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Partners At Care Transitions (PACT): a qualitative study exploring older peoples' experiences of transitioning from hospital to home.

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4 **Partners At Care Transitions (PACT): a qualitative study**
5 **exploring older peoples' experiences of transitioning from**
6 **hospital to home.**
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11 Corresponding author: Dr Natasha Kate Hardicre, Yorkshire Quality and Safety Research
12 Group, Bradford Institute for Health Research, Temple Bank House, Bradford Royal
13 Infirmary, Duckworth Lane, Bradford, West Yorkshire, BD9 6RJ.

14 Email: Natasha.hardicre@bthft.nhs.uk.

15 ORCID: 0000-0002-3639-5556

16 Telephone: 01274383428
17
18
19

20
21 Co-authors:

22 Professor Yvonne Birks, Social Policy Research Unit, University of York, York, UK.
23

24 Dr Jenni Murray, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
25 Research, Bradford, UK.
26
27

28 Dr Laura Sheard, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
29 Research, Bradford, UK.
30
31

32 Dr Lesley Hughes, Yorkshire Quality and Safety Research Group, Bradford Institute for
33 Health Research, Bradford, UK.
34
35

36 Dr Jane Heyhoe, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
37 Research, Bradford, UK.
38

39 Dr Alison Cracknell, Leeds Centre for Older People's Medicine, Leeds Teaching Hospitals NHS
40 Trust, Leeds, UK.
41
42

43 Professor Rebecca Lawton, School of Psychology, University of Leeds, Leeds, UK.
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Partners At Care Transitions (PACT): a qualitative study exploring older peoples' experiences of transitioning from hospital to home.

Abstract

Introduction: Lengths of hospital inpatient stays have reduced benefiting patients, who prefer to be at home, and hospitals, who can treat more people. However, patients may leave hospital sicker, with ongoing care needs. This transition period can be risky, particularly for older patients with complex needs. Improving patient experience, through greater patient involvement, may improve outcomes for patients and is a key indicator of care quality and safety. In this research we aim to: capture the experiences of older patients and their families during the transition from hospital to home; and identify opportunities for greater patient involvement in care. Informed by a resilience approach to safety we will learn about what goes well at transitions of care and what could be improved.

Methods and Analysis: A 'focused ethnography' comprising observations, 'Go-Along' and semi-structured interviews will be used to capture patient and carer experiences longitudinally during the care transition from admission to 90 days after discharge. We will recruit 30 patients and their carers from six hospital departments across two NHS Trusts. Analysis of observations and interviews will use a Framework approach to identify themes to understand the experience of transitions and generate ideas about how patients could be more actively involved in care at transitions. This will include exploring what 'good' care at transitions look like and seeking out examples of success, as well as recommendations for improvement.

Ethics and dissemination: Ethical approval was received from the NHS Research Ethics Committee in Wales. The research findings will add to a growing body of knowledge about patient experience of transitions, in particular providing insight into the experiences of patients and carers throughout the transitions process, in 'real time'. Importantly, the data will be used to inform the development of a patient-centred intervention to improve the quality and safety of transitions.

Strengths and limitations

- The study will explore patient involvement and experiences of transitions of care from hospital admission and throughout the transitions period, from the point of view of older people and their carers.
- The findings will be used to develop a person-centred intervention that aims to improve the quality and safety of care during the transitions period, and reduce hospital readmissions.

- The study design enables in-depth data to be captured from a small number of older people and their carers, resulting in rich narratives and enabling deep understandings of the transitions process from the point of view of the participants. This method does mean, however, that results are not generalisable to all people that transition from hospital to home.

Introduction

Reduced lengths of stay in hospital can result in patients being discharged from hospital to home with ongoing treatment and care needs. Although shorter stays in hospital have benefits for both patients, who prefer to be at home, and hospitals, who can treat more patients if stays are shorter, reduced stays can result in an increased reliance on care outside the inpatient setting, for example, wound or catheter care, changes to medication, or input from therapy services. 'Discharge' from hospital is, therefore, more likely to be a stage in a process involving the *transfer* of care, rather than being an *end-point* of care. The movement and transfer of care from hospital to home – sometimes referred to as the 'transition period' – is likely to involve input from multiple agencies in order to meet patients' ongoing care needs. It is a highly variable and complex process that is contingent upon on several factors, for example service provision, resource capacity, and knowledge transfer within and between secondary care teams, GPs and corollary services, community therapy teams, and adult social care services;[1] alongside the social support networks and resources that patients themselves have access to (or not). Consequently, the transition of care from hospital into community settings can be a risky one.

As many as one in five patients experience an adverse event in the transition from hospital to home, 62% of which could be prevented;[2] this is double the number of adverse events experienced by patients during a hospital stay.[3] For older patients, who are more likely to have complex health and social needs, and who may be anxious, confused, and disorientated,[4, 5] the risks associated with transitions of care may be greater than that of the general population. This may result in a higher than average rate of readmission to hospital,[6] thereby prolonging the overall patient stay. This counteracts the benefit of reduced patient stays, and further exposes patients to risks associated with hospital inpatient stays. Krumholtz[7] argues, for example, that hospitalisation causes 'substantial stress' to patients, through causes such as disrupted sleep, poor nourishment, 'a baffling array of mentally challenging situations', changes to medication, and deconditioning associated with inactivity and bedrest. Older people are particularly vulnerable to such stressors as they are more likely to have multiple morbidities, take multiple medications, and remain inactive.[8, 9] Moreover, older people are the highest users of the NHS and, with the number of people in the UK aged 75 and over set to double in the next 30 years, this group of patients is an important target for support.[10] Increased risk associated with both hospitalisation and the transition period suggests that improving the quality and safety of care during this time ought to be a focus of this targeted support.

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3 Patient experience of care is a key indicator of quality and safety [11] and so an important
4 target for intervention. Indeed, this strong relationship between patient experience and
5 outcomes suggests that those interested in improving health outcomes (quality, safety, and
6 cost savings) should strive first to improve patient experiences, especially by focusing on
7 activities such as patient engagement. However, despite a growing emphasis on shared care
8 and patient empowerment [12] the involvement of patients in their care before, during,
9 and after transitions remains minimal, with patients feeling that they are not always
10 listened to and that they did not have a 'lot of say' in their care.[13-16] A recent systematic
11 review of patient experiences of transitions highlighted the necessity of involving older
12 people and their carers in the discharge process, but reported variability in the degree to
13 which this was achieved.[17] The study described in this protocol forms the first of six
14 interlinked 'work packages' (WP) in an NIHR-funded Programme Grant for Applied Health
15 Research (PGfAR) that aims to understand and improve the experience, and safety, of care
16 for older patients during transitions and, by doing so, reduce readmissions and NHS costs. In
17 particular, we want to explore whether greater involvement of patients and their families
18 can improve patient experience and safety at the transitions of care. This will involve
19 exploring patient experience of transitions and using these data to develop and test a
20 patient-centred intervention that supports the involvement of older people, and their
21 families, in their care. Utilising a resilience engineering approach to safety in healthcare,[18]
22 we especially want to learn from what goes well at transitions, rather than focusing only on
23 what goes wrong; doing so "sheds light on otherwise unrecognised and unspecified
24 pathways to success".[19] This will enable us to take a proactive approach towards care
25 during the transitions period; developing an intervention that helps to inform people about
26 what they can do to make the transitions process 'good'.
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36 The research study described here focuses on understanding the transitions process from
37 the perspective of those experiencing it – patients and their families. There are two main
38 foci of the research:
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- 40 1) EXPERIENCE: Describing the transitions process from the point of view of older patients
41 and their carers;
- 42 2) INVOLVEMENT: Exploring where the opportunities are for improving patient
43 involvement in the transitions process.
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45 Research questions are:
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- 47 1) a. What do patients and their families experience during the transition of care from
48 hospital to place of residence?
49 b. What do patients think, feel, and believe about this process?
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- 51 2) How can people be more involved in their care:
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- a. To what extent do people feel involved in their care? What are their perspectives on this?
- b. Where are the opportunities for patients to be more involved in their care?
- c. To what extent do people feel *able* to be (more) involved in their care? What has, or would help them to, feel able to be (more) involved in their care?

Methods and analysis

Recruiting patients

Thirty older patients (aged 75+), and their immediate carers, will be recruited to the study. Patients and carers will be recruited from six departments specialising in elderly medical care, respiratory care, orthopaedic care of the elderly, and stroke, across two hospitals. The departments have been selected for the study to reflect different transitional challenges, emergency and elective admissions (including elective surgery), acute and chronic illness, and multi-morbidity or poly-pharmacy issues.

We will attempt to recruit a diverse sample of patients from different ethnicities, and gender groups, as well as a variety of ages – including the ‘oldest old’ (aged 85+) – wherever possible. One of the hospitals serves a large South-East Asian population, some of whom do not speak or read English. To facilitate inclusion, a translator will work with researchers to approach and consent patients who speak Urdu and/or Potwari – the languages most commonly spoken amongst the largest non-English speaking group in that area – and provide translation services during the course of the research. We will also try to ensure that people with and without carers are included in the research, as carer involvement is likely to have an impact on the patient’s experience of transition. Opportunity sampling will be employed initially; we will monitor the diversity of the sample as participants are recruited. Should the sample lack variation, sampling will become purposive.

We are excluding patients who are at the end of their life or whose care has become palliative, so as not to place additional burden on themselves or their families. We will, however, be approaching people with cognitive or language impairments, including patients who lack or have variable capacity to consent to the research for themselves, if they have suitable support in place to help them to participate in the research. This group of patients are likely to be especially vulnerable during the transitions period; thus, it is particularly important to capture their experiences and those of the people who care for them to explore opportunities to reduce risk to this population. All the researchers working on the study have received additional training on taking informed consent in adults lacking capacity. When a patient is identified as not having the capacity to give consent, in line with the Mental Capacity Act 2005,[20] the researcher will take reasonable steps to identify a personal consultee to advise on the presumed wishes and feelings of participants unable to

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3 consent for themselves and on their inclusion and participation in the research. We will also
4 seek to recruit the consultee as a participant in the study, so that they can provide support
5 to the patient-participant throughout the research process.
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10 **Data collection**

11 As part of a focused ethnographic approach, we will employ the following methods to
12 explore experiences and identify likely influences on outcomes:
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- 15 • Non-participant observation, with discussions about 'key moments';
- 16 • 'Go-Along' interviews;
- 17 • Individual semi-structured interviews.
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20 These data collection methods will be combined flexibly within this study to enable us to
21 gather rich insightful data into what patients think, feel, and believe about the process of
22 leaving hospital to return home. Two researchers will be responsible for data collection,
23 each following the patients they recruit for their entire 'transitions journey' (where
24 possible).
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28 **Observations**

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30 Observations will be used to explore what happens to a patient at various time points and
31 locations as they transition from hospital to home, including within the admitting hospital, a
32 transitional care facility, the patient's residence, and other care settings. Non-participant
33 observation offers a direct view of behaviours in their natural setting.[21, 22] It allows the
34 researcher insight into what is done, and how, by various people involved in delivering care
35 over the transition period (for example, healthcare professionals, support and
36 administrative staff, the voluntary sector, and patients and their carers themselves).
37 Observations will provide the foundation for short informal conversations (approximately
38 10-15 minutes) to follow up on 'key moments' observed on a previous occasion. These will
39 happen as close to the original event as possible, to enable accurate recall. Observations
40 and conversations will be captured through field notes. An observation framework will be
41 developed for this study as a prompt for observer field notes, ensuring accurate, in-depth
42 recording of observations and facilitating analysis.
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49 **Go-Along Interviews**

50 'Go-Along' interviewing is a participatory method that is person-centred and interactive,
51 that is, they focus on understanding the experiences of a person within changing contexts in
52 real-time. Interviewing someone whilst they are experiencing something in real-time can
53 facilitate articulation of attachments, feelings and memories that might otherwise remain
54 unconscious or unsaid.[23, 24] With this in mind, the researcher will accompany the
55 participant within the context in which care is being delivered, with all conversation
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3 recorded digitally. Recordings will be supplemented by field notes to provide context and
4 aid interpretation of transcribed data.[24] We are aware that a 'Go-Along' interview may
5 not be appropriate in all circumstances and so we will use this method sensitively according
6 to the context in which the researcher and patient are in and what is happening at that
7 time.
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10 **Interviews**

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12 Observations and 'Go-Along' interviews will be supplemented by more formal semi-
13 structured interviews that will use a guide (see appendix 1) to provide a framework to the
14 discussions. This guide will contain some key questions, informed by the COM-B
15 framework[25] so addressing issues of capability, motivation and opportunity for patients
16 to be involved in their care at transitions, but will also be informed by the observations that
17 have occurred up to that point. Interviews will be co-generated by both participant and
18 researcher; to ensure that discussions are relevant to the research, the researcher will use
19 the interview schedule as a 'map' to guide the conversation, whilst remaining flexible
20 enough to follow participants as they express their experiences about being in hospital and
21 transitioning from hospital to home. Interviews will be recorded digitally. Individual
22 interviews are likely to take place in the hospital and in the patient's own home; if an
23 interview does take place in a setting that is not the patient's home, we will ensure that
24 these occur in a space that is sufficiently private. We may also conduct telephone interviews
25 to speak with participants about an episode of care that has been delivered but not
26 observed by the researchers (visiting their GP, for example).
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34 We expect that each of these methods will be used to gather data from each participant,
35 but to remain sensitive to the needs of the patient or carer, the context within which health
36 care is delivered, and the needs of the research, we will employ them flexibly and
37 sensitively. For example, sometimes it may not be appropriate to use a more participatory
38 approach, such as a 'Go-Along' interview, because it is important that we capture
39 interactions between health care professionals and patients as they would naturally occur,
40 without the participation of the researcher. Also, important care may be being delivered
41 and the participation of the researcher in the interaction would disrupt the delivery of that
42 care (within a rehabilitation therapy session, for example). At other times, however, it may
43 be helpful to use the time spent with patients as they are moving from one location to
44 another, for example, capturing their thoughts, feelings, and beliefs about what has and is
45 happening to them in that moment, alongside their expectations about what will happen in
46 the future. Within this context a more structured non-participant observation would likely
47 fail to capture the richness of the patient's experience. More formal semi-structured
48 interviews will complement both types of observational work.
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55 **Timing of Data Collection**

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3 'Time' and 'place' are two important features of any transitions process. We have therefore
4 designed the research to capture as much of the temporospatial aspects of the transition
5 from hospital to home as possible. This includes collecting data from participants at various
6 time points within the transitions process, and in various locations. It also involves exploring
7 the significance of 'time' and 'place' with participants.
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10 Data collection will be organised around five 'episodes', over a period of 3-4 months:

- 11 1. Upon, or shortly after, admission to hospital;
 - 12 2. Shortly prior to and/ or during discharge from the admitting hospital;
 - 13 3. A day or two after discharge in the home or intermediate care;
 - 14 4. Several weeks after discharge;
 - 15 5. Three months after discharge or on readmission if sooner.
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23 Data collection may occur within the admitting hospital, an intermediate care facility, and in
24 the home of the participant. In addition, if the patient gives us permission, we will follow the
25 patients to appointments that form part of their 'discharge care package' (appointments
26 with therapists or district nurses, for example). We anticipate that we will see each patient
27 approximately five times (once within each 'transition episode'). However, the actual
28 number of times that we will see the participant will be guided by the needs and
29 experiences of the patient. For example, someone experiencing fatigue as an outcome of
30 stroke may require more visits of a short duration to avoid placing unnecessary burden on
31 the participant. Alternatively, some patients may have multiple appointments at the point
32 of discharge and be happy for us to accompany them to each of these appointments. Data
33 collection will remain sufficiently flexible to meet the needs of the participants and the
34 research.
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40 **Data Analysis**

41 All interviews will be digitally recorded and transcribed verbatim. Relevant contextual
42 details will be added to the interview transcripts from notes made by the researcher.
43 Researchers will make field notes during observations. After an observation session, the
44 researchers will use a digital recorder to describe what they observed and to digitally
45 capture their own interpretation of the session; this will then be transcribed verbatim.
46 Transcription will be done by an external agency and checked by the researcher who
47 collects the data.
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53 Data analysis will be inductive and flexible, utilising a Framework approach [9] to identify
54 themes and analytical categories. Framework analysis allows the researcher to move from
55 raw data to wider explanatory accounts through a series of conceptual groupings and
56 meanings assigned to the data.[26, 27] The key stages of Framework analysis are:
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3 familiarisation with data; identifying a thematic framework; indexing and sorting data;
4 reviewing and refining the thematic framework, and then summarising and displaying the
5 data through the construction of thematic matrices.[28] These matrices allow the data to
6 be reduced and distilled, whilst staying close to the original text. The matrices also facilitate
7 comparison within- and between- themes and cases (participants). Within-case comparison
8 will be particularly helpful when exploring the temporal aspects of the transitions process,
9 as it will allow exploration of changes in individual attitudes and experience over time. Data
10 analysis will be conducted by both researchers involved in data collection.
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15 The thematic frameworks will be constructed by both researchers, using the interview guide
16 as a tool for organising the data. Each researcher will label and sort their own data using the
17 thematic framework but discussion about emergent findings will happen on a regular basis
18 and will be used to refine the thematic framework. The comparison work to identify
19 analytical categories and explanatory accounts will be done together and will also involve
20 members of the project patient panel. Qualitative data analysis software (NVivo 10 for
21 Windows) will be used to help manage and organise the data into thematic matrices.
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25 26 **Patient and public involvement**

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28 The Yorkshire Quality and Safety Research Group currently supports a patient and public
29 panel of 25 people representing the local patient community. This group have been involved
30 from the beginning of the PACT research study and will continue to provide input when
31 necessary. In addition, we have recruited a panel of people who will work with the PACT
32 research team over the course of the study. Panel members will meet regularly as a group
33 to support the PACT study as a whole; panel members will also be working in pairs to
34 support one of the first three work-packages, including this study of patient experience. We
35 anticipate that the PACT patient panel will contribute to the analysis and interpretation of
36 research findings and to the development of the intervention in light of these findings. Panel
37 members will be supported by a research nurse with an expertise in patient and public
38 involvement in research.
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45 **Ethics**

46 47 ***Ethics***

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49 This study has been approved by the Wales 7 Research Ethics Committee (reference:
50 17/WA/0057).
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53 Prior to approaching any patient, the researcher will speak with a senior health care
54 professional to find out which patients may be approached to take part in the research. This
55 is to ensure that we do not approach people who are very unwell or at the end of their life.
56 At first approach, the researcher will be accompanied by a member of the clinical team, who
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3 will make the first introduction. All potential participants will be provided with: verbal and
4 written information about the study; the opportunity to ask questions; and time to consider
5 whether they would like to participate. Informed consent will be gained from all participants
6 (patients and carers) who can consent for themselves. All research documents, such as
7 information sheets and consent forms are written in plain English using large print, and laid
8 out clearly to facilitate readability and understanding. Verbal consent scripts will be used
9 with people who struggle with written language or who have a physical impairment that
10 prevents them from signing a consent form.

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15 We recognise that consent is an ongoing process. Therefore, at every research encounter
16 we will check whether participants still wish to take part prior to starting any data
17 collection. As far as possible the same researcher will do all follow-up work with the same
18 patient to promote the building of a relationship and to avoid confusion for the older person
19 and/or their carer. Participants will be free to withdraw from the study at any time and can
20 choose whether the data collected about them is included in the analysis.

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24 All personal identifiable data will be kept securely in line with legal requirements and best
25 practice recommendations to ensure confidentiality. Participants will be assigned
26 pseudonyms so that they cannot be identified.

27 28 29 **Dissemination**

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31 The findings of the study will contribute to the other work packages (WP) within the
32 programme of work. Particular contributions include using the data to: inform the
33 development (and subsequent testing) of a patient-centred intervention that aims to
34 improve the transitions experience and reduce hospital readmissions (WPs 4, 5, 6); and to
35 inform the development of a measure of the quality of transitions, which will be used as a
36 secondary outcome measure within the PACT RCT (WPs 3, 6).

