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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-011222
Article Type:	Research
Date Submitted by the Author:	21-Jan-2016
Complete List of Authors:	Scott, Jason; Newcastle University, Institute of Health and Society Heavey, Emily; University of York, Social Policy Research Unit Waring, Justin; University of Nottingham, Centre for Health Innovation, Leadership & Learning / Nottingham University Business School Jones, Diana; Northumbria University, Dawson, Pamela; Northumbria University, Faculty of Health and Life Sciences
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Qualitative research
Keywords:	Patient safety, Patient experience, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH

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Co-design and validation of a mechanism for service users to feedback patient safety experiences following a care transfer

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Funding: This research was funded by the North East Strategic Health Authority, Northumbria University and The Health Foundation (grant number 7204).

Number of tables: 3

Number of figures: 1

Key words: patient safety, patient experience, quality in health care, qualitative research

Word count: 4,451

Competing interests: The authors declare no competing interests.

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Abstract

Objective

To develop and validate a mechanism for patients to provide feedback on safety experiences following a care transfer between organisations.

Design

Qualitative study using participatory methods (co-design workshops) and cognitive interviews. Workshop data were analysed concurrently with participants and cognitive interviews were thematically analysed using a deductive approach based on the structure of the developed mechanism.

Participants

Expert patients (n=5) and healthcare professionals (n=11) were recruited purposively to develop the feedback mechanism in two workshops. Workshop one explored principles underpinning safety feedback mechanisms, and workshop two included the practical development of the feedback mechanism. Final design and content of the mechanism (a safety survey) were verified by workshop participants, and cognitive interviews (n=28) were conducted with patients.

Results

Workshop participants identified that safety feedback mechanisms should be patient-centred, short and concise with clear signposting, with an option to be anonymous and balanced between positive (safe) and negative (unsafe) experiences. The agreed mechanism consisted of a survey split across three stages of the care transfer; departure, journey and arrival. Care across organisational boundaries was recognised as being complex, with healthcare professionals acknowledging the difficulty of implementing changes that impact on other organisations. Cognitive interview participants agreed the content of the survey was relevant but identified barriers to completion relating to the survey formatting and understanding of a care transfer.

Conclusions

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Participatory, co-design principles helped overcome differences in understandings of safety in the complex setting of care transfers when developing a safety survey. Practical barriers to the survey's usability and acceptability to patients were identified, resulting in a modified survey design. Further research is required to determine the usability and acceptability of the survey to patients and healthcare professionals, as well as identifying how governance structures should accommodate patient feedback when relating to multiple health or social care providers.

Strengths and limitations of the study:

- This study developed a safety survey using participatory and co-design methods to bring together patient and healthcare professional perspectives.
- Cognitive interviews with 28 patients were used to validate and further refine the survey format and questions.
- Further research is required to pilot the survey to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care.
- Due to the nature of organisational care transfers, which potentially include large numbers of organisations, it is unlikely that participants represented all possible types of transfers that patients experience.
- It was not possible to explore further the governance relationships that exist between different organisations responsible for patients' care, which could impact on the implementation of the survey into practice.

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Introduction

Progress in reducing patient harm from adverse incidents in healthcare remains slow.[1] Involving patients in understanding and commenting on their own safety may help organisations to identify poorly recognised safety issues, improve their learning and safety culture and reduce rates of avoidable harm.[2 3] While advocates of strict safety engineering suggest patients do not have a role to play in their own safety,[4] it is generally argued that, when willing and able, they should be offered the opportunity to be involved, even though ultimate responsibility for safety rests with care providers.[5] A recent systematic review identified that patient experience data is positively associated with patient safety and clinical effectiveness.[6] However patients often perceive safety differently to clinicians, resulting in a lack of a shared understanding about what it means to feel safe.[7 8]

Most efforts to involve patients in safety relate to care delivered in a relatively stable secondary care setting,[9 10] in which a single provider is responsible for patient safety. There has been less attention however, to patient experiences of safety in relation to a transition between organisations. The safety implications for care transitions are shown to be complex, resulting from the difficulties of working across organisational boundaries and as leading to specific threats to safety and potential for re-admission.[11 12] Furthermore, with no one service having overall responsibility for the patient, existing safety systems are negated; in addition, with failures between organisations common,[13] organisational care transfers arguably increase the risk to patients. The patient experiences the totality of the transition, and can thus provide a unique perspective otherwise unavailable to healthcare professionals.

Patient involvement in safety can range from active participation in speaking up and challenging clinicians,[14 15] through to assessing factors that contribute to safety in hospital settings[16 17] and reporting safety incidents.[18] However it has been identified that formal incident report forms are not an appropriate mechanism for patients to report on their safety because patients were likely to report trivial matters and the process undermined trust in clinicians.[19] Another way of involving patients is to develop an understanding of, and to co-construct knowledge about safety.[20] A recent analysis of patient involvement in safety identified that a conjoint endeavour between patients and clinicians could reduce both parties' anxieties about patient involvement.[3] It is possible that taking a similar

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approach in the development of mechanisms for patients to report on their safety can lead to a mechanism that is more appropriate for patients than incident report forms.

