: WP2 First round of qualitative interviews data collection; 2nd advisory board meeting;
- Months 13-15: 3rd PPI meeting; WP2 data analysis of 1st qualitative interview
- Months 16-18: 3rd advisory board meeting; WP2 Second semi-structured interviews data collection and data analysis
- Months 19-21: 4th PPI meeting; WP3 integrative data analysis and development (conceptual model) 4th advisory board meeting
- Months 22-24: final report writing; writing papers, dissemination workshop / feedback meetings.

Table 1. Timetable for the study

	2015			2016												2017								
Time (months)	**O**	**N**	**D**	**J**	**F**	**M**	**A**	**M**	**J**	**J**	**A**	**S**	**O**	**N**	**D**	**J**	**F**	**M**	**A**	**M**	**J**	**J**	**A**	**S**
Project month	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	**23**	**24**
Project management																								
REC / R&D approval	▨	▨	▨	▨																				
Team meetings / data clinics	▨		▨		▨		▨		▨		▨		▨		▨		▨		▨		▨		▨	
Advisory meetings						▨						▨						▨						▨
PPI meetings		▨						▨						▨						▨				
Work package 1																								
Literature review	▨	▨	▨	▨	▨	▨	▨	▨	▨															
Citizens' panels					▨	▨	▨	▨	▨															
Work package 2																								
Interview 1										▨	▨	▨	▨	▨	▨									
Interview 2																▨	▨	▨	▨	▨	▨			
Work package 3																								
Integrative analysis and conceptual model													▨	▨	▨	▨	▨	▨	▨	▨	▨			
Dissemination																								
HS&DR Progress reports						▨						▨						▨						▨
Interim report										▨	▨	▨												
Final report																						▨	▨	▨
Writing papers																						▨	▨	▨
Dissemination workshop/ Feedback meetings																						▨	▨	▨

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Appendix 1. Flow diagram of the research plan