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39 We will also develop 'patient experience of transitions' resources in the form of anonymised
40 stories to help communicate the main findings of the project to both academic and clinical
41 groups. For example, the Academic Health Science Network Improvement Academy and
42 educational institutions will be used to disseminate these resources to people undergoing
43 training and/or quality improvement work. We will also be hosting a national conference to
44 showcase findings from this project and two of the other linked work-packages.

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47 We will publish our research findings in academic and professional journals and present our
48 work at relevant national and international conferences. We also plan to support
49 dissemination through a website, social media, and through networks. We have experience
50 of using these formats for reaching a variety of audiences, but particularly our local clinical
51 networks. Twitter has proved a particularly effective method for sharing our ideas, alerting
52 people to our recent findings, and discussing new ideas and concepts.

Our dissemination strategy has been developed in partnership with various stakeholders, including our patient panel. We will continue to engage with and involve these groups to ensure that the research findings can be translated effectively into clinical practice and to maximise the impact of the research locally and nationally.

Discussion

Strengths and weaknesses

This study seeks to explore and describe the experience of older people and their families as they transition from hospital to home. Utilising multiple in-depth qualitative research methods enables us to capture detailed accounts of experiences and perceptions of experiences, alongside the context within which care is occurring. Being informed by a resilience engineering approach, this will involve exploring what goes well, alongside identifying areas for improvement. The study design means that the findings will not be generalisable to all older people transitioning from hospital to home. Nonetheless, the research accounts have the capacity to provide data which are credible, dependable and transferable to others.[29] Moreover, Rossman and Rallis, 2003 [30] argue that ‘the ultimate goal of qualitative research is learning, that is, the transformation of data in to information that can be used. *Use can be considered an ethical mandate*’. The use of the findings of this study can be considered to fulfil this ethical mandate.

The findings of the research will contribute to the development and testing of a person-centred intervention that aims to improve patient experience and reduce the risk of hospital readmission. It is anticipated that improving the patient experience of the transitions process /will contribute to improved safety and quality of care [11, 31] during this transition period. It is also anticipated that providing good transitional care will reduce hospital readmissions. This has benefits for patients and their families, as being in hospital is associated with a number of risks and has a psychological and physical impact on patients and their families.[13, 15] Risks such as hospital-acquired infections are increased, for example, and issues such as disrupted sleep, nutritional deficiencies and problems caused by poor nourishment, increased stress and anxiety, and deconditioning due to inactivity and bedrest can place additional burdens on people already dealing with one or more conditions or trauma.[7] Reducing readmissions also has benefits for the health service which is under pressure to deliver more care with less resource. Moreover, NHS Trusts now incur financial penalties for readmissions within 30 days; reducing readmissions would reduce spending on such penalties.

Conclusions

We want to learn from older people and their families about what works for them in the care that they receive and to find out what would improve their experience of the transitions process. Exploring the transitions process from their perspective, particularly

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3 looking at where and how people can be involved in their care, and using this data to
4 develop an intervention, means that the patient is at the heart of quality improvement. This
5 research will also add to an existing body of knowledge about patient experiences of care at
6 transitions.[32-35] Importantly, this research will capture the temporospatial experiences
7 of transitions by following older people and their families during their transition journey
8 from admission through to three months post-discharge. This element is missing from
9 existing research. Also, by being informed by a resilience-engineering approach to safety,
10 the positive contribution that all people can make to the delivery of good quality, safe
11 healthcare – patients, their families, and healthcare providers – is acknowledged and on this
12 basis genuine partnership can be harnessed to improve patient experience and clinical
13 outcomes.
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21 **Author's Contributions**

22
23 RL, AC, LS and YB designed the overall programme of research and conception of studies
24 within. All authors were involved in the design of the current study and have contributed to
25 the drafting, reviewing and final approval of the manuscript.
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39 the Department of Health.
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44 **Competing Interests Statement**

45
46 None declared.
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BMJ Open

Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning from hospital to home in the UK: protocol for an observation and interview study of older people and their families to understand patient experience and involvement in care at transitions.

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Manuscripts

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4 Partners At Care Transitions (PACT). Exploring older peoples'
5 experiences of transitioning from hospital to home in the UK:
6 protocol for an observation and interview study of older people and
7 their families to understand patient experience and involvement in
8 care at transitions.
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14
15 Corresponding author: Dr Natasha Kate Hardicre, Yorkshire Quality and Safety Research
16 Group, Bradford Institute for Health Research, Temple Bank House, Bradford Royal
17 Infirmary, Duckworth Lane, Bradford, West Yorkshire, BD9 6RJ.

18 Email: Natasha.hardicre@bthft.nhs.uk.

19 ORCID: 0000-0002-3639-5556

20 Telephone: 01274383428
21
22
23

24 Co-authors:

25
26 Professor Yvonne Birks, Social Policy Research Unit, University of York, York, UK.

27
28 Dr Jenni Murray, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
29 Research, Bradford, UK.

30
31 Dr Laura Sheard, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
32 Research, Bradford, UK.

33
34 Dr Lesley Hughes, Yorkshire Quality and Safety Research Group, Bradford Institute for
35 Health Research, Bradford, UK.

36
37 Dr Jane Heyhoe, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
38 Research, Bradford, UK.

39
40 Dr Alison Cracknell, Leeds Centre for Older People's Medicine, Leeds Teaching Hospitals NHS
41 Trust, Leeds, UK.

42
43 Professor Rebecca Lawton, School of Psychology, University of Leeds, Leeds, UK.
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3 Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning
4 from hospital to home in the UK: a qualitative study protocol.
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7 **Abstract**

8
9 Introduction: Lengths of hospital inpatient stays have reduced. This benefits patients, who
10 prefer to be at home, and hospitals, which can treat more people when stays are shorter.
11 Patients may, however, leave hospital sicker, with ongoing care needs. The transition period
12 from hospital to home, can be risky, particularly for older patients with complex health and
13 social needs. Improving patient experience, especially through greater patient involvement,
14 may improve outcomes for patients and is a key indicator of care quality and safety. In this
15 research we aim to: capture the experiences of older patients and their families during the
16 transition from hospital to home; and identify opportunities for greater patient involvement
17 in care, particularly where this contributes to greater individual- and organisational-level
18 resilience.
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23 Methods and Analysis: A 'focused ethnography' comprising observations, 'Go-Along' and
24 semi-structured interviews will be used to capture patient and carer experiences during
25 different points in the care transition from admission to 90 days after discharge. We will
26 recruit 30 patients and their carers from six hospital departments across two NHS Trusts.
27 Analysis of observations and interviews will use a Framework approach to identify themes
28 to understand the experience of transitions and generate ideas about how patients could be
29 more actively involved in their care. This will include exploring what 'good' care at
30 transitions look like and seeking out examples of success, as well as recommendations for
31 improvement.
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36 Ethics and dissemination: Ethical approval was received from the NHS Research Ethics
37 Committee in Wales. The research findings will add to a growing body of knowledge about
38 patient experience of transitions, in particular providing insight into the experiences of
39 patients and carers throughout the transitions process, in 'real time'. Importantly, the data
40 will be used to inform the development of a patient-centred intervention to improve the
41 quality and safety of transitions.
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46 **Strengths and limitations**

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- Utilising a range of qualitative methods, the study will generate rich, in depth data to contextualise patient involvement and experiences of transitions of care from hospital admission and throughout the transitions period, from the point of view of older people and their carers.
 - The longitudinal approach enables us to gain insight into how patient experience and how involvement changes over time.

- While the study design enables in-depth data to be captured from a small number of older people and their carers, as is the nature of qualitative inquiry, this limits generalisability of findings. The study is situated within a larger programme which will allow greater generalisability, as the programme of work progresses informed by this phase.
- Although non-participant observation can generate rich contextual data that are not as easily accessed via other methods, the presence of a researcher has the potential to affect the behaviour of those being observed.

Introduction

Reduced lengths of stay in hospital can result in patients being discharged from hospital to home with ongoing treatment and care needs. Although shorter stays in hospital have benefits for both patients, who prefer to be at home, and hospitals, who can treat more patients if stays are shorter, reduced stays can result in an increased reliance on care outside the inpatient setting, for example, wound or catheter care, changes to medication, or input from therapy services. 'Discharge' from hospital is, therefore, more likely to be a stage in a process involving the *transfer* of care, rather than being an *end-point* of care. The movement and transfer of care from hospital to home – sometimes referred to as the 'transition period' – is likely to involve input from multiple agencies in order to meet patients' ongoing care needs. It is a highly variable and complex process that is contingent upon on several factors, for example service provision, resource capacity, and knowledge transfer within and between secondary care teams, GPs and corollary services, community therapy teams, and adult social care services;^[1] alongside the social support networks and resources that patients themselves have access to (or not). Consequently, the transition of care from hospital into community settings can be a risky one. Additionally, older people may experience more than one 'transition' in a single hospital admission episode, for example, moving between wards or via intermediate care at a different location. Likewise, some older people may experience readmissions within a short period of time. The transitions process may not, therefore, be a linear one, resulting in further complexity.

As many as one in five patients experience an adverse event in the transition from hospital to home, 62% of which could be prevented;^[2] this is double the number of adverse events experienced by patients during a hospital stay.^[3] For older patients, who are more likely to have complex health and social needs, and who may be anxious, confused, and disorientated,^[4, 5] the risks associated with transitions of care may be greater than that of the general population. This may result in a higher than average rate of readmission to hospital,^[6] thereby prolonging the overall patient stay. This counteracts the benefit of reduced patient stays, and further exposes patients to risks associated with hospital inpatient stays. Krumholtz^[7] argues, for example, that hospitalisation causes 'substantial stress' to patients, through causes such as disrupted sleep, poor nourishment, 'a baffling array of mentally challenging situations', changes to medication, and deconditioning

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3 associated with inactivity and bedrest. Older people are particularly vulnerable to such
4 stressors as they are more likely to have multiple morbidities, take multiple medications,
5 and remain inactive.[8, 9] Moreover, older people are the highest users of the NHS and,
6 with the number of people in the UK aged 75 and over set to double in the next 30 years,
7 this group of patients is an important target for support.[10] Increased risk associated with
8 both hospitalisation and the transition period suggests that improving the quality and safety
9 of care during this time ought to be a focus of this targeted support.
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13 Patient experience of care is a key indicator of quality and safety [11] and so an important
14 target for intervention. Indeed, this strong relationship between patient experience and
15 outcomes suggests that those interested in improving health outcomes (quality, safety, and
16 cost savings) should strive first to improve patient experiences, especially by focusing on
17 activities such as patient engagement. However, despite a growing emphasis on shared care
18 and patient empowerment [12] the involvement of patients in their care before, during,
19 and after transitions remains minimal, with patients feeling that they are not always
20 listened to and that they did not have a 'lot of say' in their care.[13-19] A recent systematic
21 review of patient experiences of transitions highlighted the necessity of involving older
22 people and their carers in the discharge process, but reported variability in the degree to
23 which this was achieved.[20] The study described in this protocol forms the first of six
24 interlinked 'work packages' (WP) in an NIHR-funded Programme Grant for Applied Health
25 Research (PGfAR) that aims to understand and improve the experience, and safety, of care
26 for older patients during transitions and, by doing so, reduce readmissions and NHS costs. In
27 particular, we want to explore whether greater involvement of patients and their families
28 can improve patient experience and safety at the transitions of care. This will involve
29 exploring patient experience of transitions and using these data to develop and test a
30 patient-centred intervention that supports the involvement of older people, and their
31 families, in their care.
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40 The programme of work utilises a resilience engineering approach to safety in
41 healthcare,[21] and we especially want to learn from what goes well at transitions, rather
42 than focusing only on what goes wrong; doing so "sheds light on otherwise unrecognised
43 and unspecified pathways to success".[22] Within this project, we want to understand the
44 things that patients, relatives and health service staff (or others) do to enable patients and
45 their families to be resilient within the transitions process. However, we also want to
46 explore the ways in which patients and their carers do or could contribute to organisational
47 resilience. Schubert *et al*,[23] for example, suggest that patients/caregivers can "identify
48 and prevent mistakes from happening, and participate in improving their care" by
49 navigating a "fragmented system" through the co-ordination of tasks across multiple health
50 care settings and providers. This will enable us to take a proactive approach towards care
51 during the transitions period; developing an intervention that helps to inform people about
52 what they can do to make the transitions process 'good'. We believe this is a novel approach
53 towards understanding and improving care at the transitions period.
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3 The research study described here focuses on understanding the transitions process from
4 the perspective of those experiencing it – patients and their families. There are two main
5 foci of the research:
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8 1) EXPERIENCE: Describing the transitions process from the point of view of older patients
9 and their carers;
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11 2) INVOLVEMENT: Exploring where the opportunities are for improving patient
12 involvement in the transitions process.
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15 Research questions are:
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- 17 1. a. What do patients and their families experience during the transition of care from
18 hospital to place of residence?
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20 b. What do patients think, feel, and believe about this process?
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22 2. How can people be more involved in their care:
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24 a. To what extent do people feel involved in their care? What are their perspectives on
25 this?
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27 b. Where are the opportunities for patients to be more involved in their care?
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29 c. To what extent do people feel *able* to be (more) involved in their care? What has, or
30 would help them to, feel able to be (more) involved in their care?
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36 Methods and analysis

37 *Recruiting patients*

38 Beginning in May 2017, thirty older patients (aged 75+), and their immediate carers, will be
39 recruited to the study. Patients and carers will be recruited from six departments
40 specialising in elderly medical care, respiratory care, orthopaedic care of the elderly, and
41 stroke, across two hospitals. The departments have been selected for the study to reflect
42 different transitional challenges, emergency and elective admissions (including elective
43 surgery), acute and chronic illness, and multi-morbidity or poly-pharmacy issues.
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46 We will attempt to recruit a diverse sample of patients from different ethnicities, and
47 gender groups, as well as a variety of ages – including the ‘oldest old’ (aged 85+) – wherever
48 possible. One of the hospitals serves a large South-East Asian population, some of whom do
49 not speak or read English. To facilitate inclusion, a translator will work with researchers to
50 approach and consent patients who speak Urdu and/or Potwari – the languages most
51 commonly spoken amongst the largest non-English speaking group in that area – and
52 provide translation services during the course of the research. We will also try to ensure
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3 that people with and without carers are included in the research, as carer involvement is
4 likely to have an impact on the patient's experience of transition. Opportunity sampling will
5 be employed initially; we will monitor the diversity of the sample as participants are
6 recruited. Should the sample lack variation, sampling will become purposive. We anticipate
7 that a sample of 30 patients is likely to allow us to capture some diversity and is also likely
8 to achieve theoretical saturation; however, this will be reviewed as analysis proceeds to
9 ensure any gaps are covered.
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13 We are excluding patients who are at the end of their life or whose care has become
14 palliative, so as not to place additional burden on themselves or their families. We will,
15 however, be approaching people with cognitive or language impairments, including patients
16 who lack or have variable capacity to consent to the research for themselves, if they have
17 suitable support in place to help them to participate in the research. This group of patients
18 are likely to be especially vulnerable during the transitions period; thus, it is particularly
19 important to capture their experiences and those of the people who care for them to
20 explore opportunities to reduce risk to this population. All the researchers working on the
21 study have received additional training on taking informed consent in adults lacking
22 capacity. When a patient is identified as not having the capacity to give consent, in line with
23 the Mental Capacity Act 2005,[24] the researcher will take reasonable steps to identify a
24 personal consultee to advise on the presumed wishes and feelings of participants unable to
25 consent for themselves and on their inclusion and participation in the research. We will also
26 seek to recruit the consultee as a participant in the study, so that they can provide support
27 to the patient-participant throughout the research process.
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34 *Data collection*

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36 As part of a focused ethnographic approach,[25] we will employ the following methods to
37 explore experiences and identify likely influences on outcomes:
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- 39 • Non-participant observation, with discussions about 'key moments';
 - 40 • 'Go-Along' interviews[26,27]
 - 41 • Individual semi-structured interviews.
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45 These data collection methods will be combined flexibly within this study to enable us to
46 gather rich insightful data into what patients think, feel, and believe about the process of
47 leaving hospital to return home. Two researchers will be responsible for data collection,
48 each following the patients they recruit for their entire 'transitions journey' (where
49 possible).
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52 **Observations**

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54 Observations will be used to explore what happens to a patient at various time points and
55 locations as they transition from hospital to home, including within the admitting hospital, a
56 transitional care facility, the patient's residence, and other care settings. Non-participant
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3 observation offers a direct view of behaviours in their natural setting.[28, 29] It allows the
4 researcher insight into what is done, and how, by various people involved in delivering care
5 over the transition period (for example, healthcare professionals, support and
6 administrative staff, the voluntary sector, and patients and their carers themselves).
7 Observations will provide the foundation for short informal conversations (approximately
8 10-15 minutes) to follow up on 'key moments' observed on a previous occasion. These will
9 happen as close to the original event as possible, to enable accurate recall. Observations
10 and conversations will be captured through field notes. An observation framework will be
11 developed for this study as a prompt for observer field notes, ensuring accurate, in-depth
12 recording of observations and facilitating analysis.
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17 **Go-Along Interviews**

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19 'Go-Along' interviewing is a participatory method that is person-centred and interactive,
20 that is, they focus on understanding the experiences of a person within changing contexts in
21 real-time. Interviewing someone whilst they are experiencing something in real-time can
22 facilitate articulation of attachments, feelings and memories that might otherwise remain
23 unconscious or unsaid.[26, 27] With this in mind, the researcher will accompany the
24 participant within the context in which care is being delivered, with all conversation
25 recorded digitally. Recordings will be supplemented by field notes to provide context and
26 aid interpretation of transcribed data.[27] We are aware that a 'Go-Along' interview may
27 not be appropriate in all circumstances and so we will use this method sensitively according
28 to the context in which the researcher and patient are in and what is happening at that
29 time. For example, we will not observe intimate patient care such as using the toilet or
30 showering. We will always be guided by what the participant (and those also present) are
31 comfortable with and consent to.
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38 **Interviews**

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40 Observations and 'Go-Along' interviews will be supplemented by more formal semi-
41 structured interviews that will use a guide (see appendix 1) to provide a framework to the
42 discussions. This guide will contain some key questions, informed by the COM-B
43 framework[30] so addressing issues of capability, motivation and opportunity for patients
44 to be involved in their care at transitions, but will also be informed by the observations that
45 have occurred up to that point. Interviews will be co-generated by both participant and
46 researcher; to ensure that discussions are relevant to the research, the researcher will use
47 the interview schedule as a 'map' to guide the conversation, whilst remaining flexible
48 enough to follow participants as they express their experiences about being in hospital and
49 transitioning from hospital to home. Interviews will be recorded digitally. Individual
50 interviews are likely to take place in the hospital and in the patient's own home; if an
51 interview does take place in a setting that is not the patient's home, we will ensure that
52 these occur in a space that is sufficiently private. We may also conduct telephone interviews
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3 to speak with participants about an episode of care that has been delivered but not
4 observed by the researchers (visiting their GP, for example).
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6 We expect that each of these methods will be used to gather data from each participant,
7 but to remain sensitive to the needs of the patient or carer, the context within which health
8 care is delivered, and the needs of the research, we will employ them flexibly and
9 sensitively. For example, sometimes it may not be appropriate to use a more participatory
10 approach, such as a 'Go-Along' interview, because it is important that we capture
11 interactions between health care professionals and patients as they would naturally occur,
12 without the participation of the researcher. Also, important care may be being delivered
13 and the participation of the researcher in the interaction would disrupt the delivery of that
14 care (within a rehabilitation therapy session, for example). At other times, however, it may
15 be helpful to use the time spent with patients as they are moving from one location to
16 another, for example, capturing their thoughts, feelings, and beliefs about what has and is
17 happening to them in that moment, alongside their expectations about what will happen in
18 the future. Within this context a more structured non-participant observation would likely
19 fail to capture the richness of the patient's experience. More formal semi-structured
20 interviews will complement both types of observational work.
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27 Timing of Data Collection

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30 'Time' and 'place' are two important features of any transitions process. We have therefore
31 designed the research to capture as much of the temporospatial aspects of the transition
32 from hospital to home as possible. This includes collecting data from participants at various
33 time points within the transitions process, and in various locations. It also involves exploring
34 the significance of 'time' and 'place' with participants.
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37 Data collection will be organised around five 'episodes', over a period of 3-4 months:

- 38 1. Upon, or shortly after, admission to hospital;
 - 39 2. Shortly prior to and/ or during discharge from the admitting hospital;
 - 40 3. A day or two after discharge in the home or intermediate care;
 - 41 4. Several weeks after discharge;
 - 42 5. Three months after discharge or on readmission if sooner.
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50 Data collection may occur within the admitting hospital, an intermediate care facility, and in
51 the home of the participant. In addition, if the patient gives us permission, we will follow the
52 patients to appointments that form part of their 'discharge care package' (appointments
53 with therapists or district nurses, for example). We anticipate that we will see each patient
54 approximately five times (once within each 'transition episode'). However, the actual
55 number of times that we will see the participant will be guided by the needs and
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3 experiences of the patient. For example, someone experiencing fatigue as an outcome of
4 stroke may require more visits of a short duration to avoid placing unnecessary burden on
5 the participant. Alternatively, some patients may have multiple appointments at the point
6 of discharge and be happy for us to accompany them to each of these appointments. Data
7 collection will remain sufficiently flexible to meet the needs of the participants and the
8 research. We anticipate that all data collection will be complete by March 2018.
9

10 11 *Data Analysis*

12 All interviews will be digitally recorded and transcribed verbatim. Relevant contextual
13 details will be added to the interview transcripts from notes made by the researcher.
14 Researchers will make field notes during observations. After an observation session, the
15 researchers will use a digital recorder to describe what they observed and to digitally
16 capture their own interpretation of the session; this will then be transcribed verbatim.
17 Transcription will be done by an external agency and checked by the researcher who
18 collects the data.
19

20 Data analysis will be inductive and flexible, utilising a Framework approach [9] to identify
21 themes and analytical categories. Framework analysis allows the researcher to move from
22 raw data to wider explanatory accounts through a series of conceptual groupings and
23 meanings assigned to the data.[31, 32] The key stages of Framework analysis are:
24 familiarisation with data; identifying a thematic framework; indexing and sorting data;
25 reviewing and refining the thematic framework, and then summarising and displaying the
26 data through the construction of thematic matrices.[33] These matrices allow the data to
27 be reduced and distilled, whilst staying close to the original text. The matrices also facilitate
28 comparison within- and between- themes and cases (participants). Within-case comparison
29 will be particularly helpful when exploring the temporal aspects of the transitions process,
30 as it will allow exploration of changes in individual attitudes and experience over time. Data
31 analysis will be conducted by both researchers involved in data collection.
32

33 The thematic frameworks will be constructed by both researchers, using the interview guide
34 as a tool for organising the data. Each researcher will label and sort their own data using the
35 thematic framework but discussion about emergent findings will happen on a regular basis
36 and will be used to refine the thematic framework. The comparison work to identify
37 analytical categories and explanatory accounts will be done together and will also involve
38 members of the project patient panel. Qualitative data analysis software (NVivo 10 for
39 Windows) will be used to help manage and organise the data into thematic matrices.
40

41 42 **Patient and public involvement**

43 The Yorkshire Quality and Safety Research Group currently supports a patient and public
44 panel of 25 people representing the local patient community. This group have been involved
45 from the beginning of the PACT research study and will continue to provide input when
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3 necessary. In addition, we have recruited a panel of people who will work with the PACT
4 research team over the course of the study. Panel members will meet regularly as a group
5 to support the PACT study as a whole; panel members will also be working in pairs to
6 support one of the first three work-packages, including this study of patient experience. We
7 anticipate that the PACT patient panel will contribute to the analysis and interpretation of
8 research findings and to the development of the intervention in light of these findings. Panel
9 members will be supported by a research nurse with an expertise in patient and public
10 involvement in research.
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14 15 16 Ethics

17 18 19 *Ethics*

20 This study has been approved by the Wales 7 Research Ethics Committee (reference:
21 17/WA/0057).
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24 Prior to approaching any patient, the researcher will speak with a senior health care
25 professional to find out which patients may be approached to take part in the research. This
26 is to ensure that we do not approach people who are very unwell or at the end of their life.
27 At first approach, the researcher will be accompanied by a member of the clinical team, who
28 will make the first introduction. All potential participants will be provided with: verbal and
29 written information about the study; the opportunity to ask questions; and time to consider
30 whether they would like to participate. Informed consent will be gained from all participants
31 (patients and carers) who can consent for themselves. All research documents, such as
32 information sheets and consent forms are written in plain English using large print, and laid
33 out clearly to facilitate readability and understanding. Verbal consent scripts will be used
34 with people who struggle with written language or who have a physical impairment that
35 prevents them from signing a consent form.
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40 We recognise that consent is an ongoing process. Therefore, at every research encounter
41 we will check whether participants still wish to take part prior to starting any data
42 collection. As far as possible the same researcher will do all follow-up work with the same
43 patient to promote the building of a relationship and to avoid confusion for the older person
44 and/or their carer. Participants will be free to withdraw from the study at any time and can
45 choose whether the data collected about them is included in the analysis.
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50 All personal identifiable data will be kept securely in line with legal requirements and best
51 practice recommendations to ensure confidentiality. Participants will be assigned
52 pseudonyms so that they cannot be identified.
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55 When healthcare staff are present during an observation, verbal consent will be sought
56 from the staff member at that time. If they agree to observation and/or audio-recording,
57 the observation will continue as planned. If they do not agree to be observed, the
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3 researcher will seek to understand what the staff member is and is not comfortable with
4 and proceed accordingly. For example, a member of staff may agree for a researcher to be
5 present but would not like any details about them or their actions recorded in any way. In
6 this circumstance, and with the patient's permission, the researcher may stay and observe
7 but will not record any information about the staff member. If the staff member declines all
8 observation, then the researcher will not observe the interaction and will follow up with
9 research participants after the interaction is over and the staff member is no longer present.
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12 *Safeguarding*

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15 Consent will be obtained on the understanding that all interactions are confidential unless
16 the researcher witnesses actions which cause them to be concerned for an individual's
17 safety. Should a researcher believe that a research participant (or other person) is at risk of
18 harm, through observation or disclosure during an interview, the researcher will encourage
19 the person to raise this with a relevant professional, or offer to raise it on their behalf.
20 Should consent not be given by the person, if the researcher feels that the person is at risk
21 then the researcher will disclose the issue/incident without consent but in the interest of
22 the person's safety and well-being. Guidance will be sought from local clinical collaborators
23 regarding appropriateness to escalate concerns. In emergency or urgent situations (e.g.
24 witnessing a person fall, or experience life-threatening symptoms such as severe breathing
25 difficulties), the researcher will immediately contact the appropriate emergency services.
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31 *Dissemination*

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33 The findings of the study will contribute to the other work packages (WP) within the
34 programme of work. Particular contributions include using the data to: inform the
35 development (and subsequent testing) of a patient-centred intervention that aims to
36 improve the transitions experience and reduce hospital readmissions (WPs 4, 5, 6); and to
37 inform the development of a measure of the quality of transitions, which will be used as a
38 secondary outcome measure within the PACT RCT (WPs 3, 6).
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42 We will also develop 'patient experience of transitions' resources in the form of anonymised
43 stories to help communicate the main findings of the project to both academic and clinical
44 groups. For example, the Academic Health Science Network Improvement Academy and
45 educational institutions will be used to disseminate these resources to people undergoing
46 training and/or quality improvement work. We will also be hosting a national conference to
47 showcase findings from this project and two of the other linked work-packages.
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51 We will publish our research findings in academic and professional journals and present our
52 work at relevant national and international conferences. We also plan to support
53 dissemination through a website, social media, and through networks. We have experience
54 of using these formats for reaching a variety of audiences, but particularly our local clinical
55 networks. Twitter has proved a particularly effective method for sharing our ideas, alerting
56 people to our recent findings, and discussing new ideas and concepts.
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3 Our dissemination strategy has been developed in partnership with various stakeholders,
4 including our patient panel. We will continue to engage with and involve these groups to
5 ensure that the research findings can be translated effectively into clinical practice and to
6 maximise the impact of the research locally and nationally.
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9 Discussion

10 *Strengths and weaknesses*

11
12 This study seeks to explore and describe the experience of older people and their families as
13 they transition from hospital to home. Utilising multiple in-depth qualitative research
14 methods enables us to capture detailed accounts of experiences and perceptions of
15 experiences, alongside the context within which care is occurring. Nonetheless, we
16 recognise that observational methods have the potential to introduce bias into the study,
17 because people (in this case, health service staff) may change their behaviour when they
18 know they are being observed. However, in agreement with McNaughton Nicholls *et al*,
19 2014 [34] we believe that the strengths of observational methods, e.g. access to rich data
20 that would not be accessible otherwise, alongside insight into “interactions, processes and
21 behaviours that goes beyond... verbal accounts”, outweighs the potential risk inherent
22 within the research process.
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26 Being informed by a resilience engineering approach, the research will involve exploring
27 what goes well, alongside identifying areas for improvement. The study design means that
28 the findings will not be generalisable to all older people transitioning from hospital to home.
29 Nonetheless, the research accounts have the capacity to provide data which are credible,
30 dependable and transferable to others.[35] Moreover, Rossman and Rallis, 2003 [36] argue
31 that ‘the ultimate goal of qualitative research is learning, that is, the transformation of data
32 in to information that can be used. *Use can be considered an ethical mandate*’. The use of
33 the findings of this study as a basis for a new patient-centred intervention can be
34 considered to fulfil this ethical mandate and is thus a strength of this research.
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38 The findings of the research will contribute to the development and testing of a person-
39 centred intervention that aims to improve patient experience and reduce the risk of hospital
40 readmission. It is anticipated that improving the patient experience of the transitions
41 process /will contribute to improved safety and quality of care [11, 37] during this transition
42 period. It is also anticipated that providing good transitional care will reduce hospital
43 readmissions. This has benefits for patients and their families, as being in hospital is
44 associated with a number of risks and has a psychological and physical impact on patients
45 and their families.[13, 15] Risks such as hospital-acquired infections are increased, for
46 example, and issues such as disrupted sleep, nutritional deficiencies and problems caused
47 by poor nourishment, increased stress and anxiety, and deconditioning due to inactivity and
48 bedrest can place additional burdens on people already dealing with one or more conditions
49 or trauma.[7] Reducing readmissions also has benefits for the health service which is under
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3 pressure to deliver more care with less resource. Moreover, NHS Trusts now incur financial
4 penalties for readmissions within 30 days; reducing readmissions would reduce spending on
5 such penalties.
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8 We want to learn from older people and their families about what works for them in the
9 care that they receive and to find out what would improve their experience of the
10 transitions process. Exploring the transitions process from their perspective, particularly
11 looking at where and how people can be involved in their care, and using this data to
12 develop an intervention, means that the patient is at the heart of quality improvement. This
13 research will also add to an existing body of knowledge about patient experiences of care at
14 transitions.[14, 16-20] Importantly, this research will capture the temporospatial
15 experiences of transitions by following older people and their families during their transition
16 journey from admission through to three months post-discharge. This element is missing
17 from existing research, most of which captures patient experience data at only one time
18 point. Moreover, much of the existing research exploring patient experience data about
19 care at transitions appears to capture what goes wrong, or the ways in which individuals are
20 dissatisfied with the care they receive. Conversely, our research will be exploring what goes
21 well at transitions of care, as well as seeking to identify areas for improvement. By doing so,
22 we will add an important dimension to the growing knowledge base about care at the
23 transition from hospital to home. Also, the adoption of a resilience-engineering approach to
24 safety acknowledges the positive contribution that all people can make to the delivery of
25 good quality, safe healthcare –and engenders the harnessing of a genuine partnership to
26 improve patient experience and clinical outcomes.
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37 Author's Contributions

38 RL, AC, LS and YB designed the overall programme of research and conception of studies
39 within. All authors were involved in the design of the current study and have contributed to
40 the drafting, reviewing and final approval of the manuscript.
41
42

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45
46

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Competing Interests Statement

None declared.

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Appendix

PACT WP1 Interview Guide

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PACT WP1 Interview Guide

Section 1: Getting to know people (ADMISSION)

Find out about their life e.g. where they live, who they live with, what job they used to do, do they have any children etc.

Section 2: Being admitted to hospital (ADMISSION)

a) Why have they been admitted to hospital? How did they get here?

If they mention a condition, is it their main/only health concern? If not, what is?

Probe for: **causative factors**, *expected duration of problems*, **expectations of treatments etc**, *impact on life*, **(if the problem preceded this hospital admission) what/who helps them to cope with/manage daily life?**

b) Could anything have avoided them coming into hospital?

c) Before they came into hospital, what contact did they have with health and/or social care professionals? Is this normal for them?

d) How do they feel about being in hospital?

e) What makes hospital care 'good'? What would make it better?

f) What do they think will happen next? What information have they been given? Do they feel they feel they have had had enough information?

Probe for: **patient's understanding of why things are happening**, *how they know what is happening*.

g) How do they feel about going home?

Section 3: Questions about involvement (ADMISSION & POST-DISCHARGE)

h) How involved have they been in discussions about them and their treatment and care? How do they feel about this? Probe for: *choice*, **decision-making**, *information (given and received)*, **consultation about discharge process?**

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- i) How involved have they been able to be in their self-care whilst in hospital? E.g. normal daily activities?
 - j) What things are they able or would like to be able to do for themselves?
 - k) What would they like to be done for them?
 - l) Who else is involved in their care (e.g. family members)?
 - m) Do they have any questions about their condition, treatment, or care? If so, have they asked anyone these questions?

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Section 4: Health and social issues (ADMISSION & POST-DISCHARGE – all interactions)

How are they managing their medication (getting them, taking them, understand them)? Have they fallen/problems with mobility? Any problems with equipment (e.g. catheters or adaptive equipment)? Any wound problems? Pressure ulcers? Appetite and thirst? Sleep? How are they managing with normal daily activities (e.g. washing, dressing, going to the toilet, getting around, shopping, seeing friends and family)? Any issues with appointments (making them, keeping them, or travelling to them)? Company? Energy levels? Pain (if so, well-managed)?

Section 5: Perceptions of risks & concerns at the moment (ADMISSION)

- n) QUESTION: 'How safe and cared for do you feel at the moment?' (Probe: why/why not)
- o) Has there been anything that has concerned them about the care they've had since being in hospital?
- p) Is there anything in your life that is worrying or concerning them at the moment?
- q) Have they shared their concerns with anyone? (Prompt for details e.g. who, how did they do it)
- r) Do they have any ideas about what could make them feel... better/less worried/more comfortable/more confident (use patient's own words if appropriate)?
- s) What things do they wish that staff knew and understood about them and their life?

Section 6: Perceptions of risks & concerns about the future (ADMISSION)

- t) What issues do they think they could face when they leave hospital to go home?

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3 u) Have they spoken to anybody about these things? If so, who?
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5 v) Do they have any ideas about what things could be done so that [issues raised] don't happen/are
6 avoided?
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8 w) QUESTION: What do you think might be expected of you when you get home?
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11 **Section 7: Gaining an update (ALL SUBSEQUENT INTERACTIONS)**
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14 x) How are they at the moment?
15
16 y) Can you tell me what has happened to you [today...yesterday...etc/since I saw you last/since you
17 came into hospital]? (Probe for their understandings about why these things have happened)
18
19 z) What have people done to help them feel supported and cared for, recently?
20
21 aa) How involved have they been in their care? How do they feel about this?
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25 **Section 8: Being at home (POST-DISCHARGE)**
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- 27 bb) QUESTION: How do you feel about being at home?
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29 cc) Can you tell me what's happened since the last time I spoke to you (give day/date/location) if
30 possible?
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32 dd) What do you think and feel about [what has happened to you]?
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35 ee) Who has been providing support or help since you came home?
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38 ff) Do they feel that life is back to normal now? What have they been doing to make life as normal as
39 possible? (Prompt for motives)
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42 gg) What makes it easier to come home after being in hospital? What could stop them going into
43 hospital?
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46 hh) If they needed help with anything, what would they do/who would they ask?
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49 **Section 9: Summarising (FINAL INTERVIEW)**
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- 51 ii) Thinking about being in hospital, what was good? What could have been better?
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53 jj) Thinking about the discharge, what was good? What could have been better?
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55 kk) Thinking about any treatment or care you have had since being at home, what has been good? What
56 could be better?
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3 ll) Did they feel ready to be discharged?
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5 mm) Looking back, is there anything that anyone or anything the hospital did that made it easier for
6 them to come home?
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8 nn) Is there anything that anyone has done for them/they've done for themselves that has helped them
9 get back to normal?
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12 **Section 10: Readmission (READMISSION)**
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14 oo) Why have they been readmitted to hospital?
15

16 pp) How did they come to be in hospital? (Prompt: did someone refer them? Transport to hospital?)
17

18 qq) Before they came into hospital, what contact did they have with HSCPs? Is that normal for them?
19

20 rr) How do they feel about being back in hospital?
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22 ss) What do they think is going to happen next?
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24 tt) QUESTION: Do you think anything could have avoided you having to come back to hospital?
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BMJ Open

Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning from hospital to home in the UK: protocol for an observation and interview study of older people and their families to understand patient experience and involvement in care at transitions.

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4 Partners At Care Transitions (PACT). Exploring older peoples'
5 experiences of transitioning from hospital to home in the UK:
6 protocol for an observation and interview study of older people and
7 their families to understand patient experience and involvement in
8 care at transitions.
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15 Corresponding author: Dr Natasha Kate Hardicre, Yorkshire Quality and Safety Research
16 Group, Bradford Institute for Health Research, Temple Bank House, Bradford Royal
17 Infirmary, Duckworth Lane, Bradford, West Yorkshire, BD9 6RJ.

18 Email: Natasha.hardicre@bthft.nhs.uk.

19 ORCID: 0000-0002-3639-5556

20 Telephone: 01274383428
21
22
23

24 Co-authors:

25
26 Professor Yvonne Birks, Social Policy Research Unit, University of York, York, UK.

27
28 Dr Jenni Murray, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
29 Research, Bradford, UK.

30
31 Dr Laura Sheard, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
32 Research, Bradford, UK.

33
34 Dr Lesley Hughes, Yorkshire Quality and Safety Research Group, Bradford Institute for
35 Health Research, Bradford, UK.

36
37 Dr Jane Heyhoe, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
38 Research, Bradford, UK.

39
40 Dr Alison Cracknell, Leeds Centre for Older People's Medicine, Leeds Teaching Hospitals NHS
41 Trust, Leeds, UK.

42
43 Professor Rebecca Lawton, School of Psychology, University of Leeds, Leeds, UK.
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3 Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning
4 from hospital to home in the UK: a qualitative study protocol.
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7 **Abstract**

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9 Introduction: Lengths of hospital inpatient stays have reduced. This benefits patients, who
10 prefer to be at home, and hospitals, which can treat more people when stays are shorter.
11 Patients may, however, leave hospital sicker, with ongoing care needs. The transition period
12 from hospital to home, can be risky, particularly for older patients with complex health and
13 social needs. Improving patient experience, especially through greater patient involvement,
14 may improve outcomes for patients and is a key indicator of care quality and safety. In this
15 research we aim to: capture the experiences of older patients and their families during the
16 transition from hospital to home; and identify opportunities for greater patient involvement
17 in care, particularly where this contributes to greater individual- and organisational-level
18 resilience.
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23 Methods and Analysis: A 'focused ethnography' comprising observations, 'Go-Along' and
24 semi-structured interviews will be used to capture patient and carer experiences during
25 different points in the care transition from admission to 90 days after discharge. We will
26 recruit 30 patients and their carers from six hospital departments across two NHS Trusts.
27 Analysis of observations and interviews will use a Framework approach to identify themes
28 to understand the experience of transitions and generate ideas about how patients could be
29 more actively involved in their care. This will include exploring what 'good' care at
30 transitions look like and seeking out examples of success, as well as recommendations for
31 improvement.
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36 Ethics and dissemination: Ethical approval was received from the NHS Research Ethics
37 Committee in Wales. The research findings will add to a growing body of knowledge about
38 patient experience of transitions, in particular providing insight into the experiences of
39 patients and carers throughout the transitions process, in 'real time'. Importantly, the data
40 will be used to inform the development of a patient-centred intervention to improve the
41 quality and safety of transitions.
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46 **Strengths and limitations**

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- Utilising a range of qualitative methods, the study will generate rich, in depth data to contextualise patient involvement and experiences of transitions of care from hospital admission and throughout the transitions period, from the point of view of older people and their carers.
 - The longitudinal approach enables us to gain insight into how patient experience and involvement change over time.