The aim of this study was to co-design a mechanism with patients and clinicians for patients to provide feedback on their safety experiences following a transfer between organisations. To achieve this, the objectives were to:

1. Identify principles that should underpin patient feedback on safety experiences;
2. Co-design and construct a mechanism based on these principles and patient perceptions of safety; and.
3. Determine the face validity of the survey design with patients who have recently been discharged from hospital

Methods

Data were collected across two complementary studies that were informed by previous interviews with patients[8] (figure), with the focus of study 1 being the development of the feedback mechanism and study 2 acting as the validation process of the feedback mechanism. In study 1, the primary method of developing the reporting mechanism was via two workshops using participatory and co-design methods, which are receiving increased attention in healthcare for their ability to increase participation and engagement.[21] The workshops were designed to bring together a wide variety of stakeholders, including patients and healthcare professionals, and afforded the opportunity for different stakeholders to present their unique experiences and perspectives. In study 2, which was part of a larger feasibility project,[22] cognitive interviews were used to determine the face validity of the developed reporting mechanism. Approval for study 1 was provided by Northumbria University School of Health, Community and Education Studies Ethics Committee, Sunderland Research Ethics Committee (reference: 09:H0904/57) and R&D departments at each of the included NHS sites. Approval for study 2 was provided by Yorkshire & The Humber - Leeds West Research Ethics Committee (reference: 13/YH/0372) and R&D departments at each of the included NHS sites.

[Insert figure around here: Process of development and validation of the patient feedback mechanism across studies]

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Sample

Participants were sampled purposively using criterion sampling[23] for the two workshops to ensure that participants represented different types of organisations involved in the transfer of patients. The patients' voice was provided by five expert patients, identified as such due to their active involvement in either a Patient, Carer and Public Engagement (PCPE) network (n=3), which had also acted as a steering group for the study, or from the Northumbria University Service User Network (n=2), which consisted of service users who are involved in the education of pre- and post-registration healthcare professionals.

Eleven healthcare professionals also participated in the workshops. These included NHS community care team nurses (n=3), social care home managers (n=2) and a private nursing home manager (n=1) who were all involved in the identification and recruitment of participants to an earlier phase of the study where perceptions of safety were explored with patients who had recently completed an organisational care transfer.[8] Additional participants included ambulance service staff (n=4) and a representative of the Strategic Health Authority Patient Safety Team (n=1).

Cognitive interviews were conducted with 28 patients (18 male, 10 female) who had completed the safety survey following discharge from hospital from one of four clinical areas; cardiology (n=13), care of older people (n=3), orthopaedics (n=7) or stroke (n=5). Participant ages ranged from 53 to 86 (mean = 68, standard deviation = 10). Cognitive interviews have proven useful in pre-testing of survey questions in a healthcare setting, particularly when they may be complex or of a sensitive nature,[24] as in this study.

Data Collection

The first workshop, facilitated by JS and PD, was used to explore the key principles of capturing patient feedback on their experiences of safety. Four questions were posed to the group to ascertain what the mechanism should look like, the format of the mechanism and how the mechanism would fit with current systems. Participants were split into two mixed groups of healthcare professionals and expert patients to discuss answers to the questions. Numerous methods captured discussions to

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reduce the impact of potential power relationships between healthcare professionals and expert patients, including voice-recordings, flipchart paper, observations and notes from the facilitators and post-it notes.

The second workshop, facilitated by JS and DJ, was structured to have an emphasis on the practical outcome of designing a reporting mechanism, based in part on the results of the first workshop. Components of a Thinking Differently toolkit[25] were utilised to encourage creativity amongst participants when designing the mechanism. Participants were split into two groups and given four Thinking Differently tools; 'fresh eyes, 'reframing by word play', 'pause, notice, observe' and 'random word, picture or object'.[25].

Cognitive interviews involved inviting interviewees to describe their thought processes in response to survey questions, in order to identify any potential misunderstandings or other problems with those questions. We extended this beyond the questions to also ask about other components of the survey, including the introductory text, the description of different sections and the overall structure.

Data Analysis

As the workshop data were emergent it was not possible to plan the data analysis *a priori*. Instead, for the first workshop data were analysed inductively based upon the different themes and concepts that arose. For the second workshop, data analysis was conducted concurrently with participants drawing upon each other's ideas and working as individual groups to assess these shared ideas and bring them into a tangible mechanism for patients to provide feedback on their safety experiences (figure). A final discussion was held with all workshop participants about which parts of each group's chosen mechanism were the strongest. This contributed to a process whereby the participants were involved as co-researchers in both data collection and analysis,[26] occurring in a participatory open forum.

Following the second workshop, a researcher (JS) constructed the survey electronically using the final design agreed by the participants as a template. Additional data that were collected in the second workshop, such as voice recordings and flipcharts, were used post-workshop to ensure that the reporting mechanism had accurately captured what the participants had discussed. Upon completion,

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the final design was circulated amongst all participants for verification that it was an accurate reflection of the discussions and proposed designs.

Cognitive interviews were transcribed verbatim, then coded and analysed using NVivo qualitative analysis software. Interviews were thematically analysed using a deductive approach based on the structure and the questions asked in the survey by one researcher (EH), with codes and themes verified by JS, PD and JW. Findings from the two studies are reported concurrently.

