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Article:

Haracre, Natasha, Lawton, Rebecca, Sheard, Laura et al. (4 more authors) (2017) 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. *BMJ Open*. pp. 1-9. ISSN 2044-6055

<https://doi.org/10.1136/bmjopen-2017-018054>

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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.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-018054.R4
Article Type:	Protocol
Date Submitted by the Author:	03-Nov-2017
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Primary Subject Heading:	Health services research
Secondary Subject Heading:	Qualitative research
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, GERIATRIC MEDICINE

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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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50 Word count: 5275
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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**

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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 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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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.[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).

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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.[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).
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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.
24
25

26
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.
40
41

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.
5

6
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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17
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 20 Acknowledgement

21
22 The research is supported by the NIHR CLAHRC Yorkshire and Humber. www.clahrc-yh.nihr.ac.uk.
23

24 25 Funding Statement

26
27 This report is independent research funded by the National Institute for Health Research
28 (National Institute for Health Research Programme Grants for Applied Health Research,
29 Partners at Care Transitions (PACT): Improving patient experience and safety at transitions
30 in care, RP-PG-1214-20017. The views expressed in this publication are those of the
31 author(s) and not necessarily those of the NHS, the National Institute for Health Research or
32 the Department of Health.
33
34

35 36 37 Competing Interests Statement

38
39 None declared.
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17 Appendix

18 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 & 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?
14
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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
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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 oo) Why have they been readmitted to hospital?
17

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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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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50 Word count: 5275
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Partners At Care Transitions (PACT). Exploring older peoples' experiences of transitioning from hospital to home in the UK: a qualitative study protocol.

Abstract

Introduction: Lengths of hospital inpatient stays have reduced. This benefits patients, who prefer to be at home, and hospitals, which can treat more people when stays are shorter. Patients may, however, leave hospital sicker, with ongoing care needs. The transition period from hospital to home, can be risky, particularly for older patients with complex health and social needs. Improving patient experience, especially 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, particularly where this contributes to greater individual- and organisational-level resilience.

Methods and Analysis: A 'focused ethnography' comprising observations, 'Go-Along' and semi-structured interviews will be used to capture patient and carer experiences during different points in 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 their care. 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

- 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**
43 **outlined here will, instead, recruit people whilst in hospital, and follow them until**
44 **approximately three months post-discharge. The longitudinal nature of the study will**
45 **enable us to capture continuity and change in experience and involvement over time and**
46 **will thus contribute new data and findings to a growing body of literature on care at**
47 **transitions. Moreover, the programme of work utilises a resilience engineering approach**
48 **to safety in healthcare.[21] We especially want to learn from what goes well at**
49 **transitions, rather than focusing only on what goes wrong; doing so "sheds light on**
50 **otherwise unrecognised and unspecified pathways to success".[22] Within this project,**
51 **we want to understand resilience at two levels: 1) how patients and carers themselves**
52 **bounce back, adapt and essentially cope with the transition process and what helps them**
53 **to do this; and 2) how do patients and relatives get involved to prop up the transition**
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3 **process, in other words what work do they, and their informal and formal carers do to**
4 **adapt to and overcome obstacles arising from a less than ideal system (e.g. discharge**
5 **letters arriving at primary care days after discharge). In this latter case we will explore the**
6 **ways that those people involved in the transitions process contribute to system resilience.**

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8 Schubert *et al*, [23] for example, suggest that patients/caregivers can “identify and prevent
9 mistakes from happening, and participate in improving their care” by navigating a
10 “fragmented system” through the co-ordination of tasks across multiple health care settings
11 and providers. This will enable us to take a proactive approach towards care during the
12 transitions period; developing an intervention that helps to support older people to be more
13 involved in the transition and so make the transitions process ‘good’. We believe this is a
14 novel approach towards understanding and 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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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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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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55 **Beginning in May 2017**, thirty older patients (aged 75+), and their immediate carers, will be
56 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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9 **Sampling aims to capture maximum variation in respondents.[24] We will purposively aim**
10 **to recruit a diverse group of patients from different ethnicities, and gender groups, as well**
11 **as a variety of ages – including the ‘oldest old’ (aged 85+) – wherever possible. We will**
12 **also try to ensure that people with and without carers are included in the research, as**
13 **carer involvement is likely to have an impact on the patient’s experience of transition.**
14 **Although sampling will be purposive, we recognise that in this context and population**
15 **there is likely to be a degree of opportunistic recruitment; initially, the researchers will**
16 **speak to clinical staff on each ward to identify eligible patients, selecting those who meet**
17 **the criteria and who are available to approach at that time. The diversity of the sample**
18 **will be monitored as participants are recruited. We anticipate that a sample of 30 patients**
19 **is likely to allow us to capture some diversity and is also likely to achieve theoretical**
20 **saturation; however, this will be reviewed as analysis proceeds to ensure any gaps are**
21 **covered. One of the hospitals serves a large South-East Asian population, some of whom**
22 **do not speak or read English. To facilitate inclusion, a translator will work with researchers**
23 **to approach and consent patients who speak Urdu and/or Potwari – the languages most**
24 **commonly spoken amongst the largest non-English speaking group in that area – and**
25 **provide translation services during the 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*