- While the study design enables in-depth data to be captured from a small number of older people and their carers, as is the nature of qualitative inquiry, this limits generalisability of findings. The study is situated within a larger programme which will allow greater generalisability, as the programme of work progresses informed by this phase.
- Although non-participant observation can generate rich contextual data that are not as easily accessed via other methods, the presence of a researcher has the potential to affect the behaviour of those being observed.

Introduction

Reduced lengths of stay in hospital can result in patients being discharged from hospital to home with ongoing treatment and care needs. Shorter stays in hospital have benefits for both patients, who prefer to be at home, and hospitals, which can treat more patients if stays are shorter. However, reduced stays can also result in an increased reliance on care outside the inpatient setting, for example, wound or catheter care, changes to medication, or input from therapy services. 'Discharge' from hospital is, therefore, more likely to be a stage in a process involving the *transfer* of care, rather than being an *end-point* of care. The movement and transfer of care from hospital to home – sometimes referred to as the 'transition period' – is likely to involve input from multiple agencies to meet patients' ongoing care needs. It is a highly variable and complex process that is contingent upon on several factors, for example service provision, resource capacity, and knowledge transfer within and between secondary care teams, GPs and corollary services, community therapy teams, and adult social care services;^[1] alongside the social support networks and resources that patients themselves have access to (or not). Consequently, the transition of care from hospital into community settings can be a risky one. Additionally, older people may experience more than one 'transition' in a single hospital admission episode, for example, moving between wards or via intermediate care at a different location. Likewise, some older people may experience readmissions within a short period of time. The transitions process may not, therefore, be a linear one, resulting in further complexity.

As many as one in five patients experience an adverse event in the transition from hospital to home, 62% of which could be prevented;^[2] this is double the number of adverse events experienced by patients during a hospital stay.^[3] For older patients, who are more likely to have complex health and social needs, and who may be anxious, confused, and disorientated,^[4, 5] the risks associated with transitions of care may be greater than that of the general population. This may result in a higher than average rate of readmission to hospital,^[6] thereby prolonging the overall patient stay. This counteracts the benefit of reduced patient stays, and further exposes patients to risks associated with being in hospital. Krumholtz^[7] argues, for example, that hospitalisation causes 'substantial stress' to patients, through causes such as disrupted sleep, poor nourishment, 'a baffling array of mentally challenging situations', changes to medication, and deconditioning associated with

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3 inactivity and bedrest. Older people are particularly vulnerable to such stressors as they are
4 more likely to have multiple morbidities, take multiple medications, and remain inactive.[8,
5 9] Moreover, older people are the highest users of the NHS and, with the number of people
6 in the UK aged 75 and over set to double in the next 30 years, this group of patients is an
7 important target for support.[10] Increased risk associated with both hospitalisation and
8 the transition period suggests that improving the quality and safety of care during this time
9 ought to be a focus of this targeted support.
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13 Patient experience of care is a key indicator of quality and safety [11] and so an important
14 target for intervention. Indeed, this strong relationship between patient experience and
15 outcomes suggests that those interested in improving health outcomes (quality, safety, and
16 cost savings) should strive first to improve patient experiences, especially by focusing on
17 activities such as patient engagement. However, despite a growing emphasis on shared care
18 and patient empowerment [12] the involvement of patients in their care before, during,
19 and after transitions remains minimal, with patients feeling that they are not always
20 listened to and that they did not have a 'lot of say' in their care.[13-19] A recent systematic
21 review of patient experiences of transitions highlighted the necessity of involving older
22 people and their carers in the discharge process, but reported variability in the degree to
23 which this was achieved.[20] The study described in this protocol forms the first of six
24 interlinked 'work packages' (WP) in an NIHR-funded Programme Grant for Applied Health
25 Research (PGfAR) that aims to understand and improve the experience, and safety, of care
26 for older patients during transitions and, by doing so, reduce readmissions and NHS costs. In
27 particular, we want to explore whether greater involvement of patients and their families
28 can improve patient experience and safety at the transitions of care. This will involve
29 exploring patient experience of transitions and using these data to develop and test a
30 patient-centred intervention that supports the involvement of older people, and their
31 families, in their care.
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40 There are several published studies that have explored patient and carer perspectives on
41 care at transitions [13-20]. However, much of this work appears to capture people's
42 experiences at a single time point, often retrospectively after discharge. However, this study
43 will recruit people whilst in the inpatient hospital setting, and follow them until
44 approximately three months post-discharge. The longitudinal nature of the study will enable
45 us to capture continuity and change in experience and involvement over time and will thus
46 contribute new data and findings to a growing body of literature on care at transitions.
47 Moreover, the programme of work utilises a resilience engineering approach to safety in
48 healthcare.[21] We especially want to learn from what goes well at transitions, rather than
49 focusing only on what goes wrong; doing so "sheds light on otherwise unrecognised and
50 unspecified pathways to success".[22] Within this project, we want to understand the
51 things that patients, relatives and health service staff (or others) do to enable patients and
52 their families to be resilient within the transitions process. However, we also want to
53 explore the ways in which patients and their carers do or could contribute to organisational
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3 resilience. Schubert *et al*,[23] for example, suggest that patients/caregivers can “identify
4 and prevent mistakes from happening, and participate in improving their care” by
5 navigating a “fragmented system” through the co-ordination of tasks across multiple health
6 care settings and providers. This will enable us to take a proactive approach towards care
7 during the transitions period; developing an intervention that helps to inform people about
8 what they can do to make the transitions process ‘good’. We believe this is a novel approach
9 towards understanding and improving care at the transitions period.
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13 The research study described here focuses on understanding the transitions process from
14 the perspective of those experiencing it – patients and their families. There are two main
15 foci of the research:
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- 17 1) EXPERIENCE: Describing the transitions process from the point of view of older patients
18 and their carers;
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- 20 2) INVOLVEMENT: Exploring where the opportunities are for improving patient
21 involvement in the transitions process.
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25 Research questions are:
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- 27 1. a. What do patients and their families experience during the transition of care from
28 hospital to place of residence?
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30 b. What do patients think, feel, and believe about this process?
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- 33 2. How can people be more involved in their care:
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35 a. To what extent do people feel involved in their care? What are their perspectives on
36 this?
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38 b. Where are the opportunities for patients to be more involved in their care?
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40 c. To what extent do people feel *able* to be (more) involved in their care? What has, or
41 would help them to, feel able to be (more) involved in their care?
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46 Methods and analysis

47 *Recruiting patients*

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49 Beginning in May 2017, thirty older patients (aged 75+), and their immediate carers, will be
50 recruited to the study. Patients and carers will be recruited from six departments
51 specialising in elderly medical care, respiratory care, orthopaedic care of the elderly, and
52 stroke, across two hospitals. The departments have been selected for the study to reflect
53 different transitional challenges, emergency and elective admissions (including elective
54 surgery), acute and chronic illness, and multi-morbidity or poly-pharmacy issues.
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3 We will attempt to recruit a diverse sample of patients from different ethnicities, and
4 gender groups, as well as a variety of ages – including the ‘oldest old’ (aged 85+) – wherever
5 possible. One of the hospitals serves a large South-East Asian population, some of whom do
6 not speak or read English. To facilitate inclusion, a translator will work with researchers to
7 approach and consent patients who speak Urdu and/or Potwari – the languages most
8 commonly spoken amongst the largest non-English speaking group in that area – and
9 provide translation services during the course of the research. We will also try to ensure
10 that people with and without carers are included in the research, as carer involvement is
11 likely to have an impact on the patient’s experience of transition. Opportunity sampling will
12 be employed initially; we will monitor the diversity of the sample as participants are
13 recruited. Should the sample lack variation, sampling will become purposive. We anticipate
14 that a sample of 30 patients is likely to allow us to capture some diversity and is also likely
15 to achieve theoretical saturation; however, this will be reviewed as analysis proceeds to
16 ensure any gaps are covered.
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23 We are excluding patients who are at the end of their life or whose care has become
24 palliative, so as not to place additional burden on themselves or their families. We will,
25 however, be approaching people with cognitive or language impairments, including patients
26 who lack or have variable capacity to consent to the research for themselves, if they have
27 suitable support in place to help them to participate in the research. This group of patients
28 are likely to be especially vulnerable during the transitions period; thus, it is particularly
29 important to capture their experiences and those of the people who care for them to
30 explore opportunities to reduce risk to this population. All the researchers working on the
31 study have received additional training on taking informed consent in adults lacking
32 capacity. When a patient is identified as not having the capacity to give consent, in line with
33 the Mental Capacity Act 2005,[24] the researcher will take reasonable steps to identify a
34 personal consultee to advise on the presumed wishes and feelings of participants unable to
35 consent for themselves and on their inclusion and participation in the research. We will also
36 seek to recruit the consultee as a participant in the study, so that they can provide support
37 to the patient-participant throughout the research process.
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44 *Data collection*

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46 As part of a focused ethnographic approach,[25] we will employ the following methods to
47 explore experiences and identify likely influences on outcomes:
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- 49 • Non-participant observation, with discussions about 'key moments';
 - 50 • ‘Go-Along’ interviews[26,27]
 - 51 • Individual semi-structured interviews.
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55 These data collection methods will be combined flexibly within this study to enable us to
56 gather rich insightful data into what patients think, feel, and believe about the process of
57 leaving hospital to return home. Two researchers will be responsible for data collection,
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3 each following the patients they recruit for their entire 'transitions journey' (where
4 possible).
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6 7 **Observations**

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9 Observations will be used to explore what happens to a patient at various time points and
10 locations as they transition from hospital to home, including within the admitting hospital, a
11 transitional care facility, the patient's residence, and other care settings. Non-participant
12 observation offers a direct view of behaviours in their natural setting.[28, 29] It allows the
13 researcher insight into what is done, and how, by various people involved in delivering care
14 over the transition period (for example, healthcare professionals, support and
15 administrative staff, the voluntary sector, and patients and their carers themselves).
16
17 Observations will provide the foundation for short informal conversations (approximately
18 10-15 minutes) to follow up on 'key moments' observed on a previous occasion. These will
19 happen as close to the original event as possible, to enable accurate recall. Observations
20 and conversations will be captured through field notes. An observation framework will be
21 developed for this study as a prompt for observer field notes, ensuring accurate, in-depth
22 recording of observations and facilitating analysis.
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27 **Go-Along Interviews**

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29 'Go-Along' interviewing is a participatory method that is person-centred and interactive,
30 that is, they focus on understanding the experiences of a person within changing contexts in
31 real-time. Interviewing someone whilst they are experiencing something in real-time can
32 facilitate articulation of attachments, feelings and memories that might otherwise remain
33 unconscious or unsaid.[26, 27] With this in mind, the researcher will accompany the
34 participant within the context in which care is being delivered, with all conversation
35 recorded digitally. Recordings will be supplemented by field notes to provide context and
36 aid interpretation of transcribed data.[27] We are aware that a 'Go-Along' interview may
37 not be appropriate in all circumstances and so we will use this method sensitively according
38 to the context in which the researcher and patient are in and what is happening at that
39 time. For example, we will not observe intimate patient care such as using the toilet or
40 showering. We will always be guided by what the participant (and those also present) are
41 comfortable with and consent to.
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48 **Interviews**

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50 Observations and 'Go-Along' interviews will be supplemented by more formal semi-
51 structured interviews that will use a guide (see appendix 1) to provide a framework to the
52 discussions. Informed by the COM-B framework[30], this guide will contain some key
53 questions addressing issues of capability, motivation and opportunity for patients to be
54 involved in their care at transitions; it will also be informed by the observations that have
55 occurred up to that point. Interviews will be co-generated by both participant and
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3 researcher; to ensure that discussions are relevant to the research, the researcher will use
4 the interview schedule as a 'map' to guide the conversation, whilst remaining flexible
5 enough to follow participants as they express their experiences about being in hospital and
6 transitioning from hospital to home. Interviews will be recorded digitally. Individual
7 interviews are likely to take place in the hospital and in the patient's own home; if an
8 interview does take place in a setting that is not the patient's home, we will ensure that
9 these occur in a space that is sufficiently private. We may also conduct telephone interviews
10 to speak with participants about an episode of care that has been delivered but not
11 observed by the researchers (visiting their GP, for example).
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16 We expect that each of these methods will be used to gather data from each participant,
17 but to remain sensitive to the needs of the patient or carer, the context within which health
18 care is delivered, and the needs of the research, we will employ them flexibly and
19 sensitively. For example, sometimes it may not be appropriate to use a more participatory
20 approach, such as a 'Go-Along' interview, because it is important that we capture
21 interactions between health care professionals and patients as they would naturally occur,
22 without the participation of the researcher. Also, important care may be being delivered
23 and the participation of the researcher in the interaction would disrupt the delivery of that
24 care (within a rehabilitation therapy session, for example). At other times, however, it may
25 be helpful to use the time spent with patients as they are moving from one location to
26 another, for example, capturing their thoughts, feelings, and beliefs about what has and is
27 happening to them in that moment, alongside their expectations about what will happen in
28 the future. Within this context a more structured non-participant observation would likely
29 fail to capture the richness of the patient's experience. More formal semi-structured
30 interviews will complement both types of observational work.
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37 Timing of Data Collection

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39 'Time' and 'place' are two important features of any transitions process. We have therefore
40 designed the research to capture as much of the temporospatial aspects of the transition
41 from hospital to home as possible. This includes collecting data from participants at various
42 time points within the transitions process, and in various locations. It also involves exploring
43 the significance of 'time' and 'place' with participants.
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47 Data collection will be organised around five 'episodes', over a period of 3-4 months:

- 48 1. Upon, or shortly after, admission to hospital;
 - 49 2. Shortly prior to and/ or during discharge from the admitting hospital;
 - 50 3. A day or two after discharge in the home or intermediate care;
 - 51 4. Several weeks after discharge;
 - 52 5. Three months after discharge or on readmission if sooner.
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3 Data collection may occur within the admitting hospital, an intermediate care facility, and in
4 the home of the participant. In addition, if the patient gives us permission, we will follow the
5 patients to appointments that form part of their 'discharge care package' (appointments
6 with therapists or district nurses, for example). We anticipate that we will see each patient
7 approximately five times (once within each 'transition episode'). However, the actual
8 number of times that we will see the participant will be guided by the needs and
9 experiences of the patient. For example, someone experiencing fatigue as an outcome of
10 stroke may require more visits of a short duration to avoid placing unnecessary burden on
11 the participant. Alternatively, some patients may have multiple appointments at the point
12 of discharge and be happy for us to accompany them to each of these appointments. Data
13 collection will remain sufficiently flexible to meet the needs of the participants and the
14 research. We anticipate that all data collection will be complete by March 2018.

20 *Data Analysis*

21 All interviews will be digitally recorded and transcribed verbatim. Relevant contextual
22 details will be added to the interview transcripts from notes made by the researcher.
23 Researchers will make field notes during observations. After an observation session, the
24 researchers will use a digital recorder to describe what they observed and to digitally
25 capture their own interpretation of the session; this will then be transcribed verbatim.
26 Transcription will be done by an external agency and checked by the researcher who
27 collects the data.

28
29 Data analysis will be inductive and flexible, utilising a Framework approach [9] to identify
30 themes and analytical categories. Framework analysis allows the researcher to move from
31 raw data to wider explanatory accounts through a series of conceptual groupings and
32 meanings assigned to the data.[31, 32] The key stages of Framework analysis are:
33 familiarisation with data; identifying a thematic framework; indexing and sorting data;
34 reviewing and refining the thematic framework, and then summarising and displaying the
35 data through the construction of thematic matrices.[33] These matrices allow the data to
36 be reduced and distilled, whilst staying close to the original text. The matrices also facilitate
37 comparison within- and between- themes and cases (participants). Within-case comparison
38 will be particularly helpful when exploring the temporal aspects of the transitions process,
39 as it will allow exploration of changes in individual attitudes and experience over time. Data
40 analysis will be conducted by both researchers involved in data collection.

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42 The thematic frameworks will be constructed by both researchers, using the interview guide
43 as a tool for organising the data. Each researcher will label and sort their own data using the
44 thematic framework but discussion about emergent findings will happen on a regular basis
45 and will be used to refine the thematic framework. The comparison work to identify
46 analytical categories and explanatory accounts will be done together and will also involve
47 members of the project patient panel. Qualitative data analysis software (NVivo 10 for
48 Windows) will be used to help manage and organise the data into thematic matrices.

Patient and public involvement

The Yorkshire Quality and Safety Research Group currently supports a patient and public panel of 25 people representing the local patient community. This group have been involved from the beginning of the PACT research study and will continue to provide input when necessary. In addition, we have recruited a panel of people who will work with the PACT research team over the course of the study. Panel members will meet regularly as a group to support the PACT study as a whole; panel members will also be working in pairs to support one of the first three work-packages, including this study of patient experience. We anticipate that the PACT patient panel will contribute to the analysis and interpretation of research findings and to the development of the intervention in light of these findings. Panel members will be supported by a research nurse with an expertise in patient and public involvement in research.

Ethics

Ethics

This study has been approved by the Wales 7 Research Ethics Committee (reference: 17/WA/0057).

Prior to approaching any patient, the researcher will speak with a senior health care professional to find out which patients may be approached to take part in the research. This is to ensure that we do not approach people who are very unwell or at the end of their life. At first approach, the researcher will be accompanied by a member of the clinical team, who will make the first introduction. All potential participants will be provided with: verbal and written information about the study; the opportunity to ask questions; and time to consider whether they would like to participate. Informed consent will be gained from all participants (patients and carers) who can consent for themselves. All research documents, such as information sheets and consent forms are written in plain English using large print, and laid out clearly to facilitate readability and understanding. Verbal consent scripts will be used with people who struggle with written language or who have a physical impairment that prevents them from signing a consent form.

We recognise that consent is an ongoing process. Therefore, at every research encounter we will check whether participants still wish to take part prior to starting any data collection. As far as possible the same researcher will do all follow-up work with the same patient to promote the building of a relationship and to avoid confusion for the older person and/or their carer. Participants will be free to withdraw from the study at any time and can choose whether the data collected about them is included in the analysis.