Findings

The findings are reported in four sections. The first two sections, *principles of patient feedback* and *integration with existing systems*, represent themes identified in the first workshop that should underpin the development of patient reporting mechanisms applied specifically to capturing patient safety feedback. More specifically, *principles of patient feedback* represents the essential design principles of the patient reporting mechanisms, and *integration with existing systems* represented the acknowledgement by participants that where multiple organisations are involved in the care of the patient, particularly as patients cross organisational boundaries, feedback needs to be compatible with multiple patient safety and patient experience systems. The second two sections, *development of the safety survey* and *validation and refinement of the survey* report on the development and validation of the survey. These include why participants chose a safety survey as the most appropriate mechanism, how the final design was developed by the participants and cognitive interview findings, including where confusion arose around the question format and the overall survey design.

Principles of patient feedback

Participants made recommendations and references to the principles on which the feedback mechanism should be based. There was agreement that the reporting mechanism needed to be short with options to expand on answers so that service users could report what was of most importance to them. This is highlighted in a conversation during a workshop between a community care team nurse and patient:

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"From a professional wanting to know what a patient would want, you'd want something that's short but open-ended…" [Community care team nurse]

"Yes" [Patient]

"… so it allows the patient to… discuss one aspect that you felt safe. That's a massive topic but if you had sort of four or five questions like, 'were you happy with that element of care?', 'did you find that was safe?', and that sort of thing" [Community care team nurse]

"Yeah, and, 'if not, why not?'" [Patient]

Participants also agreed that a short and concise mechanism would increase response rates. A conversation between a community care team nurse, social care home manager and a patient highlights this agreement, and in doing so they begin to discuss the need for the mechanism to be objective, or unbiased, through the presentation of positive (safe) and negative (unsafe) experiences.

"So to capture that [transfers of care are different], would we say that they would want the questionnaire to be sort of short and concise to encourage people to actually do it?" [Community care team nurse]

"Got to be fairly concise. The longer it is I think the less chance there is of getting involved with it, and especially if you're asking for positive as well as negative feedback or just general commentary" [Social care home manager]

"That's a very important point. It shouldn't all be whinging. You need to capture the positives as well" [Patient]

"So objective, yeah?" [Community care team nurse]

"Yeah" [Patient]

This unbiased approach was emphasised by both health care professionals and patients to emphasise the necessity to be appreciative. In a conversation between a social care home manager and a community care team nurse, the uneven balance of negative rather than positive feedback is discussed. Notably, it was perceived that this imbalance is caused by a lack of recording of positive feedback.

"You don't get much feedback unless it's a complaint" [Social care home manager]

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> "But I think, I think a lot of people do get feedback. I just think there's an emphasis on the negative. There's a lot of people, like I'm sure you've probably had a patient, where they feedback that you do a grand job. That never gets captured." [Community care team nurse]

Participants felt that the reporting mechanism should have an option to be anonymous as some service users would want to avoid going through a formal complaints procedure. However there were concerns over the usability of patient feedback if it could not be traced to a particular incident, thus impacting on potential learning.

> "The only problem is with it being anonymous is... tracing it back because it's actually more effective when you can look. […] So you can improve practice generally, but for that specific case you might want to look at it in more detail." [Social care home manager]

Integration with existing systems

A number of discussion points arose that focused on how the potential mechanism would fit with current mechanisms. Firstly it was acknowledged that such a system for collecting patient feedback relating to admissions and discharge was required as there was no existing means for patients to provide feedback on this stage of their care, "what we haven't got is just before [service users] get to us, and just after we discharge them." [social care home manager]. A paramedic reported that feedback was limited to complaints or compliments, with a gap existing for the routine collection of patient feedback:

> "We've all got process in place that if there's something we're concerned about we can bring it up. But looking what feedback we get from patients, I know certainly on an ambulance point of view, we get no feedback. The only feedback we get is either a complaint coming in or a letter of thanks." [Ambulance service paramedic]

An additional consideration arose in the second workshop, where care home managers from both private and social care settings discussed utilising patient feedback when it relates to care delivered across organisational boundaries. In particular, it was reported and agreed that whilst patient feedback can be used to change practice, and systems can be changed to incorporate this feedback, they felt there was no opportunity to influence other parts of the health or social care systems. This

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resulted in a conflicting stance, with healthcare professionals wanting to receive meaningful feedback from patients, but knowing existing organisational structures prohibited being able to respond to this information and change practice. In turn this had the potential to impact upon the utility of any potential reporting mechanism for patients crossing organisational boundaries.

> "We want instant [patient] feedback to change our systems" [Social care home manager]
>
> "And so we can change the system within our environment but we can't change the system anywhere else" [Private nursing care home manager]

Development of the safety survey

In workshop 2, participants were encouraged to explore how non-healthcare organisations receive feedback. These included some of the more traditional mechanisms, such as noticeboards, postcards and questionnaires, and more novel methods, including an aviation-based reporting system, the Royal Society for the Protection of Birds' annual bird watch and supermarket tokens. Table 1 contains a brief description of each of the proposed mechanisms.