55 As part of a focused ethnographic approach,[26] we will employ the following methods to
56 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**
11 **carers were rarely involved in their care, it is valuable, in terms of targeting the**
12 **intervention to understand whether this is because patients are unwilling to be involved**
13 **(low motivation), they just don't feel they have the knowledge or skills (low capability) or**
14 **that the formal carers dismiss attempts by patients to be involved (low opportunity). The**
15 **COM-B complements our broader conceptualisation of transitions within a resilience**
16 **framework because it focuses on understanding what patients actually do (work as done),**
17 **rather than assuming that they do what is imagined (by those caring for them, for**
18 **example).** Interviews will be co-generated by both participant and researcher; to ensure
19 that discussions are relevant to the research, the researcher will use the interview schedule
20 as a 'map' to guide the conversation, whilst remaining flexible enough to follow participants
21 as they express their experiences about being in hospital and transitioning from hospital to
22 home. Interviews will be recorded digitally. Individual interviews are likely to take place in
23 the hospital and in the patient's own home; if an interview does take place in a setting that
24 is not the patient's home, we will ensure that these occur in a space that is sufficiently
25 private. We may also conduct telephone interviews to speak with participants about an
26 episode of care that has been delivered but not observed by the researchers (visiting their
27 GP, for example).

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37 We expect that each of these methods will be used to gather data from each participant,
38 but to remain sensitive to the needs of the patient or carer, the context within which health
39 care is delivered, and the needs of the research, we will employ them flexibly and
40 sensitively. For example, sometimes it may not be appropriate to use a more participatory
41 approach, such as a 'Go-Along' interview, because it is important that we capture
42 interactions between health care professionals and patients as they would naturally occur,
43 without the participation of the researcher. Also, important care may be being delivered
44 and the participation of the researcher in the interaction would disrupt the delivery of that
45 care (within a rehabilitation therapy session, for example). At other times, however, it may
46 be helpful to use the time spent with patients as they are moving from one location to
47 another, for example, capturing their thoughts, feelings, and beliefs about what has and is
48 happening to them in that moment, alongside their expectations about what will happen in
49 the future. Within this context a more structured non-participant observation would likely
50 fail to capture the richness of the patient's experience. More formal semi-structured
51 interviews will complement both types of observational work.
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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).
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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**
49 **of harm, through observation or disclosure during an interview, the researcher will**
50 **encourage the person to raise this with a relevant professional, or offer to raise it on their**
51 **behalf. Should consent not be given by the person, if the researcher feels that the person**
52 **is at risk then the researcher will disclose the issue/incident without consent but in the**
53 **interest of the person's safety and well-being. Guidance will be sought from local clinical**
54 **collaborators regarding appropriateness to escalate concerns. In emergency or urgent**
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3 **situations (e.g. witnessing a person fall, or experience life-threatening symptoms such as**
4 **severe breathing difficulties), the researcher will immediately contact the appropriate**
5 **emergency services.**
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8 Dissemination

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

44 *Strengths and weaknesses*

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

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

20 Acknowledgement

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23 The research is supported by the NIHR CLAHRC Yorkshire and Humber. www.clahrc-yh.nihr.ac.uk.
24

25 Funding Statement

26
27 This report is independent research funded by the National Institute for Health Research
28 (National Institute for Health Research Programme Grants for Applied Health Research,
29 Partners at Care Transitions (PACT): Improving patient experience and safety at transitions
30 in care, RP-PG-1214-20017. The views expressed in this publication are those of the
31 author(s) and not necessarily those of the NHS, the National Institute for Health Research or
32 the Department of Health.
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37 Competing Interests Statement

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39 None declared.
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17 Appendix

18 PACT WP1 Interview Guide
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