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3 All personal identifiable data will be kept securely in line with legal requirements and best
4 practice recommendations to ensure confidentiality. Participants will be assigned
5 pseudonyms so that they cannot be identified.
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8 When healthcare staff are present during an observation, verbal consent will be sought
9 from the staff member at that time. If they agree to observation and/or audio-recording,
10 the observation will continue as planned. If they do not agree to be observed, the
11 researcher will seek to understand what the staff member is and is not comfortable with
12 and proceed accordingly. For example, a member of staff may agree for a researcher to be
13 present but would not like any details about them or their actions recorded in any way. In
14 this circumstance, and with the patient's permission, the researcher may stay and observe
15 but will not record any information about the staff member. If the staff member declines all
16 observation, then the researcher will not observe the interaction and will follow up with
17 research participants after the interaction is over and the staff member is no longer present.
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22 *Safeguarding*

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24 Consent will be obtained on the understanding that all interactions are confidential unless
25 the researcher witnesses actions which cause them to be concerned for an individual's
26 safety. Should a researcher believe that a research participant (or other person) is at risk of
27 harm, through observation or disclosure during an interview, the researcher will encourage
28 the person to raise this with a relevant professional, or offer to raise it on their behalf.
29 Should consent not be given by the person, if the researcher feels that the person is at risk
30 then the researcher will disclose the issue/incident without consent but in the interest of
31 the person's safety and well-being. Guidance will be sought from local clinical collaborators
32 regarding appropriateness to escalate concerns. In emergency or urgent situations (e.g.
33 witnessing a person fall, or experience life-threatening symptoms such as severe breathing
34 difficulties), the researcher will immediately contact the appropriate emergency services.
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40 **Dissemination**

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42 The findings of the study will contribute to the other work packages (WP) within the
43 programme of work. Particular contributions include using the data to: inform the
44 development (and subsequent testing) of a patient-centred intervention that aims to
45 improve the transitions experience and reduce hospital readmissions (WPs 4, 5, 6); and to
46 inform the development of a measure of the quality of transitions, which will be used as a
47 secondary outcome measure within the PACT RCT (WPs 3, 6).
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51 We will also develop 'patient experience of transitions' resources in the form of anonymised
52 stories to help communicate the main findings of the project to both academic and clinical
53 groups. For example, the Academic Health Science Network Improvement Academy and
54 educational institutions will be used to disseminate these resources to people undergoing
55 training and/or quality improvement work. We will also be hosting a national conference to
56 showcase findings from this project and two of the other linked work-packages.
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3 We will publish our research findings in academic and professional journals and present our
4 work at relevant national and international conferences. We also plan to support
5 dissemination through a website, social media, and through networks. We have experience
6 of using these formats for reaching a variety of audiences, but particularly our local clinical
7 networks. Twitter has proved a particularly effective method for sharing our ideas, alerting
8 people to our recent findings, and discussing new ideas and concepts.
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12 Our dissemination strategy has been developed in partnership with various stakeholders,
13 including our patient panel. We will continue to engage with and involve these groups to
14 ensure that the research findings can be translated effectively into clinical practice and to
15 maximise the impact of the research locally and nationally.
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18 Discussion

19 *Strengths and weaknesses*

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21 This study seeks to explore and describe the experience of older people and their families as
22 they transition from hospital to home. Utilising multiple in-depth qualitative research
23 methods enables us to capture detailed accounts of experiences and perceptions of
24 experiences, alongside the context within which care is occurring. Nonetheless, we
25 recognise that observational methods have the potential to introduce bias into the study,
26 because people (in this case, health service staff) may change their behaviour when they
27 know they are being observed. However, in agreement with McNaughton Nicholls *et al*,
28 2014 [34] we believe that the strengths of observational methods, e.g. access to rich data
29 that would not be accessible otherwise, alongside insight into “interactions, processes and
30 behaviours that goes beyond... verbal accounts”, outweighs the potential risk inherent
31 within the research process.
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39 Being informed by a resilience engineering approach, the research will involve exploring
40 what goes well, alongside identifying areas for improvement. The study design means that
41 the findings will not be generalisable to all older people transitioning from hospital to home.
42 Nonetheless, the research accounts have the capacity to provide data which are credible,
43 dependable and transferable to others.[35] Moreover, Rossman and Rallis, 2003 [36] argue
44 that ‘the ultimate goal of qualitative research is learning, that is, the transformation of data
45 in to information that can be used. *Use can be considered an ethical mandate*’. The use of
46 the findings of this study as a basis for a new patient-centred intervention can be
47 considered to fulfil this ethical mandate and is thus a strength of this research.
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52 The findings of the research will contribute to the development and testing of a person-
53 centred intervention that aims to improve patient experience and reduce the risk of hospital
54 readmission. It is anticipated that improving the patient experience of the transitions
55 process /will contribute to improved safety and quality of care [11, 37] during this transition
56 period. It is also anticipated that providing good transitional care will reduce hospital
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3 readmissions. This has benefits for patients and their families, as being in hospital is
4 associated with a number of risks and has a psychological and physical impact on patients
5 and their families.[13, 15] Risks such as hospital-acquired infections are increased, for
6 example, and issues such as disrupted sleep, nutritional deficiencies and problems caused
7 by poor nourishment, increased stress and anxiety, and deconditioning due to inactivity and
8 bedrest can place additional burdens on people already dealing with one or more conditions
9 or trauma.[7] Reducing readmissions also has benefits for the health service which is under
10 pressure to deliver more care with less resource. Moreover, NHS Trusts now incur financial
11 penalties for readmissions within 30 days; reducing readmissions would reduce spending on
12 such penalties.
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17 We want to learn from older people and their families about what works for them in the
18 care that they receive and to find out what would improve their experience of the
19 transitions process. Exploring the transitions process from their perspective, particularly
20 looking at where and how people can be involved in their care, and using this data to
21 develop an intervention, means that the patient is at the heart of quality improvement. This
22 research will also add to an existing body of knowledge about patient experiences of care at
23 transitions.[14, 16-20] Importantly, this research will capture the temporospatial
24 experiences of transitions by following older people and their families during their transition
25 journey from admission through to three months post-discharge. This element is missing
26 from existing research, most of which captures patient experience data at only one time
27 point. Moreover, much of the existing research exploring patient experience data about
28 care at transitions appears to capture what goes wrong, or the ways in which individuals are
29 dissatisfied with the care they receive. Conversely, our research will be exploring what goes
30 well at transitions of care, as well as seeking to identify areas for improvement. By doing so,
31 we will add an important dimension to the growing knowledge base about care at the
32 transition from hospital to home. Also, the adoption of a resilience-engineering approach to
33 safety acknowledges the positive contribution that all people can make to the delivery of
34 good quality, safe healthcare –and engenders the harnessing of a genuine partnership to
35 improve patient experience and clinical outcomes.
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46 Author's Contributions

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48 RL, AC, LS and YB designed the overall programme of research and conception of studies
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Competing Interests Statement

None declared.

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Appendix

PACT WP1 Interview Guide

PACT WP1 Interview Guide

Section 1: Getting to know people (ADMISSION)

Find out about their life e.g. where they live, who they live with, what job they used to do, do they have any children etc.

Section 2: Being admitted to hospital (ADMISSION)

a) Why have they been admitted to hospital? How did they get here?

If they mention a condition, is it their main/only health concern? If not, what is?

Probe for: **causative factors**, *expected duration of problems*, **expectations of treatments etc**, *impact on life*, **(if the problem preceded this hospital admission) what/who helps them to cope with/manage daily life?**

b) Could anything have avoided them coming into hospital?

c) Before they came into hospital, what contact did they have with health and/or social care professionals? Is this normal for them?

d) How do they feel about being in hospital?

e) What makes hospital care 'good'? What would make it better?

f) What do they think will happen next? What information have they been given? Do they feel they feel they have had had enough information?

Probe for: **patient's understanding of why things are happening**, *how they know what is happening*.

g) How do they feel about going home?

Section 3: Questions about involvement (ADMISSION & POST-DISCHARGE & FINAL INTERVIEW)

h) How involved have they been in discussions about them and their treatment and care? How do they feel about this? Probe for: *choice*, **decision-making**, *information (given and received)*, **consultation about discharge process?**

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- i) How involved have they been able to be in their self-care whilst in hospital? E.g. normal daily activities?
 - j) What things are they able or would like to be able to do for themselves?
 - k) What would they like to be done for them?
 - l) Who else is involved in their care (e.g. family members)?
 - m) Do they have any questions about their condition, treatment, or care? If so, have they asked anyone these questions?

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Section 4: Health and social issues (ADMISSION & POST-DISCHARGE – all interactions)

How are they managing their medication (getting them, taking them, understand them)? Have they fallen/problems with mobility? Any problems with equipment (e.g. catheters or adaptive equipment)? Any wound problems? Pressure ulcers? Appetite and thirst? Sleep? Energy levels? Pain (if so, well-managed)? How are they managing with normal daily activities (e.g. washing, dressing, going to the toilet, getting around, shopping, seeing friends and family)? Company? Any issues with appointments (making them, keeping them, or travelling to them)?

Section 5: Perceptions of risks & concerns at the moment (ADMISSION)

- n) QUESTION: 'How safe and cared for do you feel at the moment?' (Probe: why/why not)
- o) Has there been anything that has concerned them about the care they've had since being in hospital?
- p) Is there anything in your life that is worrying or concerning them at the moment?
- q) Have they shared their concerns with anyone? (Prompt for details e.g. who, how did they do it)
- r) Do they have any ideas about what could make them feel... better/less worried/more comfortable/more confident (use patient's own words if appropriate)?
- s) What things do they wish that staff knew and understood about them and their life?

Section 6: Perceptions of risks & concerns about the future (ADMISSION)

- t) What issues do they think they could face when they leave hospital to go home?

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3 u) Have they spoken to anybody about these things? If so, who?
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5 v) Do they have any ideas about what things could be done so that [issues raised] don't happen/are
6 avoided?
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8 w) QUESTION: What do you think might be expected of you when you get home?
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11 **Section 7: Gaining an update (ALL SUBSEQUENT INTERACTIONS)**
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14 x) How are they at the moment?
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16 y) QUESTION: Can you tell me what has happened to you [today...yesterday...etc/since I saw you
17 last/since you came into hospital]? (Probe for their understandings about why these things have
18 happened)
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20 z) What have people done to help them feel supported and cared for, recently?
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22 aa) How involved have they been in their care? How do they feel about this?
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26 **Section 8: Being at home (POST-DISCHARGE)**
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- 28 bb) QUESTION: How do you feel about being at home?
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30 cc) Can you tell me what's happened since the last time I spoke to you (give day/date/location) if
31 possible?
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34 dd) What do you think and feel about [what has happened to you]?
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37 ee) Who has been providing support or help since you came home?
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39 ff) Do they feel that life is back to normal now? What have they been doing to make life as normal as
40 possible? (Prompt for motives)
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43 gg) What makes it easier to come home after being in hospital? What could stop them going into
44 hospital?
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48 hh) If they needed help with anything, what would they do/who would they ask?
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50 **Section 9: Summarising (FINAL INTERVIEW)**
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53 ii) Thinking about being in hospital, what was good? What could have been better?
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55 jj) Thinking about the discharge, what was good? What could have been better?
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57 kk) Did they feel ready to be discharged?
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3 ll) Thinking about any treatment or care they have had since being at home, what has been good?
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5 What could be better?
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7 mm) Looking back, is there anything that anyone or anything the hospital did that made it easier for
8 them to come home?
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10 nn) Is there anything that anyone has done for them/they've done for themselves that has helped them
11 (get back to 'normal'/avoid going back into hospital/stay at home)?
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14 **Section 10: Readmission (READMISSION)**
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16 oo) Why have they been readmitted to hospital?
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18 pp) How did they come to be in hospital? (Prompt: did someone refer them? Transport to hospital?)
19
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21 qq) Before they came into hospital, what contact did they have with HSCPs? Is that normal for them?
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24 rr) How do they feel about being back in hospital?
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27 ss) What do they think is going to happen next?
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30 tt) QUESTION: Do you think anything could have avoided you having to come back to hospital?
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BMJ Open

Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning from hospital to home in the UK: protocol for an observation and interview study of older people and their families to understand patient experience and involvement in care at transitions.

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4 Partners At Care Transitions (PACT). Exploring older peoples'
5 experiences of transitioning from hospital to home in the UK:
6 protocol for an observation and interview study of older people and
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8 care at transitions.
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14
15 Corresponding author: Dr Natasha Kate Hardicre, Yorkshire Quality and Safety Research
16 Group, Bradford Institute for Health Research, Temple Bank House, Bradford Royal
17 Infirmary, Duckworth Lane, Bradford, West Yorkshire, BD9 6RJ.

18 Email: Natasha.hardicre@bthft.nhs.uk.

19 ORCID: 0000-0002-3639-5556

20 Telephone: 01274383428
21
22
23

24 Co-authors:

25
26 Professor Yvonne Birks, Social Policy Research Unit, University of York, York, UK.

27
28 Dr Jenni Murray, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
29 Research, Bradford, UK.

30
31 Dr Laura Sheard, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
32 Research, Bradford, UK.

33
34 Dr Lesley Hughes, Yorkshire Quality and Safety Research Group, Bradford Institute for
35 Health Research, Bradford, UK.

36
37 Dr Jane Heyhoe, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
38 Research, Bradford, UK.

39
40 Dr Alison Cracknell, Leeds Centre for Older People's Medicine, Leeds Teaching Hospitals NHS
41 Trust, Leeds, UK.

42
43 Professor Rebecca Lawton, School of Psychology, University of Leeds, Leeds, UK.
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3 Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning
4 from hospital to home in the UK: a qualitative study protocol.
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6

7 **Abstract**

8
9 Introduction: Lengths of hospital inpatient stays have reduced. This benefits patients, who
10 prefer to be at home, and hospitals, which can treat more people when stays are shorter.
11 Patients may, however, leave hospital sicker, with ongoing care needs. The transition period
12 from hospital to home, can be risky, particularly for older patients with complex health and
13 social needs. Improving patient experience, especially through greater patient involvement,
14 may improve outcomes for patients and is a key indicator of care quality and safety. In this
15 research we aim to: capture the experiences of older patients and their families during the
16 transition from hospital to home; and identify opportunities for greater patient involvement
17 in care, particularly where this contributes to greater individual- and organisational-level
18 resilience.
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23 Methods and Analysis: A 'focused ethnography' comprising observations, 'Go-Along' and
24 semi-structured interviews will be used to capture patient and carer experiences during
25 different points in the care transition from admission to 90 days after discharge. We will
26 recruit 30 patients and their carers from six hospital departments across two NHS Trusts.
27 Analysis of observations and interviews will use a Framework approach to identify themes
28 to understand the experience of transitions and generate ideas about how patients could be
29 more actively involved in their care. This will include exploring what 'good' care at
30 transitions look like and seeking out examples of success, as well as recommendations for
31 improvement.
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36 Ethics and dissemination: Ethical approval was received from the NHS Research Ethics
37 Committee in Wales. The research findings will add to a growing body of knowledge about
38 patient experience of transitions, in particular providing insight into the experiences of
39 patients and carers throughout the transitions process, in 'real time'. Importantly, the data
40 will be used to inform the development of a patient-centred intervention to improve the
41 quality and safety of transitions.
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46 **Strengths and limitations**

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- Utilising a range of qualitative methods, the study will generate rich, in depth data to contextualise patient involvement and experiences of transitions of care from hospital admission and throughout the transitions period, from the point of view of older people and their carers.
 - The longitudinal approach enables us to gain insight into how patient experience and involvement change over time.

- While the study design enables in-depth data to be captured from a small number of older people and their carers, as is the nature of qualitative inquiry, this limits generalisability of findings. The study is situated within a larger programme which will allow greater generalisability, as the programme of work progresses informed by this phase.
- Although non-participant observation can generate rich contextual data that are not as easily accessed via other methods, the presence of a researcher has the potential to affect the behaviour of those being observed.

Introduction

Reduced lengths of stay in hospital can result in patients being discharged from hospital to home with ongoing treatment and care needs. Shorter stays in hospital have benefits for both patients, who prefer to be at home, and hospitals, which can treat more patients if stays are shorter. However, reduced stays can also result in an increased reliance on care outside the inpatient setting, for example, wound or catheter care, changes to medication, or input from therapy services. 'Discharge' from hospital is, therefore, more likely to be a stage in a process involving the *transfer* of care, rather than being an *end-point* of care. The movement and transfer of care from hospital to home – sometimes referred to as the 'transition period' – is likely to involve input from multiple agencies to meet patients' ongoing care needs. It is a highly variable and complex process that is contingent upon several factors, for example service provision, resource capacity, and knowledge transfer within and between secondary care teams, GPs and corollary services, community therapy teams, and adult social care services;^[1] alongside the social support networks and resources that patients themselves have access to (or not). Consequently, the transition of care from hospital into community settings can be a risky one. Additionally, older people may experience more than one 'transition' in a single hospital admission episode, for example, moving between wards or via intermediate care at a different location. Likewise, some older people may experience readmissions within a short period of time. The transitions process may not, therefore, be a linear one, resulting in further complexity.

As many as one in five patients experience an adverse event in the transition from hospital to home, 62% of which could be prevented;^[2] this is double the number of adverse events experienced by patients during a hospital stay.^[3] For older patients, who are more likely to have complex health and social needs, and who may be anxious, confused, and disorientated,^[4, 5] the risks associated with transitions of care may be greater than that of the general population. This may result in a higher than average rate of readmission to hospital,^[6] thereby prolonging the overall patient stay. This counteracts the benefit of reduced patient stays, and further exposes patients to risks associated with being in hospital. Krumholtz^[7] argues, for example, that hospitalisation causes 'substantial stress' to patients, through causes such as disrupted sleep, poor nourishment, 'a baffling array of mentally challenging situations', changes to medication, and deconditioning associated with

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3 inactivity and bedrest. Older people are particularly vulnerable to such stressors as they are
4 more likely to have multiple morbidities, take multiple medications, and remain inactive.[8,
5 9] Moreover, older people are the highest users of the NHS and, with the number of people
6 in the UK aged 75 and over set to double in the next 30 years, this group of patients is an
7 important target for support.[10] Increased risk associated with both hospitalisation and
8 the transition period suggests that improving the quality and safety of care during this time
9 is critical.
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13 Patient experience of care is a key indicator of quality and safety [11] and so an important
14 target for intervention. Indeed, this strong relationship between patient experience and
15 outcomes suggests that those interested in improving health outcomes (quality, safety, and
16 cost savings) should strive first to improve patient experiences, especially by focusing on
17 activities such as patient engagement. However, despite a growing emphasis on shared care
18 and patient empowerment [12] the involvement of patients in their care before, during,
19 and after transitions remains minimal, with patients feeling that they are not always
20 listened to and that they did not have a 'lot of say' in their care.[13-19] A recent systematic
21 review of patient experiences of transitions highlighted the necessity of involving older
22 people and their carers in the discharge process, but reported variability in the degree to
23 which this was achieved.[20] The study described in this protocol forms the first of six
24 interlinked 'work packages' (WP) in an NIHR-funded Programme Grant for Applied Health
25 Research (PGfAR) that aims to understand and improve the experience, and safety, of care
26 for older patients during transitions and, by doing so, reduce readmissions and NHS costs. In
27 particular, we want to explore whether greater involvement of patients and their families
28 can improve patient experience and safety at the transitions of care. This will involve
29 exploring patient experience of transitions and using these data to develop and test a
30 patient-centred intervention that supports the involvement of older people, and their
31 families, in their care.
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40 There are several published studies that have explored patient and carer perspectives on
41 care at transitions [13-20]. However, much of this work appears to capture people's
42 experiences at a single time point, often retrospectively after discharge. The study outlined
43 here will, instead, recruit people whilst in hospital, and follow them until approximately
44 three months post-discharge. The longitudinal nature of the study will enable us to capture
45 continuity and change in experience and involvement over time and will thus contribute
46 new data and findings to a growing body of literature on care at transitions. Moreover, the
47 programme of work utilises a resilience engineering approach to safety in healthcare.[21]
48 We especially want to learn from what goes well at transitions, rather than focusing only on
49 what goes wrong; doing so "sheds light on otherwise unrecognised and unspecified
50 pathways to success".[22] Within this project, we want to understand resilience at two
51 levels: 1) how patients and carers themselves bounce back, adapt and essentially cope with
52 the transition process and what helps them to do this; and 2) how do patients and relatives
53 get involved to prop up the transition process, in other words what work do they, and their
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3 informal and formal carers do to adapt to and overcome obstacles arising from a less than
4 ideal system (e.g. discharge letters arriving at primary care days after discharge). In this
5 latter case we will explore the ways that those people involved in the transitions process
6 contribute to system resilience. Schubert *et al*,^[23] for example, suggest that
7 patients/caregivers can “identify and prevent mistakes from happening, and participate in
8 improving their care” by navigating a “fragmented system” through the co-ordination of
9 tasks across multiple health care settings and providers. This will enable us to take a
10 proactive approach towards care during the transitions period; developing an intervention
11 that helps to support older people to be more involved in the transition and so make the
12 transitions process ‘good’. We believe this is a novel approach towards understanding and
13 improving care at the transitions period.
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19 The research study described here focuses on understanding the transitions process from
20 the perspective of those experiencing it – patients and their families. There are two main
21 foci of the research:
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- 23
24 1) EXPERIENCE: Describing the transitions process from the point of view of older patients
25 and their carers;
26
27 2) INVOLVEMENT: Exploring where the opportunities are for improving patient
28 involvement in the transitions process.
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30
31 Research questions are:
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- 33 1. a. What do patients and their families experience during the transition of care from
34 hospital to place of residence?
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36 b. What do patients think, feel, and believe about this process?
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38 2. How can people be more involved in their care:
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40 a. To what extent do people feel involved in their care? What are their perspectives on
41 this?
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43 b. Where are the opportunities for patients to be more involved in their care?
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45 c. To what extent do people feel *able* to be (more) involved in their care? What has, or
46 would help them to, feel able to be (more) involved in their care?
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51 Methods and analysis