Mechanism	Group	Explanation
Noticeboard	1	Provided in GP waiting rooms for patients to write comments about their recent experiences.
Postcard	1	Given to service users during every part of the journey to complete, capturing the wide range of organisational care transfers.
Post boxes	1	An alternative to the noticeboard which provides privacy for service users and confidentiality for healthcare professionals.
Thermometer scale	1	Service users are able to place stickers on a large thermometer relating to how safe or unsafe they felt. Proposed as it would be quick and easy for service users.
Questionnaire	1	A simple questionnaire sent to service users post-transfer.
Aviation Reporting Tool	2	Confidential Human factors Incident Reporting Programme is used in aviation. Suggested as an idea as it is confidential and had no blame attributed to the reports.
RSPB Bird Watch	2	A method of collecting a lot of data in a systematic way over a short period of time.
Gordon Ramsey approach	2	Communication in restaurants by waiters can reduce the impact that long waiting times have.
Supermarket tokens	2	System similar to supermarket charity donation tokens. Given to service users on discharge for them to place in a 'safe' or 'unsafe' box
Reverse transfer	2	Increase safety by reducing the number of organisational care transfers through increased care in the community.
Internet questionnaire	2	An automatic email sent to everyone that had gone through an organisational care transfer.

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Hospital waiting area information	2	Provide information, either in person or via electronic screens regarding length of wait and delays.
Discharge lounge	2	Place for service users to go prior to a discharge to free up a bed. Somebody could be there to coordinate transfers, provide information and receive feedback.

Table 1: Mechanisms identified by workshop participants for patients to provide feedback on their experiences of safety

Each component of the mechanism was designed by the participants using flipchart paper to draw examples to be discussed. One group decided that the postcard was the best mechanism to take forward and develop due to its simplicity and applicability to a wide variety of settings. This included using a simple scoring system with a three-point scale that incorporated smiley faces: safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

> "One side with a smiley face and one side with a… [unhappy face]. And then straight away you can see" [Private care home manager]
>
> […]
>
> "Something simple. I think the most simple ideas are the most effective" [Patient safety team representative]

However, it was also recognised by participants that having an overly-simplistic system may result in data that lacked meaning, although participants did not stipulate the minimum or maximum amount of complexity or sensitivity required in order for the data to be meaningful. For example there was a debate whether a three-point likert scale would produce results sensitive enough to identify outliers in safe or unsafe care.

> "As you were saying where you should have a red, a green, amber, and identifying how happy you were, but the detail this lady's describing would need to be addressed quite intricately" [Ambulance service safeguarding lead]

The other group chose to develop a leaflet-based mechanism, split into three sections directed towards the discharge, transfer and admission of the service user. In particular, their decision to split

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the transfer into the three stages was summarised by a facilitator (DJ) when feeding back on behalf of the group.

> "We thought that most journeys, and I like your idea of defining a journey and what service user safety is, have a beginning, and a middle and an end. So, we would like to start with this panel, which is… we've got a day and a date… place of departure, so where did you depart from?" [Facilitator, DJ]

This three-stage structure was utilised in the final design, although transfer was changed to journey after the workshop, following feedback from one participant during verification of the design. Table 2 provides an overview of the survey structure and questions.

> *I'm never happy with transfer because people… some people, particularly the public, would automatically think you're talking about wheels, as opposed to the journey* [Email correspondence, community care team nurse]

Please tick which of the following affected how safe or unsafe you felt.		
Discharge	Journey	Arrival or Admission
Communication from staff	Communication from staff	Communication from staff
Staff listening to you	Staff listening to you	Staff listening to you
Departure running to schedule	Journey running to schedule	Waiting times
Falling or potential falls	Falling or potential falls	Falling or potential falls
Medication problems or concerns	Medication problems or concerns	Medication problems or concerns
Hygiene	Hygiene	Hygiene
Please use this space to tell us if there was another reason why you felt safe or unsafe or to expand on your answers above		
What could we have done to make you feel safer during your transfer?		

Table 2: Structure and question format of the safety survey following initial development

Validation and refinement of the survey

In the cognitive interviews, there was some diversity of opinion on the appropriateness of the paper format and the three-face design. While some participants suggested that an online or telephone survey might be easier to complete, there was a general consensus that varying access to computers,

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as well as time and cost restraints, meant that a paper version was more appropriate for most people. Patient 1867 summarised:

> "I would quite happily fill it in on an App, but [people] who are not computer literate would just back away from that. I think paperwork is probably the best way that would cover every age group." [Patient 1867]

Most participants found the three-point scale with smiley faces easy to use and understand. The statement from Patient 4300 makes this point, as well as reinforcing the workshop participants' preference for the survey to be concise:

> "Smiley faces and sad faces and things like that, you know red faces, it looked simple, it was easy, it caught your eye. It wasn't too wordy cos I think there's nothing worse than wordy surveys where you get half way through and you think, 'You know what, I can't be bothered'". [Patient 4300]

However, it should be noted that some participants expressed a preference for 'yes/no/maybe' style questions, with one suggesting that asking whether a patient felt safe, neutral, or unsafe was confusing and even "loaded" [Patient 3954]. Another participant suggested that three faces were not enough, and that there should be 5 in varying shades. Despite this diversity, there was general agreement that the paper survey with the three faces tick-box system was easy to use.

It was reported that two aspects of the survey design caused difficulties for many participants; the division into three stages of the care transfer (Departure, Journey, Arrival) and the way in which the questions were asked. For the stages of the transfer, patients were unclear on which departure, journey, and arrival they were being asked about. Some interpreted the questions in the 'Journey' section to be relating to their journey *to* hospital rather than *from* hospital or thought they were being asked "to give an average" assessment of the two journeys (P1189); others though that 'Arrival' referred to their initial arrival on the ward, rather than at their next destination.