52 *Recruiting patients*

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56 Beginning in May 2017, thirty older patients (aged 75+), and their immediate carers, will be
57 recruited to the study. Patients and carers will be recruited from six departments
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3 specialising in elderly medical care, respiratory care, orthopaedic care of the elderly, and
4 stroke, across two hospitals. The departments have been selected for the study to reflect
5 different transitional challenges, emergency and elective admissions (including elective
6 surgery), acute and chronic illness, and multi-morbidity or poly-pharmacy issues.
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10 Sampling aims to capture maximum variation in respondents. We will purposively aim to
11 recruit a diverse group of patients from different ethnicities, and gender groups, as well as a
12 variety of ages – including the ‘oldest old’ (aged 85+) – wherever possible. We will also try to
13 ensure that people with and without carers are included in the research, as carer
14 involvement is likely to have an impact on the patient’s experience of transition. Although
15 sampling will be purposive, we recognise that in this context and population there is likely to
16 be a degree of opportunistic recruitment; initially, the researchers will speak to clinical staff
17 on each ward to identify eligible patients, selecting those who meet the criteria and who are
18 available to approach at that time. The diversity of the sample will be monitored as
19 participants are recruited. We anticipate that a sample of 30 patients is likely to allow us to
20 capture some diversity and is also likely to achieve theoretical saturation; however, this will
21 be reviewed as analysis proceeds to ensure any gaps are covered. One of the hospitals
22 serves a large South-East Asian population, some of whom do not speak or read English. To
23 facilitate inclusion, a translator will work with researchers to approach and consent patients
24 who speak Urdu and/or Potwari – the languages most commonly spoken amongst the
25 largest non-English speaking group in that area – and provide translation services during the
26 course of the research.
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33 We are excluding patients who are at the end of their life or whose care has become
34 palliative, so as not to place additional burden on themselves or their families. We will,
35 however, be approaching people with cognitive or language impairments, including patients
36 who lack or have variable capacity to consent to the research for themselves, if they have
37 suitable support in place to help them to participate in the research. This group of patients
38 are likely to be especially vulnerable during the transitions period; thus, it is particularly
39 important to capture their experiences and those of the people who care for them to
40 explore opportunities to reduce risk to this population. All the researchers working on the
41 study have received additional training on taking informed consent in adults lacking
42 capacity. When a patient is identified as not having the capacity to give consent, in line with
43 the Mental Capacity Act 2005,[24] the researcher will take reasonable steps to identify a
44 personal consultee to advise on the presumed wishes and feelings of participants unable to
45 consent for themselves and on their inclusion and participation in the research. We will also
46 seek to recruit the consultee as a participant in the study, so that they can provide support
47 to the patient-participant throughout the research process.
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54 *Data collection*

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56 As part of a focused ethnographic approach,[25] we will employ the following methods to
57 explore experiences and identify likely influences on outcomes:
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- Non-participant observation, with discussions about 'key moments';
- 'Go-Along' interviews[26,27]
- Individual semi-structured interviews.

These data collection methods will be combined flexibly within this study to enable us to gather rich insightful data into what patients think, feel, and believe about the process of leaving hospital to return home. Two researchers will be responsible for data collection, each following the patients they recruit for their entire 'transitions journey' (where possible).

Observations

Observations will be used to explore what happens to a patient at various time points and locations as they transition from hospital to home, including within the admitting hospital, a transitional care facility, the patient's residence, and other care settings. Non-participant observation offers a direct view of behaviours in their natural setting.[28, 29] It allows the researcher insight into what is done, and how, by various people involved in delivering care over the transition period (for example, healthcare professionals, support and administrative staff, the voluntary sector, and patients and their carers themselves). Observations will provide the foundation for short informal conversations (approximately 10-15 minutes) to follow up on 'key moments' observed on a previous occasion. These will happen as close to the original event as possible, to enable accurate recall. Observations and conversations will be captured through field notes. An observation framework will be developed for this study as a prompt for observer field notes, ensuring accurate, in-depth recording of observations and facilitating analysis.

Go-Along Interviews

'Go-Along' interviewing is a participatory method that is person-centred and interactive, that is, they focus on understanding the experiences of a person within changing contexts in real-time. Interviewing someone whilst they are experiencing something in real-time can facilitate articulation of attachments, feelings and memories that might otherwise remain unconscious or unsaid.[26, 27] With this in mind, the researcher will accompany the participant within the context in which care is being delivered, with all conversation recorded digitally. Recordings will be supplemented by field notes to provide context and aid interpretation of transcribed data.[27] We are aware that a 'Go-Along' interview may not be appropriate in all circumstances and so we will use this method sensitively according to the context in which the researcher and patient are in and what is happening at that time. For example, we will not observe intimate patient care such as using the toilet or showering. We will always be guided by what the participant (and those also present) are comfortable with and consent to.

Interviews

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3 Observations and 'Go-Along' interviews will be supplemented by more formal semi-
4 structured interviews that will use a guide (see appendix 1) to provide a framework to the
5 discussions. Informed by the COM-B framework[30], this guide will contain some key
6 questions addressing issues of capability, motivation and opportunity for patients to be
7 involved in their care at transitions; it will also be informed by the observations that have
8 occurred up to that point. The COM-B framework is particularly valuable as a tool for
9 understanding the factors that act as both barriers and facilitators for behaviour prior to
10 intervention development. If, for example, we were to identify that patients and their carers
11 were rarely involved in their care, it is valuable, in terms of targeting the intervention to
12 understand whether this is because patients are unwilling to be involved (low motivation),
13 they just don't feel they have the knowledge or skills (low capability) or that the formal
14 carers dismiss attempts by patients to be involved (low opportunity). The COM-B
15 complements our broader conceptualisation of transitions within a resilience framework
16 because it focuses on understanding what patients actually do (work as done), rather than
17 assuming that they do what is imagined (by those caring for them, for example). Interviews
18 will be co-generated by both participant and researcher; to ensure that discussions are
19 relevant to the research, the researcher will use the interview schedule as a 'map' to guide
20 the conversation, whilst remaining flexible enough to follow participants as they express
21 their experiences about being in hospital and transitioning from hospital to home.
22 Interviews will be recorded digitally. Individual interviews are likely to take place in the
23 hospital and in the patient's own home; if an interview does take place in a setting that is
24 not the patient's home, we will ensure that these occur in a space that is sufficiently private.
25 We may also conduct telephone interviews to speak with participants about an episode of
26 care that has been delivered but not observed by the researchers (visiting their GP, for
27 example).

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29 We expect that each of these methods will be used to gather data from each participant,
30 but to remain sensitive to the needs of the patient or carer, the context within which health
31 care is delivered, and the needs of the research, we will employ them flexibly and
32 sensitively. For example, sometimes it may not be appropriate to use a more participatory
33 approach, such as a 'Go-Along' interview, because it is important that we capture
34 interactions between health care professionals and patients as they would naturally occur,
35 without the participation of the researcher. Also, important care may be being delivered
36 and the participation of the researcher in the interaction would disrupt the delivery of that
37 care (within a rehabilitation therapy session, for example). At other times, however, it may
38 be helpful to use the time spent with patients as they are moving from one location to
39 another, for example, capturing their thoughts, feelings, and beliefs about what has and is
40 happening to them in that moment, alongside their expectations about what will happen in
41 the future. Within this context a more structured non-participant observation would likely
42 fail to capture the richness of the patient's experience. More formal semi-structured
43 interviews will complement both types of observational work.

Timing of Data Collection

'Time' and 'place' are two important features of any transitions process. We have therefore designed the research to capture as much of the temporospatial aspects of the transition from hospital to home as possible. This includes collecting data from participants at various time points within the transitions process, and in various locations. It also involves exploring the significance of 'time' and 'place' with participants.

Data collection will be organised around five 'episodes', over a period of 3-4 months:

1. Upon, or shortly after, admission to hospital;
2. Shortly prior to and/ or during discharge from the admitting hospital;
3. A day or two after discharge in the home or intermediate care;
4. Several weeks after discharge;
5. Three months after discharge or on readmission if sooner.

Data collection may occur within the admitting hospital, an intermediate care facility, and in the home of the participant. In addition, if the patient gives us permission, we will follow the patients to appointments that form part of their 'discharge care package' (appointments with therapists or district nurses, for example). We anticipate that we will see each patient approximately five times (once within each 'transition episode'). However, the actual number of times that we will see the participant will be guided by the needs and experiences of the patient. For example, someone experiencing fatigue as an outcome of stroke may require more visits of a short duration to avoid placing unnecessary burden on the participant. Alternatively, some patients may have multiple appointments at the point of discharge and be happy for us to accompany them to each of these appointments. Data collection will remain sufficiently flexible to meet the needs of the participants and the research. We anticipate that all data collection will be complete by March 2018.

Data Analysis

All interviews will be digitally recorded and transcribed verbatim. Relevant contextual details will be added to the interview transcripts from notes made by the researcher. Researchers will make field notes during observations. After an observation session, the researchers will use a digital recorder to describe what they observed and to digitally capture their own interpretation of the session; this will then be transcribed verbatim. Transcription will be done by an external agency and checked by the researcher who collects the data.

Data analysis will be inductive and flexible, utilising a Framework approach [9] to identify themes and analytical categories. Framework analysis allows the researcher to move from raw data to wider explanatory accounts through a series of conceptual groupings and

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3 meanings assigned to the data.[31, 32] The key stages of Framework analysis are:
4 familiarisation with data; identifying a thematic framework; indexing and sorting data;
5 reviewing and refining the thematic framework, and then summarising and displaying the
6 data through the construction of thematic matrices.[33] These matrices allow the data to
7 be reduced and distilled, whilst staying close to the original text. The matrices also facilitate
8 comparison within- and between- themes and cases (participants). Within-case comparison
9 will be particularly helpful when exploring the temporal aspects of the transitions process,
10 as it will allow exploration of changes in individual attitudes and experience over time. Data
11 analysis will be conducted by both researchers involved in data collection.
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16 The thematic frameworks will be constructed by both researchers, using the interview guide
17 as a tool for organising the data. Each researcher will label and sort their own data using the
18 thematic framework but discussion about emergent findings will happen on a regular basis
19 and will be used to refine the thematic framework. The comparison work to identify
20 analytical categories and explanatory accounts will be done together and will also involve
21 members of the project patient panel. Qualitative data analysis software (NVivo 10 for
22 Windows) will be used to help manage and organise the data into thematic matrices.
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28 Patient and public involvement

29 The Yorkshire Quality and Safety Research Group currently supports a patient and public
30 panel of 25 people representing the local patient community. This group have been involved
31 from the beginning of the PACT research study and will continue to provide input when
32 necessary. In addition, we have recruited a panel of people who will work with the PACT
33 research team over the course of the study. Panel members will meet regularly as a group
34 to support the PACT study as a whole; panel members will also be working in pairs to
35 support one of the first three work-packages, including this study of patient experience. We
36 anticipate that the PACT patient panel will contribute to the analysis and interpretation of
37 research findings and to the development of the intervention in light of these findings. Panel
38 members will be supported by a research nurse with an expertise in patient and public
39 involvement in research.
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46 Ethics

47 *Ethics*

48 This study has been approved by the Wales 7 Research Ethics Committee (reference:
49 17/WA/0057).
50

51 Prior to approaching any patient, the researcher will speak with a senior health care
52 professional to find out which patients may be approached to take part in the research. This
53 is to ensure that we do not approach people who are very unwell or at the end of their life.
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3 At first approach, the researcher will be accompanied by a member of the clinical team, who
4 will make the first introduction. All potential participants will be provided with: verbal and
5 written information about the study; the opportunity to ask questions; and time to consider
6 whether they would like to participate. Informed consent will be gained from all participants
7 (patients and carers) who can consent for themselves. All research documents, such as
8 information sheets and consent forms are written in plain English using large print, and laid
9 out clearly to facilitate readability and understanding. Verbal consent scripts will be used
10 with people who struggle with written language or who have a physical impairment that
11 prevents them from signing a consent form.
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16 We recognise that consent is an ongoing process. Therefore, at every research encounter
17 we will check whether participants still wish to take part prior to starting any data
18 collection. As far as possible the same researcher will do all follow-up work with the same
19 patient to promote the building of a relationship and to avoid confusion for the older person
20 and/or their carer. Participants will be free to withdraw from the study at any time and can
21 choose whether the data collected about them is included in the analysis.
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25 All personal identifiable data will be kept securely in line with legal requirements and best
26 practice recommendations to ensure confidentiality. Participants will be assigned
27 pseudonyms so that they cannot be identified.
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30 When healthcare staff are present during an observation, verbal consent will be sought
31 from the staff member at that time. If they agree to observation and/or audio-recording,
32 the observation will continue as planned. If they do not agree to be observed, the
33 researcher will seek to understand what the staff member is and is not comfortable with
34 and proceed accordingly. For example, a member of staff may agree for a researcher to be
35 present but would not like any details about them or their actions recorded in any way. In
36 this circumstance, and with the patient's permission, the researcher may stay and observe
37 but will not record any information about the staff member. If the staff member declines all
38 observation, then the researcher will not observe the interaction and will follow up with
39 research participants after the interaction is over and the staff member is no longer present.
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45 *Safeguarding*

46 Consent will be obtained on the understanding that all interactions are confidential unless
47 the researcher witnesses actions which cause them to be concerned for an individual's
48 safety. Should a researcher believe that a research participant (or other person) is at risk of
49 harm, through observation or disclosure during an interview, the researcher will encourage
50 the person to raise this with a relevant professional, or offer to raise it on their behalf.
51 Should consent not be given by the person, if the researcher feels that the person is at risk
52 then the researcher will disclose the issue/incident without consent but in the interest of
53 the person's safety and well-being. Guidance will be sought from local clinical collaborators
54 regarding appropriateness to escalate concerns. In emergency or urgent situations (e.g.
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3 witnessing a person fall, or experience life-threatening symptoms such as severe breathing
4 difficulties), the researcher will immediately contact the appropriate emergency services.
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7 Dissemination

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9 The findings of the study will contribute to the other work packages (WP) within the
10 programme of work. Particular contributions include using the data to: inform the
11 development (and subsequent testing) of a patient-centred intervention that aims to
12 improve the transitions experience and reduce hospital readmissions (WPs 4, 5, 6); and to
13 inform the development of a measure of the quality of transitions, which will be used as a
14 secondary outcome measure within the PACT RCT (WPs 3, 6).
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18 We will also develop 'patient experience of transitions' resources in the form of anonymised
19 stories to help communicate the main findings of the project to both academic and clinical
20 groups. For example, the Academic Health Science Network Improvement Academy and
21 educational institutions will be used to disseminate these resources to people undergoing
22 training and/or quality improvement work. We will also be hosting a national conference to
23 showcase findings from this project and two of the other linked work-packages.
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27 We will publish our research findings in academic and professional journals and present our
28 work at relevant national and international conferences. We also plan to support
29 dissemination through a website, social media, and through networks. We have experience
30 of using these formats for reaching a variety of audiences, but particularly our local clinical
31 networks. Twitter has proved a particularly effective method for sharing our ideas, alerting
32 people to our recent findings, and discussing new ideas and concepts.
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36 Our dissemination strategy has been developed in partnership with various stakeholders,
37 including our patient panel. We will continue to engage with and involve these groups to
38 ensure that the research findings can be translated effectively into clinical practice and to
39 maximise the impact of the research locally and nationally.
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42 Discussion

43 *Strengths and weaknesses*

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45 This study seeks to explore and describe the experience of older people and their families as
46 they transition from hospital to home. Utilising multiple in-depth qualitative research
47 methods enables us to capture detailed accounts of experiences and perceptions of
48 experiences, alongside the context within which care is occurring. Nonetheless, we
49 recognise that observational methods have the potential to introduce bias into the study,
50 because people (in this case, health service staff) may change their behaviour when they
51 know they are being observed. However, in agreement with McNaughton Nicholls *et al*,
52 2014 [34] we believe that the strengths of observational methods, e.g. access to rich data
53 that would not be accessible otherwise, alongside insight into "interactions, processes and
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3 behaviours that goes beyond... verbal accounts", outweighs the potential risk inherent
4 within the research process.
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7 The study design means that the findings will not be generalisable to all older people
8 transitioning from hospital to home. Nonetheless, the research accounts have the capacity
9 to provide data which are credible, dependable and transferable to others.[35] Moreover,
10 Rossman and Rallis, 2003 [36] argue that 'the ultimate goal of qualitative research is
11 learning, that is, the transformation of data in to information that can be used. *Use can be*
12 *considered an ethical mandate*'. The use of the findings of this study as a basis for a new
13 patient-centred intervention can be considered to fulfil this ethical mandate and is thus a
14 strength of this research.
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18 The findings of the research will contribute to the development and testing of a person-
19 centred intervention that aims to improve patient experience and reduce the risk of hospital
20 readmission. It is anticipated that improving the patient experience of the transitions
21 process /will contribute to improved safety and quality of care [11, 37] during this transition
22 period. It is also anticipated that providing good transitional care will reduce hospital
23 readmissions. This has benefits for patients and their families, as being in hospital is
24 associated with a number of risks and has a psychological and physical impact on patients
25 and their families.[13, 15] Risks such as hospital-acquired infections are increased, for
26 example, and issues such as disrupted sleep, nutritional deficiencies and problems caused
27 by poor nourishment, increased stress and anxiety, and deconditioning due to inactivity and
28 bedrest can place additional burdens on people already dealing with one or more conditions
29 or trauma.[7] Reducing readmissions also has benefits for the health service which is under
30 pressure to deliver more care with less resource. Moreover, NHS Trusts now incur financial
31 penalties for readmissions within 30 days; reducing readmissions would reduce spending on
32 such penalties.
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39 We want to learn from older people and their families about what works for them in the
40 care that they receive and to find out what would improve their experience of the
41 transitions process. Exploring the transitions process from their perspective, particularly
42 looking at where and how people can be involved in their care, and using this data to
43 develop an intervention, means that the patient is at the heart of quality improvement. This
44 research will also add to an existing body of knowledge about patient experiences of care at
45 transitions.[14, 16-20] Importantly, this research will capture the temporospatial
46 experiences of transitions by following older people and their families during their transition
47 journey from admission through to three months post-discharge. This element is missing
48 from existing research, most of which captures patient experience data at only one time
49 point. Moreover, much of the existing research exploring patient experience data about
50 care at transitions appears to capture what goes wrong, or the ways in which individuals are
51 dissatisfied with the care they receive. Conversely, our research will be exploring what goes
52 well at transitions of care, as well as seeking to identify areas for improvement. By doing so,
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3 we will add an important dimension to the growing knowledge base about care at the
4 transition from hospital to home. Also, the adoption of a resilience-engineering approach to
5 safety acknowledges the positive contribution that all people can make to the delivery of
6 good quality, safe healthcare –and engenders the harnessing of a genuine partnership to
7 improve patient experience and clinical outcomes.
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10 11 12 13 Author's Contributions

14
15 RL, AC, LS and YB designed the overall programme of research and conception of studies
16 within. NH, YB, JM, LS, LH, JH, AC and RL were involved in the design of the current study
17 and have contributed to the drafting, reviewing and final approval of the manuscript.
18

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21
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23

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26
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32 the Department of Health.
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35 36 Competing Interests Statement

37
38 None declared.
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Appendix

PACT WP1 Interview Guide

For peer review only

PACT WP1 Interview Guide

Section 1: Getting to know people (ADMISSION)

Find out about their life e.g. where they live, who they live with, what job they used to do, do they have any children etc.

Section 2: Being admitted to hospital (ADMISSION)

a) Why have they been admitted to hospital? How did they get here?

If they mention a condition, is it their main/only health concern? If not, what is?

Probe for: **causative factors**, *expected duration of problems*, **expectations of treatments etc**, *impact on life*, **(if the problem preceded this hospital admission) what/who helps them to cope with/manage daily life?**

b) Could anything have avoided them coming into hospital?

c) Before they came into hospital, what contact did they have with health and/or social care professionals? Is this normal for them?

d) How do they feel about being in hospital?

e) What makes hospital care 'good'? What would make it better?

f) What do they think will happen next? What information have they been given? Do they feel they feel they have had had enough information?

Probe for: **patient's understanding of why things are happening**, *how they know what is happening*.

g) How do they feel about going home?

Section 3: Questions about involvement (ADMISSION & POST-DISCHARGE & FINAL INTERVIEW)

h) How involved have they been in discussions about them and their treatment and care? How do they feel about this? Probe for: *choice*, **decision-making**, *information (given and received)*, **consultation about discharge process?**

- 1
2
3 i) How involved have they been able to be in their self-care whilst in hospital? E.g. normal daily
4 activities?
5
6 j) What things are they able or would like to be able to do for themselves?
7
8 k) What would they like to be done for them?
9
10 l) Who else is involved in their care (e.g. family members)?
11
12 m) Do they have any questions about their condition, treatment, or care? If so, have they asked anyone
13 these questions?
14
15
16
17
18

19 **Section 4: Health and social issues (ADMISSION & POST-DISCHARGE – all interactions)**

20
21 How are they managing their medication (getting them, taking them, understand them)? Have they
22 fallen/problems with mobility? Any problems with equipment (e.g. catheters or adaptive equipment)?
23 Any wound problems? Pressure ulcers? Appetite and thirst? Sleep? Energy levels? Pain (if so, well-
24 managed)? How are they managing with normal daily activities (e.g. washing, dressing, going to the
25 toilet, getting around, shopping, seeing friends and family)? Company? Any issues with appointments
26 (making them, keeping them, or travelling to them)?
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36 **Section 5: Perceptions of risks & concerns at the moment (ADMISSION)**

- 37
38 n) QUESTION: 'How safe and cared for do you feel at the moment?' (Probe: why/why not)
39
40 o) Has there been anything that has concerned them about the care they've had since being in
41 hospital?
42
43 p) Is there anything in your life that is worrying or concerning them at the moment?
44
45 q) Have they shared their concerns with anyone? (Prompt for details e.g. who, how did they do it)
46
47 r) Do they have any ideas about what could make them feel... better/less worried/more
48 comfortable/more confident (use patient's own words if appropriate)?
49
50 s) What things do they wish that staff knew and understood about them and their life?
51
52

53 **Section 6: Perceptions of risks & concerns about the future (ADMISSION)**

- 54
55
56 t) What issues do they think they could face when they leave hospital to go home?
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3 u) Have they spoken to anybody about these things? If so, who?
4
5 v) Do they have any ideas about what things could be done so that [issues raised] don't happen/are
6 avoided?
7
8 w) QUESTION: What do you think might be expected of you when you get home?
9

10
11 **Section 7: Gaining an update (ALL SUBSEQUENT INTERACTIONS)**
12

- 13
14 x) How are they at the moment?
15
16 y) QUESTION: Can you tell me what has happened to you [today...yesterday...etc/since I saw you
17 last/since you came into hospital]? (Probe for their understandings about why these things have
18 happened)
19
20 z) What have people done to help them feel supported and cared for, recently?
21
22 aa) How involved have they been in their care? How do they feel about this?
23
24
25

26 **Section 8: Being at home (POST-DISCHARGE)**
27

- 28 bb) QUESTION: How do you feel about being at home?
29
30 cc) Can you tell me what's happened since the last time I spoke to you (give day/date/location) if
31 possible?
32
33
34 dd) What do you think and feel about [what has happened to you]?
35
36
37 ee) Who has been providing support or help since you came home?
38
39 ff) Do they feel that life is back to normal now? What have they been doing to make life as normal as
40 possible? (Prompt for motives)
41
42
43 gg) What makes it easier to come home after being in hospital? What could stop them going into
44 hospital?
45
46
47
48 hh) If they needed help with anything, what would they do/who would they ask?
49

50 **Section 9: Summarising (FINAL INTERVIEW)**
51

- 52
53 ii) Thinking about being in hospital, what was good? What could have been better?
54
55 jj) Thinking about the discharge, what was good? What could have been better?
56
57 kk) Did they feel ready to be discharged?
58
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3 ll) Thinking about any treatment or care they have had since being at home, what has been good?

4
5 What could be better?

6
7 mm) Looking back, is there anything that anyone or anything the hospital did that made it easier for
8 them to come home?

9
10 nn) Is there anything that anyone has done for them/they've done for themselves that has helped them
11 (get back to 'normal'/avoid going back into hospital/stay at home)?
12

13
14 **Section 10: Readmission (READMISSION)**

15
16
17 oo) Why have they been readmitted to hospital?

18
19 pp) How did they come to be in hospital? (Prompt: did someone refer them? Transport to hospital?)
20

21
22 qq) Before they came into hospital, what contact did they have with HSCPs? Is that normal for them?
23

24
25 rr) How do they feel about being back in hospital?

26
27 ss) What do they think is going to happen next?
28

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30 tt) QUESTION: Do you think anything could have avoided you having to come back to hospital?
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BMJ Open

Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning from hospital to home in the UK: protocol for an observation and interview study of older people and their families to understand patient experience and involvement in care at transitions.

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Manuscripts

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4 Partners At Care Transitions (PACT). Exploring older peoples'
5 experiences of transitioning from hospital to home in the UK:
6 protocol for an observation and interview study of older people and
7 their families to understand patient experience and involvement in
8 care at transitions.
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12

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14
15 Corresponding author: Dr Natasha Kate Hardicre, Yorkshire Quality and Safety Research
16 Group, Bradford Institute for Health Research, Temple Bank House, Bradford Royal
17 Infirmary, Duckworth Lane, Bradford, West Yorkshire, BD9 6RJ.

18 Email: Natasha.hardicre@bthft.nhs.uk.

19 ORCID: 0000-0002-3639-5556

20 Telephone: 01274383428
21
22
23

24 Co-authors:

25
26 Professor Yvonne Birks, Social Policy Research Unit, University of York, York, UK.

27
28 Dr Jenni Murray, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
29 Research, Bradford, UK.

30
31 Dr Laura Sheard, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
32 Research, Bradford, UK.

33
34 Dr Lesley Hughes, Yorkshire Quality and Safety Research Group, Bradford Institute for
35 Health Research, Bradford, UK.

36
37 Dr Jane Heyhoe, Yorkshire Quality and Safety Research Group, Bradford Institute for Health
38 Research, Bradford, UK.

39
40 Dr Alison Cracknell, Leeds Centre for Older People's Medicine, Leeds Teaching Hospitals NHS
41 Trust, Leeds, UK.

42
43 Professor Rebecca Lawton, School of Psychology, University of Leeds, Leeds, UK.
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3 Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning
4 from hospital to home in the UK: a qualitative study protocol.
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6

7 **Abstract**

8
9 Introduction: Lengths of hospital inpatient stays have reduced. This benefits patients, who
10 prefer to be at home, and hospitals, which can treat more people when stays are shorter.
11 Patients may, however, leave hospital sicker, with ongoing care needs. The transition period
12 from hospital to home, can be risky, particularly for older patients with complex health and
13 social needs. Improving patient experience, especially through greater patient involvement,
14 may improve outcomes for patients and is a key indicator of care quality and safety. In this
15 research we aim to: capture the experiences of older patients and their families during the
16 transition from hospital to home; and identify opportunities for greater patient involvement
17 in care, particularly where this contributes to greater individual- and organisational-level
18 resilience.
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23 Methods and Analysis: A 'focused ethnography' comprising observations, 'Go-Along' and
24 semi-structured interviews will be used to capture patient and carer experiences during
25 different points in the care transition from admission to 90 days after discharge. We will
26 recruit 30 patients and their carers from six hospital departments across two NHS Trusts.
27 Analysis of observations and interviews will use a Framework approach to identify themes
28 to understand the experience of transitions and generate ideas about how patients could be
29 more actively involved in their care. This will include exploring what 'good' care at
30 transitions look like and seeking out examples of success, as well as recommendations for
31 improvement.
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36 Ethics and dissemination: Ethical approval was received from the NHS Research Ethics
37 Committee in Wales. The research findings will add to a growing body of knowledge about
38 patient experience of transitions, in particular providing insight into the experiences of
39 patients and carers throughout the transitions process, in 'real time'. Importantly, the data
40 will be used to inform the development of a patient-centred intervention to improve the
41 quality and safety of transitions.
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46 **Strengths and limitations**

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- Utilising a range of qualitative methods, the study will generate rich, in depth data to contextualise patient involvement and experiences of transitions of care from hospital admission and throughout the transitions period, from the point of view of older people and their carers.
 - The longitudinal approach enables us to gain insight into how patient experience and involvement change over time.

- While the study design enables in-depth data to be captured from a small number of older people and their carers, as is the nature of qualitative inquiry, this limits generalisability of findings. The study is situated within a larger programme which will allow greater generalisability, as the programme of work progresses informed by this phase.
- Although non-participant observation can generate rich contextual data that are not as easily accessed via other methods, the presence of a researcher has the potential to affect the behaviour of those being observed.

Introduction

Reduced lengths of stay in hospital can result in patients being discharged from hospital to home with ongoing treatment and care needs. Shorter stays in hospital have benefits for both patients, who prefer to be at home, and hospitals, which can treat more patients if stays are shorter. However, reduced stays can also result in an increased reliance on care outside the inpatient setting, for example, wound or catheter care, changes to medication, or input from therapy services. 'Discharge' from hospital is, therefore, more likely to be a stage in a process involving the *transfer* of care, rather than being an *end-point* of care. The movement and transfer of care from hospital to home – sometimes referred to as the 'transition period' – is likely to involve input from multiple agencies to meet patients' ongoing care needs. It is a highly variable and complex process that is contingent upon several factors, for example service provision, resource capacity, and knowledge transfer within and between secondary care teams, GPs and corollary services, community therapy teams, and adult social care services;^[1] alongside the social support networks and resources that patients themselves have access to (or not). Consequently, the transition of care from hospital into community settings can be a risky one. Additionally, older people may experience more than one 'transition' in a single hospital admission episode, for example, moving between wards or via intermediate care at a different location. Likewise, some older people may experience readmissions within a short period of time. The transitions process may not, therefore, be a linear one, resulting in further complexity.

As many as one in five patients experience an adverse event in the transition from hospital to home, 62% of which could be prevented;^[2] this is double the number of adverse events experienced by patients during a hospital stay.^[3] For older patients, who are more likely to have complex health and social needs, and who may be anxious, confused, and disorientated,^[4, 5] the risks associated with transitions of care may be greater than that of the general population. This may result in a higher than average rate of readmission to hospital,^[6] thereby prolonging the overall patient stay. This counteracts the benefit of reduced patient stays, and further exposes patients to risks associated with being in hospital. Krumholtz^[7] argues, for example, that hospitalisation causes 'substantial stress' to patients, through causes such as disrupted sleep, poor nourishment, 'a baffling array of mentally challenging situations', changes to medication, and deconditioning associated with

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3 inactivity and bedrest. Older people are particularly vulnerable to such stressors as they are
4 more likely to have multiple morbidities, take multiple medications, and remain inactive.[8,
5 9] Moreover, older people are the highest users of the NHS and, with the number of people
6 in the UK aged 75 and over set to double in the next 30 years, this group of patients is an
7 important target for support.[10] Increased risk associated with both hospitalisation and
8 the transition period suggests that improving the quality and safety of care during this time
9 is critical.
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13 Patient experience of care is a key indicator of quality and safety [11] and so an important
14 target for intervention. Indeed, this strong relationship between patient experience and
15 outcomes suggests that those interested in improving health outcomes (quality, safety, and
16 cost savings) should strive first to improve patient experiences, especially by focusing on
17 activities such as patient engagement. However, despite a growing emphasis on shared care
18 and patient empowerment [12] the involvement of patients in their care before, during,
19 and after transitions remains minimal, with patients feeling that they are not always
20 listened to and that they did not have a 'lot of say' in their care.[13-19] A recent systematic
21 review of patient experiences of transitions highlighted the necessity of involving older
22 people and their carers in the discharge process, but reported variability in the degree to
23 which this was achieved.[20] The study described in this protocol forms the first of six
24 interlinked 'work packages' (WP) in an NIHR-funded Programme Grant for Applied Health
25 Research (PGfAR) that aims to understand and improve the experience, and safety, of care
26 for older patients during transitions and, by doing so, reduce readmissions and NHS costs. In
27 particular, we want to explore whether greater involvement of patients and their families
28 can improve patient experience and safety at the transitions of care. This will involve
29 exploring patient experience of transitions and using these data to develop and test a
30 patient-centred intervention that supports the involvement of older people, and their
31 families, in their care.
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40 There are several published studies that have explored patient and carer perspectives on
41 care at transitions [13-20]. However, much of this work appears to capture people's
42 experiences at a single time point, often retrospectively after discharge. The study outlined
43 here will, instead, recruit people whilst in hospital, and follow them until approximately
44 three months post-discharge. The longitudinal nature of the study will enable us to capture
45 continuity and change in experience and involvement over time and will thus contribute
46 new data and findings to a growing body of literature on care at transitions. Moreover, the
47 programme of work utilises a resilience engineering approach to safety in healthcare.[21]
48 We especially want to learn from what goes well at transitions, rather than focusing only on
49 what goes wrong; doing so "sheds light on otherwise unrecognised and unspecified
50 pathways to success".[22] Within this project, we want to understand resilience at two
51 levels: 1) how patients and carers themselves bounce back, adapt and essentially cope with
52 the transition process and what helps them to do this; and 2) how do patients and relatives
53 get involved to prop up the transition process, in other words what work do they, and their
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3 informal and formal carers do to adapt to and overcome obstacles arising from a less than
4 ideal system (e.g. discharge letters arriving at primary care days after discharge). In this
5 latter case we will explore the ways that those people involved in the transitions process
6 contribute to system resilience. Schubert *et al*,^[23] for example, suggest that
7 patients/caregivers can “identify and prevent mistakes from happening, and participate in
8 improving their care” by navigating a “fragmented system” through the co-ordination of
9 tasks across multiple health care settings and providers. This will enable us to take a
10 proactive approach towards care during the transitions period; developing an intervention
11 that helps to support older people to be more involved in the transition and so make the
12 transitions process ‘good’. We believe this is a novel approach towards understanding and
13 improving care at the transitions period.
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19 The research study described here focuses on understanding the transitions process from
20 the perspective of those experiencing it – patients and their families. There are two main
21 foci of the research:
22

- 23
24 1) EXPERIENCE: Describing the transitions process from the point of view of older patients
25 and their carers;
26
27 2) INVOLVEMENT: Exploring where the opportunities are for improving patient
28 involvement in the transitions process.
29

30
31 Research questions are:
32

- 33 1. a. What do patients and their families experience during the transition of care from
34 hospital to place of residence?
35
36 b. What do patients think, feel, and believe about this process?
37
38 2. How can people be more involved in their care:
39
40 a. To what extent do people feel involved in their care? What are their perspectives on
41 this?
42
43 b. Where are the opportunities for patients to be more involved in their care?
44
45 c. To what extent do people feel *able* to be (more) involved in their care? What has, or
46 would help them to, feel able to be (more) involved in their care?
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51 Methods and analysis

52 *Recruiting patients*

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56 Beginning in May 2017, thirty older patients (aged 75+), and their immediate carers, will be
57 recruited to the study. Patients and carers will be recruited from six departments
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3 specialising in elderly medical care, respiratory care, orthopaedic care of the elderly, and
4 stroke, across two hospitals. The departments have been selected for the study to reflect
5 different transitional challenges, emergency and elective admissions (including elective
6 surgery), acute and chronic illness, and multi-morbidity or poly-pharmacy issues.
7
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9
10 Sampling aims to capture 'maximum variation' in respondents.[24] We will purposively aim
11 to recruit a diverse group of patients from different ethnicities, and gender groups, as well
12 as a variety of ages – including the 'oldest old' (aged 85+) – wherever possible. We will also
13 try to ensure that people with and without carers are included in the research, as carer
14 involvement is likely to have an impact on the patient's experience of transition. Although
15 sampling will be purposive, we recognise that in this context and population there is likely to
16 be a degree of opportunistic recruitment; initially, the researchers will speak to clinical staff
17 on each ward to identify eligible patients, selecting those who meet the criteria and who are
18 available to approach at that time. The diversity of the sample will be monitored as
19 participants are recruited. We anticipate that a sample of 30 patients is likely to allow us to
20 capture some diversity and is also likely to achieve theoretical saturation; however, this will
21 be reviewed as analysis proceeds to ensure any gaps are covered. One of the hospitals
22 serves a large South-East Asian population, some of whom do not speak or read English. To
23 facilitate inclusion, a translator will work with researchers to approach and consent patients
24 who speak Urdu and/or Potwari – the languages most commonly spoken amongst the
25 largest non-English speaking group in that area – and provide translation services during the
26 course of the research.
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33 We are excluding patients who are at the end of their life or whose care has become
34 palliative, so as not to place additional burden on themselves or their families. We will,
35 however, be approaching people with cognitive or language impairments, including patients
36 who lack or have variable capacity to consent to the research for themselves, if they have
37 suitable support in place to help them to participate in the research. This group of patients
38 are likely to be especially vulnerable during the transitions period; thus, it is particularly
39 important to capture their experiences and those of the people who care for them to
40 explore opportunities to reduce risk to this population. All the researchers working on the
41 study have received additional training on taking informed consent in adults lacking
42 capacity. When a patient is identified as not having the capacity to give consent, in line with
43 the Mental Capacity Act 2005,[25] the researcher will take reasonable steps to identify a
44 personal consultee to advise on the presumed wishes and feelings of participants unable to
45 consent for themselves and on their inclusion and participation in the research. We will also
46 seek to recruit the consultee as a participant in the study, so that they can provide support
47 to the patient-participant throughout the research process.
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54 *Data collection*

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56 As part of a focused ethnographic approach,[26] we will employ the following methods to
57 explore experiences and identify likely influences on outcomes:
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- Non-participant observation, with discussions about 'key moments';
- 'Go-Along' interviews[27,28]
- Individual semi-structured interviews.

These data collection methods will be combined flexibly within this study to enable us to gather rich insightful data into what patients think, feel, and believe about the process of leaving hospital to return home. Two researchers will be responsible for data collection, each following the patients they recruit for their entire 'transitions journey' (where possible).

Observations

Observations will be used to explore what happens to a patient at various time points and locations as they transition from hospital to home, including within the admitting hospital, a transitional care facility, the patient's residence, and other care settings. Non-participant observation offers a direct view of behaviours in their natural setting.[29, 30] It allows the researcher insight into what is done, and how, by various people involved in delivering care over the transition period (for example, healthcare professionals, support and administrative staff, the voluntary sector, and patients and their carers themselves). Observations will provide the foundation for short informal conversations (approximately 10-15 minutes) to follow up on 'key moments' observed on a previous occasion. These will happen as close to the original event as possible, to enable accurate recall. Observations and conversations will be captured through field notes. An observation framework will be developed for this study as a prompt for observer field notes, ensuring accurate, in-depth recording of observations and facilitating analysis.

Go-Along Interviews

'Go-Along' interviewing is a participatory method that is person-centred and interactive, that is, they focus on understanding the experiences of a person within changing contexts in real-time. Interviewing someone whilst they are experiencing something in real-time can facilitate articulation of attachments, feelings and memories that might otherwise remain unconscious or unsaid.[27, 28] With this in mind, the researcher will accompany the participant within the context in which care is being delivered, with all conversation recorded digitally. Recordings will be supplemented by field notes to provide context and aid interpretation of transcribed data.[28] We are aware that a 'Go-Along' interview may not be appropriate in all circumstances and so we will use this method sensitively according to the context in which the researcher and patient are in and what is happening at that time. For example, we will not observe intimate patient care such as using the toilet or showering. We will always be guided by what the participant (and those also present) are comfortable with and consent to.