> "The format of that is not right. It needs drastically changing, I think you should keep 'your departure from' that needs to be explained really, from where?" [Patient 3954]

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Second, some participants did not make the distinction between these three stages at all, instead answering questions in the three separate sections in relation to the entirety of the care transfer; these participants saw the three separate sections as merely repeating the same questions, without distinguishing between different transfer stages. For example, Patient 5853, when asked how they had interpreted a question relating to 'Arrival', stated

> "[The answer given does not relate to] when I was at home, I was talking probably, I thought this was probably an overall of those." *[Interviewer]: "'Your Arrival' as a summary of everything else?" [Patient 5853]:* Yeah.

On the basis of these findings, the survey was restructured into a two-page leaflet. The front and back pages provided additional information about the survey, and the middle two pages contained the survey questions (table 3). The survey still asked questions about each of the three stages of the transfer (departure, journey and arrival), however this was asked within each question. An additional explanation of the stages of the transfer was provided with increased clarity over which transfer was being referred to, and the survey questions were expanded to be more specific about what was being asked.

How safe did communication from staff make you feel? For example giving you clear and timely information or being polite
How safe did you feel with regards to staff listening to you and responding to your individual needs?
Did you experience any delays? [Yes / No] If yes, where was your longest delay? [Departure / Journey / Arrival] How did this make you feel?
How safe did you feel about the possibility of falling? For example if you felt confident that you wouldn't fall or if you were concerned that you might
How safe did you feel about your medication? For example receiving the correct medication, understanding the medication you were taking or delays in receiving your medication
How safe did you feel about hygiene and cleanliness? For example if staff washed their hands and if the surroundings were clean
Overall, how safe did you feel throughout the whole transfer including the departure, journey and arrival?

Table 3: Question format of the safety survey following cognitive interviews

Discussion

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A number of systematic reviews consider how patients can provide feedback on their safety,[9 10 19] however these focus on adverse events, typically within discrete care settings, rather than experiences of safety in the context of care transitions. Furthermore, there are relatively few studies reporting on the development of these mechanisms. One notable study has reported on the development of a patient reporting tool, though this is specific to secondary care settings.[16-18] Our study aimed to develop a mechanism for patients to provide feedback on their safety experiences following a transfer between organisations through a process of co-design. The transfer between organisations was chosen as it is a time in the patient's episode of care that is acknowledged to be particularly high in risk,[13 27] and when mistakes are likely to occur.[28]

By bringing together patients and healthcare professionals in tailored workshops, we were able to identify principles that should underpin the reporting mechanism, including that it should be patient-centred, short, concise with clear signposting, optionally anonymous and be objective with a focus on both positive (safe) and negative (unsafe) care. We built upon these principles by using participatory and co-design methods in the development of the survey, which are receiving increased attention in healthcare for their ability to increase participation and engagement,[21] and we used the Thinking Differently methodology[25] to provide a means by which to break out of existing schemas to encourage innovation. Furthermore, co-designing a mechanism ensures that it meets the requirements of different groups of users; in the case of this study, patients who are required to understand and complete the questions, and healthcare professionals who are required to collect and learn from the feedback provided. Co-design was particularly important given the differences that exist in patients' and healthcare professionals' understandings of safety, and provided an opportunity for shared learning.

Within the principles of feedback mechanisms, the provision of patient-centred care refers to the location of the patient within their care. For a feedback mechanism to be patient-centred, this in turn requires the opportunity for patients to be involved and to play an active role, thereby placing their experience of care at the forefront. The length and structure of the mechanism, in being short and concise with clear signposting, is already a feature of patient experience surveys and the benefits of brevity include increased response rates and greater acceptability and usability amongst patients.[29]

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Giving patients the option to provide anonymous feedback is particularly important when considering and discussing safety. Existing evidence suggests that patients have concerns, whether founded or not, that challenging healthcare professionals can impact upon the care received and engender feelings of suspicion and mistrust,[30] and the concept of providing anonymous feedback was enshrined in participants' comments and the final mechanism designed in this study. Finally, that both patients and healthcare professionals identified the need for feedback to be balanced between positive and negative experiences demonstrates that both groups were aware of criticisms of existing feedback mechanisms that focus on negative experiences alone, such as the use of complaints. The paradox of measuring safety by its absence was acknowledged early in the patient safety movement,[31] but this is now being reflected in proactive approaches to safety,[32] and the findings of this study suggest that the same principle should be applied to patient feedback mechanisms. The principles of being patient-centred, short, concise with clear signposting, optionally anonymous and objective with a focus on both positive and negative care can be applied by others who are interested in developing mechanisms for patients to provide feedback on their experiences of safety, and the generic nature of the principles can be applied to settings other than organisational care transfers.

Finally, the complexity associated with care being received across organisational boundaries was identified by participants and is recognised elsewhere in the literature.[12] In particular, healthcare professionals in this study acknowledged that they would be unable to implement change that impacts on or requires the input of other service providers as a result of patient feedback. This was a significant outcome, and an important consideration for future research that aims to involve the patient in their safety across organisational boundaries. Agreement between, or integration of, services may be necessary in order to promote organisational learning and change service delivery in response to patient feedback.

Limitations

This study developed a safety survey using participatory and co-design methods, including the identification of underlying principles. Whilst the survey was co-designed by healthcare professionals and patients, including cognitive interviews to validate and further refine the survey, further research

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is required to pilot the developed mechanism to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care. Furthermore, the participants involved in the development of the survey were recruited to represent a wide variety of health and social care services and patients. Due to the nature of organisational care transfers it is unlikely that they represented all possible types of transfers that patients experience. It was also not possible to explore further the governance relationships that exist between organisations, regardless of representation in this study, which could impact on the implementation of the survey into practice.

Future research

The use of participatory and co-design principles helped to overcome differences in the understanding of safety, to develop a mechanism for patients to provide feedback on their experiences of safety relating to a care transfer. Further research is required before the survey is ready to be used in practice, including piloting in relevant clinical areas in order to determine its usability and acceptability to patients and healthcare professionals. This could include determining whether asking patients about safety experiences is likely to increase awareness of patient safety, and whether patient experiences of safety can lead to quality improvement in the complex area of care transfers.

Acknowledgements

We would like to thank all participants for their invaluable contribution to the study, the Safer Care North East Patient, Carer and Public Engagement group and the PRoSOCT advisory group for their support and guidance, and the NHS Trusts involved in the study for their ongoing support. We also thank The Health Foundation (an independent charity committed to bringing about better health and health care for people in the UK), Northumbria University and the former North East Strategic Health Authority, in particular the Patient Safety Action Team and the Safer Care North East programme, for funding the studies that contributed to this paper. The research team acknowledge the support of the National Institute for Health Research, through the Comprehensive Clinical Research Network.

Author contributions

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Study 1: JS, PD and DJ designed the study, collected, analysed and interpreted the data. Study 2: JS, JW and PD designed the study. JS and EH collected, analysed and interpreted the data, with input from JW and PD. All authors contributed to the drafting of the manuscript.

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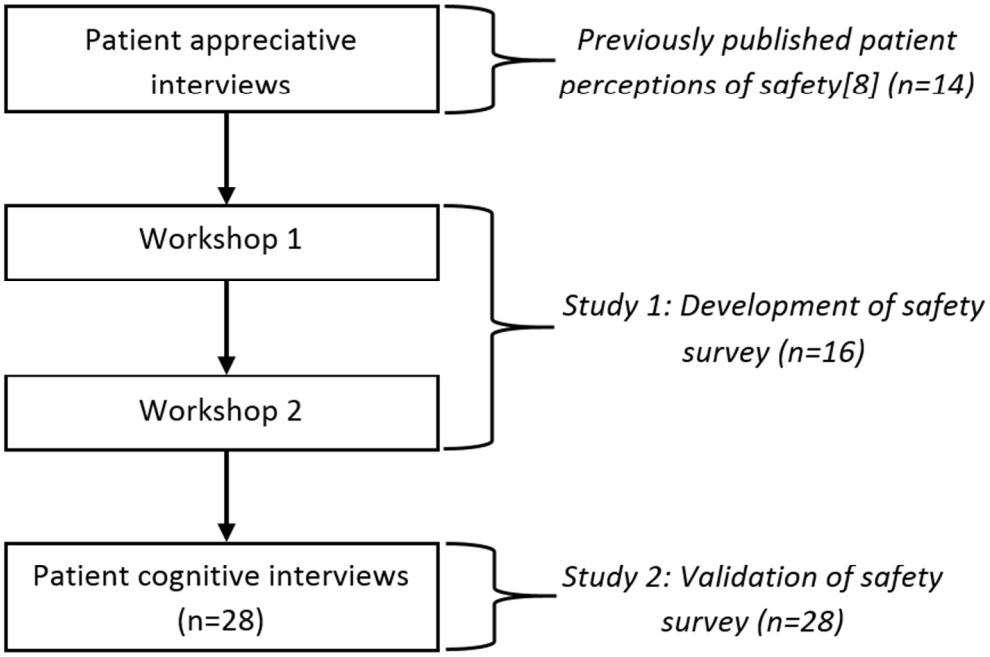

Process of development and validation of the patient feedback mechanism across studies

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BMJ Open

Healthcare professional and patient co-design and validation of a mechanism for service users to feedback patient safety experiences following a care transfer

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-011222.R1
Article Type:	Research
Date Submitted by the Author:	13-Apr-2016
Complete List of Authors:	Scott, Jason; Newcastle University, Institute of Health and Society Heavey, Emily; University of York, Social Policy Research Unit Waring, Justin; University of Nottingham, Centre for Health Innovation, Leadership & Learning / Nottingham University Business School Jones, Diana; Northumbria University, Dawson, Pamela; Northumbria University, Faculty of Health and Life Sciences
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Qualitative research
Keywords:	Patient safety, Patient experience, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH

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Healthcare professional and patient co-design and validation of a mechanism for service users to feedback patient safety experiences following a care transfer

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Funding: This research was funded by the North East Strategic Health Authority, Northumbria University and The Health Foundation (grant number 7204).

Number of tables: 4

Number of figures: 2

Key words: patient safety, patient experience, quality in health care, qualitative research

Word count: 5,574

Competing interests: The authors declare no competing interests.

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Abstract

Objective

To develop and validate a mechanism for patients to provide feedback on safety experiences following a care transfer between organisations.

Design

Qualitative study using participatory methods (co-design workshops) and cognitive interviews. Workshop data were analysed concurrently with participants and cognitive interviews were thematically analysed using a deductive approach based on the developed feedback mechanism.