Interviews

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3 Observations and 'Go-Along' interviews will be supplemented by more formal semi-
4 structured interviews that will use a guide (see appendix 1) to provide a framework to the
5 discussions. Informed by the COM-B framework[31], this guide will contain some key
6 questions addressing issues of capability, motivation and opportunity for patients to be
7 involved in their care at transitions; it will also be informed by the observations that have
8 occurred up to that point. The COM-B framework is particularly valuable as a tool for
9 understanding the factors that act as both barriers and facilitators for behaviour prior to
10 intervention development. If, for example, we were to identify that patients and their carers
11 were rarely involved in their care, it is valuable, in terms of targeting the intervention to
12 understand whether this is because patients are unwilling to be involved (low motivation),
13 they just don't feel they have the knowledge or skills (low capability) or that the formal
14 carers dismiss attempts by patients to be involved (low opportunity). The COM-B
15 complements our broader conceptualisation of transitions within a resilience framework
16 because it focuses on understanding what patients actually do (work as done), rather than
17 assuming that they do what is imagined (by those caring for them, for example). Interviews
18 will be co-generated by both participant and researcher; to ensure that discussions are
19 relevant to the research, the researcher will use the interview schedule as a 'map' to guide
20 the conversation, whilst remaining flexible enough to follow participants as they express
21 their experiences about being in hospital and transitioning from hospital to home.
22 Interviews will be recorded digitally. Individual interviews are likely to take place in the
23 hospital and in the patient's own home; if an interview does take place in a setting that is
24 not the patient's home, we will ensure that these occur in a space that is sufficiently private.
25 We may also conduct telephone interviews to speak with participants about an episode of
26 care that has been delivered but not observed by the researchers (visiting their GP, for
27 example).

28
29 We expect that each of these methods will be used to gather data from each participant,
30 but to remain sensitive to the needs of the patient or carer, the context within which health
31 care is delivered, and the needs of the research, we will employ them flexibly and
32 sensitively. For example, sometimes it may not be appropriate to use a more participatory
33 approach, such as a 'Go-Along' interview, because it is important that we capture
34 interactions between health care professionals and patients as they would naturally occur,
35 without the participation of the researcher. Also, important care may be being delivered
36 and the participation of the researcher in the interaction would disrupt the delivery of that
37 care (within a rehabilitation therapy session, for example). At other times, however, it may
38 be helpful to use the time spent with patients as they are moving from one location to
39 another, for example, capturing their thoughts, feelings, and beliefs about what has and is
40 happening to them in that moment, alongside their expectations about what will happen in
41 the future. Within this context a more structured non-participant observation would likely
42 fail to capture the richness of the patient's experience. More formal semi-structured
43 interviews will complement both types of observational work.

Timing of Data Collection

'Time' and 'place' are two important features of any transitions process. We have therefore designed the research to capture as much of the temporospatial aspects of the transition from hospital to home as possible. This includes collecting data from participants at various time points within the transitions process, and in various locations. It also involves exploring the significance of 'time' and 'place' with participants.

Data collection will be organised around five 'episodes', over a period of 3-4 months:

1. Upon, or shortly after, admission to hospital;
2. Shortly prior to and/ or during discharge from the admitting hospital;
3. A day or two after discharge in the home or intermediate care;
4. Several weeks after discharge;
5. Three months after discharge or on readmission if sooner.

Data collection may occur within the admitting hospital, an intermediate care facility, and in the home of the participant. In addition, if the patient gives us permission, we will follow the patients to appointments that form part of their 'discharge care package' (appointments with therapists or district nurses, for example). We anticipate that we will see each patient approximately five times (once within each 'transition episode'). However, the actual number of times that we will see the participant will be guided by the needs and experiences of the patient. For example, someone experiencing fatigue as an outcome of stroke may require more visits of a short duration to avoid placing unnecessary burden on the participant. Alternatively, some patients may have multiple appointments at the point of discharge and be happy for us to accompany them to each of these appointments. Data collection will remain sufficiently flexible to meet the needs of the participants and the research. We anticipate that all data collection will be complete by March 2018.

Data Analysis

All interviews will be digitally recorded and transcribed verbatim. Relevant contextual details will be added to the interview transcripts from notes made by the researcher. Researchers will make field notes during observations. After an observation session, the researchers will use a digital recorder to describe what they observed and to digitally capture their own interpretation of the session; this will then be transcribed verbatim. Transcription will be done by an external agency and checked by the researcher who collects the data.

Data analysis will be inductive and flexible, utilising a Framework approach [9] to identify themes and analytical categories. Framework analysis allows the researcher to move from raw data to wider explanatory accounts through a series of conceptual groupings and

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3 meanings assigned to the data.[32, 33] The key stages of Framework analysis are:
4 familiarisation with data; identifying a thematic framework; indexing and sorting data;
5 reviewing and refining the thematic framework, and then summarising and displaying the
6 data through the construction of thematic matrices.[34] These matrices allow the data to
7 be reduced and distilled, whilst staying close to the original text. The matrices also facilitate
8 comparison within- and between- themes and cases (participants). Within-case comparison
9 will be particularly helpful when exploring the temporal aspects of the transitions process,
10 as it will allow exploration of changes in individual attitudes and experience over time. Data
11 analysis will be conducted by both researchers involved in data collection.
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16 The thematic frameworks will be constructed by both researchers, using the interview guide
17 as a tool for organising the data. Each researcher will label and sort their own data using the
18 thematic framework but discussion about emergent findings will happen on a regular basis
19 and will be used to refine the thematic framework. The comparison work to identify
20 analytical categories and explanatory accounts will be done together and will also involve
21 members of the project patient panel. Qualitative data analysis software (NVivo 10 for
22 Windows) will be used to help manage and organise the data into thematic matrices.
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28 Patient and public involvement

29 The Yorkshire Quality and Safety Research Group currently supports a patient and public
30 panel of 25 people representing the local patient community. This group have been involved
31 from the beginning of the PACT research study and will continue to provide input when
32 necessary. In addition, we have recruited a panel of people who will work with the PACT
33 research team over the course of the study. Panel members will meet regularly as a group
34 to support the PACT study as a whole; panel members will also be working in pairs to
35 support one of the first three work-packages, including this study of patient experience. We
36 anticipate that the PACT patient panel will contribute to the analysis and interpretation of
37 research findings and to the development of the intervention in light of these findings. Panel
38 members will be supported by a research nurse with an expertise in patient and public
39 involvement in research.
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46 Ethics

47 *Ethics*

48 This study has been approved by the Wales 7 Research Ethics Committee (reference:
49 17/WA/0057).
50

51 Prior to approaching any patient, the researcher will speak with a senior health care
52 professional to find out which patients may be approached to take part in the research. This
53 is to ensure that we do not approach people who are very unwell or at the end of their life.
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3 At first approach, the researcher will be accompanied by a member of the clinical team, who
4 will make the first introduction. All potential participants will be provided with: verbal and
5 written information about the study; the opportunity to ask questions; and time to consider
6 whether they would like to participate. Informed consent will be gained from all participants
7 (patients and carers) who can consent for themselves. All research documents, such as
8 information sheets and consent forms are written in plain English using large print, and laid
9 out clearly to facilitate readability and understanding. Verbal consent scripts will be used
10 with people who struggle with written language or who have a physical impairment that
11 prevents them from signing a consent form.
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16 We recognise that consent is an ongoing process. Therefore, at every research encounter
17 we will check whether participants still wish to take part prior to starting any data
18 collection. As far as possible the same researcher will do all follow-up work with the same
19 patient to promote the building of a relationship and to avoid confusion for the older person
20 and/or their carer. Participants will be free to withdraw from the study at any time and can
21 choose whether the data collected about them is included in the analysis.
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25 All personal identifiable data will be kept securely in line with legal requirements and best
26 practice recommendations to ensure confidentiality. Participants will be assigned
27 pseudonyms so that they cannot be identified.
28
29

30 When healthcare staff are present during an observation, verbal consent will be sought
31 from the staff member at that time. If they agree to observation and/or audio-recording,
32 the observation will continue as planned. If they do not agree to be observed, the
33 researcher will seek to understand what the staff member is and is not comfortable with
34 and proceed accordingly. For example, a member of staff may agree for a researcher to be
35 present but would not like any details about them or their actions recorded in any way. In
36 this circumstance, and with the patient's permission, the researcher may stay and observe
37 but will not record any information about the staff member. If the staff member declines all
38 observation, then the researcher will not observe the interaction and will follow up with
39 research participants after the interaction is over and the staff member is no longer present.
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45 *Safeguarding*

46 Consent will be obtained on the understanding that all interactions are confidential unless
47 the researcher witnesses actions which cause them to be concerned for an individual's
48 safety. Should a researcher believe that a research participant (or other person) is at risk of
49 harm, through observation or disclosure during an interview, the researcher will encourage
50 the person to raise this with a relevant professional, or offer to raise it on their behalf.
51 Should consent not be given by the person, if the researcher feels that the person is at risk
52 then the researcher will disclose the issue/incident without consent but in the interest of
53 the person's safety and well-being. Guidance will be sought from local clinical collaborators
54 regarding appropriateness to escalate concerns. In emergency or urgent situations (e.g.
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3 witnessing a person fall, or experience life-threatening symptoms such as severe breathing
4 difficulties), the researcher will immediately contact the appropriate emergency services.
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7 Dissemination

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9 The findings of the study will contribute to the other work packages (WP) within the
10 programme of work. Particular contributions include using the data to: inform the
11 development (and subsequent testing) of a patient-centred intervention that aims to
12 improve the transitions experience and reduce hospital readmissions (WPs 4, 5, 6); and to
13 inform the development of a measure of the quality of transitions, which will be used as a
14 secondary outcome measure within the PACT RCT (WPs 3, 6).
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18 We will also develop 'patient experience of transitions' resources in the form of anonymised
19 stories to help communicate the main findings of the project to both academic and clinical
20 groups. For example, the Academic Health Science Network Improvement Academy and
21 educational institutions will be used to disseminate these resources to people undergoing
22 training and/or quality improvement work. We will also be hosting a national conference to
23 showcase findings from this project and two of the other linked work-packages.
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27 We will publish our research findings in academic and professional journals and present our
28 work at relevant national and international conferences. We also plan to support
29 dissemination through a website, social media, and through networks. We have experience
30 of using these formats for reaching a variety of audiences, but particularly our local clinical
31 networks. Twitter has proved a particularly effective method for sharing our ideas, alerting
32 people to our recent findings, and discussing new ideas and concepts.
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36 Our dissemination strategy has been developed in partnership with various stakeholders,
37 including our patient panel. We will continue to engage with and involve these groups to
38 ensure that the research findings can be translated effectively into clinical practice and to
39 maximise the impact of the research locally and nationally.
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42 Discussion

43 *Strengths and weaknesses*

44
45 This study seeks to explore and describe the experience of older people and their families as
46 they transition from hospital to home. Utilising multiple in-depth qualitative research
47 methods enables us to capture detailed accounts of experiences and perceptions of
48 experiences, alongside the context within which care is occurring. Nonetheless, we
49 recognise that observational methods have the potential to introduce bias into the study,
50 because people (in this case, health service staff) may change their behaviour when they
51 know they are being observed. However, in agreement with McNaughton Nicholls *et al*,
52 2014 [35] we believe that the strengths of observational methods, e.g. access to rich data
53 that would not be accessible otherwise, alongside insight into "interactions, processes and
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3 behaviours that goes beyond... verbal accounts", outweighs the potential risk inherent
4 within the research process.
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7 The study design means that the findings will not be generalisable to all older people
8 transitioning from hospital to home. Nonetheless, the research accounts have the capacity
9 to provide data which are credible, dependable and transferable to others.[36] Moreover,
10 Rossman and Rallis, 2003 [37] argue that 'the ultimate goal of qualitative research is
11 learning, that is, the transformation of data in to information that can be used. *Use can be*
12 *considered an ethical mandate*'. The use of the findings of this study as a basis for a new
13 patient-centred intervention can be considered to fulfil this ethical mandate and is thus a
14 strength of this research.
15
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18 The findings of the research will contribute to the development and testing of a person-
19 centred intervention that aims to improve patient experience and reduce the risk of hospital
20 readmission. It is anticipated that improving the patient experience of the transitions
21 process /will contribute to improved safety and quality of care [11, 38] during this transition
22 period. It is also anticipated that providing good transitional care will reduce hospital
23 readmissions. This has benefits for patients and their families, as being in hospital is
24 associated with a number of risks and has a psychological and physical impact on patients
25 and their families.[13, 15] Risks such as hospital-acquired infections are increased, for
26 example, and issues such as disrupted sleep, nutritional deficiencies and problems caused
27 by poor nourishment, increased stress and anxiety, and deconditioning due to inactivity and
28 bedrest can place additional burdens on people already dealing with one or more conditions
29 or trauma.[7] Reducing readmissions also has benefits for the health service which is under
30 pressure to deliver more care with less resource. Moreover, NHS Trusts now incur financial
31 penalties for readmissions within 30 days; reducing readmissions would reduce spending on
32 such penalties.
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39 We want to learn from older people and their families about what works for them in the
40 care that they receive and to find out what would improve their experience of the
41 transitions process. Exploring the transitions process from their perspective, particularly
42 looking at where and how people can be involved in their care, and using this data to
43 develop an intervention, means that the patient is at the heart of quality improvement. This
44 research will also add to an existing body of knowledge about patient experiences of care at
45 transitions.[14, 16-20] Importantly, this research will capture the temporospatial
46 experiences of transitions by following older people and their families during their transition
47 journey from admission through to three months post-discharge. This element is missing
48 from existing research, most of which captures patient experience data at only one time
49 point. Moreover, much of the existing research exploring patient experience data about
50 care at transitions appears to capture what goes wrong, or the ways in which individuals are
51 dissatisfied with the care they receive. Conversely, our research will be exploring what goes
52 well at transitions of care, as well as seeking to identify areas for improvement. By doing so,
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3 we will add an important dimension to the growing knowledge base about care at the
4 transition from hospital to home. Also, the adoption of a resilience-engineering approach to
5 safety acknowledges the positive contribution that all people can make to the delivery of
6 good quality, safe healthcare –and engenders the harnessing of a genuine partnership to
7 improve patient experience and clinical outcomes.
8
9

10 11 12 13 Author's Contributions

14
15 RL, AC, LS and YB designed the overall programme of research and conception of studies
16 within. NH, YB, JM, LS, LH, JH, AC and RL were involved in the design of the current study
17 and have contributed to the drafting, reviewing and final approval of the manuscript.
18
19

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23
24

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32 the Department of Health.
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36 37 Competing Interests Statement

38 None declared.
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Appendix

PACT WP1 Interview Guide

For peer review only

PACT WP1 Interview Guide

Section 1: Getting to know people (ADMISSION)

Find out about their life e.g. where they live, who they live with, what job they used to do, do they have any children etc.

Section 2: Being admitted to hospital (ADMISSION)

a) Why have they been admitted to hospital? How did they get here?

If they mention a condition, is it their main/only health concern? If not, what is?

Probe for: **causative factors**, *expected duration of problems*, **expectations of treatments etc**, *impact on life*, **(if the problem preceded this hospital admission) what/who helps them to cope with/manage daily life?**

b) Could anything have avoided them coming into hospital?

c) Before they came into hospital, what contact did they have with health and/or social care professionals? Is this normal for them?

d) How do they feel about being in hospital?

e) What makes hospital care 'good'? What would make it better?

f) What do they think will happen next? What information have they been given? Do they feel they feel they have had had enough information?

Probe for: **patient's understanding of why things are happening**, *how they know what is happening*.

g) How do they feel about going home?

Section 3: Questions about involvement (ADMISSION & POST-DISCHARGE & FINAL INTERVIEW)

h) How involved have they been in discussions about them and their treatment and care? How do they feel about this? Probe for: *choice*, **decision-making**, *information (given and received)*, **consultation about discharge process?**

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3 i) How involved have they been able to be in their self-care whilst in hospital? E.g. normal daily
4 activities?
5
6 j) What things are they able or would like to be able to do for themselves?
7
8 k) What would they like to be done for them?
9
10 l) Who else is involved in their care (e.g. family members)?
11
12 m) Do they have any questions about their condition, treatment, or care? If so, have they asked anyone
13 these questions?
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19 **Section 4: Health and social issues (ADMISSION & POST-DISCHARGE – all interactions)**

20
21 How are they managing their medication (getting them, taking them, understand them)? Have they
22 fallen/problems with mobility? Any problems with equipment (e.g. catheters or adaptive equipment)?
23 Any wound problems? Pressure ulcers? Appetite and thirst? Sleep? Energy levels? Pain (if so, well-
24 managed)? How are they managing with normal daily activities (e.g. washing, dressing, going to the
25 toilet, getting around, shopping, seeing friends and family)? Company? Any issues with appointments
26 (making them, keeping them, or travelling to them)?
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35 **Section 5: Perceptions of risks & concerns at the moment (ADMISSION)**

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38 n) QUESTION: 'How safe and cared for do you feel at the moment?' (Probe: why/why not)
39
40 o) Has there been anything that has concerned them about the care they've had since being in
41 hospital?
42
43 p) Is there anything in your life that is worrying or concerning them at the moment?
44
45 q) Have they shared their concerns with anyone? (Prompt for details e.g. who, how did they do it)
46
47 r) Do they have any ideas about what could make them feel... better/less worried/more
48 comfortable/more confident (use patient's own words if appropriate)?
49
50 s) What things do they wish that staff knew and understood about them and their life?
51
52

53 **Section 6: Perceptions of risks & concerns about the future (ADMISSION)**

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56 t) What issues do they think they could face when they leave hospital to go home?
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3 u) Have they spoken to anybody about these things? If so, who?
4
5 v) Do they have any ideas about what things could be done so that [issues raised] don't happen/are
6 avoided?
7
8 w) QUESTION: What do you think might be expected of you when you get home?
9

10
11 **Section 7: Gaining an update (ALL SUBSEQUENT INTERACTIONS)**
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- 13
14 x) How are they at the moment?
15
16 y) QUESTION: Can you tell me what has happened to you [today...yesterday...etc/since I saw you
17 last/since you came into hospital]? (Probe for their understandings about why these things have
18 happened)
19
20 z) What have people done to help them feel supported and cared for, recently?
21
22 aa) How involved have they been in their care? How do they feel about this?
23
24
25

26 **Section 8: Being at home (POST-DISCHARGE)**
27

- 28 bb) QUESTION: How do you feel about being at home?
29
30 cc) Can you tell me what's happened since the last time I spoke to you (give day/date/location) if
31 possible?
32
33
34 dd) What do you think and feel about [what has happened to you]?
35
36
37 ee) Who has been providing support or help since you came home?
38
39 ff) Do they feel that life is back to normal now? What have they been doing to make life as normal as
40 possible? (Prompt for motives)
41
42
43 gg) What makes it easier to come home after being in hospital? What could stop them going into
44 hospital?
45
46
47
48 hh) If they needed help with anything, what would they do/who would they ask?
49

50 **Section 9: Summarising (FINAL INTERVIEW)**
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- 52
53 ii) Thinking about being in hospital, what was good? What could have been better?
54
55 jj) Thinking about the discharge, what was good? What could have been better?
56
57 kk) Did they feel ready to be discharged?
58
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3 ll) Thinking about any treatment or care they have had since being at home, what has been good?
4

5 What could be better?
6

7 mm) Looking back, is there anything that anyone or anything the hospital did that made it easier for
8 them to come home?
9

10 nn) Is there anything that anyone has done for them/they've done for themselves that has helped them
11 (get back to 'normal'/avoid going back into hospital/stay at home)?
12
13

14 **Section 10: Readmission (READMISSION)**
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16 oo) Why have they been readmitted to hospital?
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18 pp) How did they come to be in hospital? (Prompt: did someone refer them? Transport to hospital?)
19
20

21 qq) Before they came into hospital, what contact did they have with HSCPs? Is that normal for them?
22
23

24 rr) How do they feel about being back in hospital?
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27 ss) What do they think is going to happen next?
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30 tt) QUESTION: Do you think anything could have avoided you having to come back to hospital?
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