Participants

Expert patients (n=5) and healthcare professionals (n=11) were recruited purposively to develop the feedback mechanism in two workshops. Workshop one explored principles underpinning safety feedback mechanisms, and workshop two included the practical development of the feedback mechanism. Final design and content of the feedback mechanism (a safety survey) were verified by workshop participants, and cognitive interviews (n=28) were conducted with patients.

Results

Workshop participants identified that safety feedback mechanisms should be patient-centred, short and concise with clear signposting on how to complete, with an option to be anonymous and balanced between positive (safe) and negative (unsafe) experiences. The agreed feedback mechanism consisted of a survey split across three stages of the care transfer; departure, journey and arrival. Care across organisational boundaries was recognised as being complex, with healthcare professionals acknowledging the difficulty implementing changes that impact other organisations. Cognitive interview participants agreed the content of the survey was relevant but identified barriers to completion relating to the survey formatting and understanding of a care transfer.

Conclusions

Participatory, co-design principles helped overcome differences in understandings of safety in the complex setting of care transfers when developing a safety survey. Practical barriers to the survey's

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usability and acceptability to patients were identified, resulting in a modified survey design. Further research is required to determine the usability and acceptability of the survey to patients and healthcare professionals, as well as identifying how governance structures should accommodate patient feedback when relating to multiple health or social care providers.

Strengths and limitations of the study:

- This study developed a safety survey using participatory and co-design methods to bring together patient and healthcare professional perspectives.
- Cognitive interviews with 28 patients were used to validate and further refine the survey format and questions.
- Further research is required to pilot the survey to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care.
- Due to the nature of organisational care transfers, which potentially include large numbers of organisations, it is unlikely that participants represented all possible types of transfers that patients experience.
- It was not possible to explore further the governance relationships that exist between different organisations responsible for patients' care, which could impact on the implementation of the survey into practice.

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Introduction

Progress in reducing patient harm from adverse incidents in healthcare remains slow.[1] Involving patients in understanding and commenting on their own safety may help organisations to identify poorly recognised safety issues, improve their learning and safety culture and reduce rates of avoidable harm.[2 3] While advocates of strict safety engineering suggest patients do not have a role to play in their own safety,[4] it is generally argued that, when willing and able, patients should be offered the opportunity to be involved, even though ultimate responsibility for safety rests with care providers.[5] A recent systematic review identified that patient experience data is positively associated with patient safety and clinical effectiveness.[6] However patients often perceive safety differently to clinicians, resulting in a lack of a shared understanding about what it means to feel safe.[7 8] In turn this may impact upon the ways in which patients can be involved in their safety.

Patients can be involved in the safety of their care in various ways, ranging from active participation in speaking up and challenging clinicians,[9 10] through to assessing factors that contribute to safety in hospital settings[11 12] and reporting safety incidents.[13] However it has been identified that formal incident report forms are not an appropriate mechanism for patients to report on their safety because patients were likely to report trivial matters and the process undermined trust in clinicians.[14] Another way of involving patients is to develop an understanding of, and to co-construct knowledge about safety.[15] A recent analysis of patient involvement in safety identified that a conjoint endeavour between patients and clinicians could reduce both parties' anxieties about patient involvement.[3]

Most efforts to involve patients in safety relate to care delivered in a relatively stable secondary care setting,[16 17] in which a single provider is responsible for patient safety. There has been less attention however, to patient experiences of safety in relation to a transition between organisations, defined as patients moving or being moved from one level of care to another or across different care settings.[18] The safety implications for care transitions are shown to be complex, resulting from the difficulties of working across organisational boundaries and leading to specific threats to safety and potential for re-admission.[19 20] With no one service having overall responsibility for the patient, existing safety systems are negated. In addition, with failures between organisations common,[21] organisational care transitions arguably increase the risk to patients due to deficits in communication

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and information transfer which negatively impact upon patients' continuity of care.[22] In Switzerland, it has been reported that poor coordination of care, albeit not necessarily directly related to care transitions, was the most important risk factor about which patients could provide feedback.[23] As the patient experiences the totality of the transition, there is an opportunity for patients to be involved in the safety of their care by providing a unique perspective on their transition and the continuity of care otherwise unavailable to healthcare professionals. Whilst there are an increasing number of international studies published that have sought to obtain patient perspectives on their transitions between organisations,[24 25] no known studies have developed, with patients and clinicians, a structured approach to collecting patient feedback on safety experiences in relation to organisational care transitions.

The aim of this study was to fill this knowledge gap by co-designing a mechanism with patients and clinicians for patients to provide feedback on their safety experiences following a transfer between organisations. To achieve this aim, specific objectives were to:

1. Identify principles that should underpin patient feedback on safety experiences;
2. Co-design and construct a feedback mechanism based on these principles and patient perceptions of safety; and,
3. Determine the face validity of the survey design with patients who have recently been discharged from hospital.

Methods

This study was underpinned by Appreciative Inquiry (AI), which is a methodology that concentrates on identifying what works well in organisations and attempts to ascertain how these strengths can be built upon. [20]. AI is traditionally used as a method of organisational development and is closely aligned to action research, albeit with the emphasis of building upon what works well. When used in healthcare it is often adapted to the requirements of individual projects,[21] and can even be adapted to underpin specific methods such as appreciative interviews.[22] The development of the mechanism focussed upon the 'design' stage of AI, enabling an emphasis on safe rather than unsafe care, which is synonymous with a recent shift in the patient safety movement from what fails occasionally to what succeeds often.[23]

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Data were collected across three phases (figure 1), including semi-structured interviews with patients that have been published elsewhere[8] (phase 1). The focus of phase 2 was the development of the feedback mechanism, with phase 3 acting as the validation process of the feedback mechanism. In phase 2, the primary method of developing the feedback mechanism was via two workshops using participatory and co-design methods, which are receiving increased attention in healthcare for their ability to increase participation and engagement.[26] The workshops were designed to bring together a wide variety of stakeholders, including patients and healthcare professionals, and afforded the opportunity for different stakeholders to present their unique experiences and perspectives. In phase 3, which was part of a larger feasibility project,[27] cognitive interviews were used to determine the face validity of the developed feedback mechanism. Patients were involved in choosing the focus on care transitions via the North East Strategic Health Authority's Patient, Carer and Public Engagement Network, who acted as a steering group for the study.

No incentives were provided for participation in any phase of the study. Approval for phases 1 and 2 was provided by Northumbria University School of Health, Community and Education Studies Ethics Committee, Sunderland Research Ethics Committee (reference: 09:H0904/57) and R&D departments at each of the included NHS sites. Approval for phase 3 was provided by Yorkshire & The Humber - Leeds West Research Ethics Committee (reference: 13/YH/0372) and R&D departments at each of the included NHS sites.

[Insert figure 1 around here]

Phase 1: Semi-Structured Interviews

Fourteen participants were recruited to semi-structured interviews, conducted by JS, from three community care teams spanning two NHS Trusts (n=7), two City Council Resource Centres (n=3), two private nursing and residential care homes (n=3) and via snowball sampling (n=1) but the participant was not under the care of any organisation at the time of recruitment. A topic guide was used to provide structure to the interviews, with a focus on the types of transfers participants had experienced, whether participants had felt safe during the transfer, what safety meant to participants

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and what would make participants feel safer in the future. Full details are available in a separate paper.[8]

Phase 2: Workshops

Participants were sampled purposively using criterion sampling[28] for the two workshops, which were hosted at the Strategic Health Authority and lasted approximately two hours, to ensure that participants represented different types of organisations involved in the transfer of patients. The patients' voice was provided by five expert patients, identified as such due to their active involvement in either a Patient, Carer and Public Engagement (PCPE) network (n=3), which had also acted as a steering group for the study, or from the Northumbria University Service User Network (n=2), which consisted of service users who were involved in the education of pre- and post-registration healthcare professionals.

Eleven healthcare professionals also participated in the workshops. These included NHS community care team nurses (n=3), social care home managers (n=2) and a private nursing home manager (n=1) who were all involved in the identification and recruitment of participants to an earlier phase of the study where perceptions of safety were explored with patients who had recently completed an organisational care transfer.[8] Additional participants included ambulance service staff (n=4) and a representative of the Strategic Health Authority Patient Safety Team (n=1). Participants were provided with invitation letters and information sheets to explain the purpose of the study, and that participation was voluntary and could be withdrawn at any time.

The first workshop, facilitated by JS and PD, was used to explore the key principles of capturing patient feedback on their experiences of safety. Four questions were posed to the group to ascertain what the feedback mechanism should look like, the format of the feedback mechanism and how the feedback mechanism would fit with current systems. Participants were split into two mixed groups of healthcare professionals and expert patients to discuss answers to the questions. Numerous methods captured discussions to reduce the impact of potential power relationships between healthcare professionals and expert patients, including voice-recordings, flipchart paper, observations and notes from the facilitators and post-it notes.

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The second workshop, facilitated by JS and DJ, was structured to have an emphasis on the practical outcome of designing a feedback mechanism, based in part on the results of the first workshop. Components of a Thinking Differently toolkit[29] were utilised to encourage creativity amongst participants when designing the feedback mechanism. Participants were split into two groups and given four Thinking Differently tools; 'fresh eyes, 'reframing by word play', 'pause, notice, observe' and 'random word, picture or object'.[29]. The fundamental basis of this toolkit is that individuals hold schemas, or mental structures of the world, through which thoughts are channelled. The schemas are separated from one another, meaning that it can be difficult to think outside of these mental structures, or to think differently. This in turn inhibits the potential for novel ways of doing something to be introduced into, or alongside, existing systems. Divergent thinking strategies (the Thinking Differently tools) were used in the first half of the workshop (break-out session 1) and participants were encouraged to converge their thinking in the second half of the workshop (break-out session 2; figure 2).

[Insert figure 2 around here]

As the workshop data were emergent it was not possible to plan the data analysis *a priori*. Instead, for the first workshop data were analysed inductively based upon the different themes and concepts that arose. For the second workshop, data analysis was conducted concurrently with participants drawing upon each other's ideas and working as individual groups via convergent thinking to assess these shared ideas and bring them into a tangible mechanism for patients to provide feedback on their safety experiences. A final discussion was held with all workshop participants about which parts of each group's chosen feedback mechanism were the strongest. This contributed to a process whereby the participants were involved as co-researchers in both data collection and analysis,[30] occurring in a participatory open forum.

Following the second workshop, a researcher (JS) constructed the survey electronically using the final design agreed by the participants as a template. Additional data that were collected in the second workshop, such as voice recordings and flipcharts, were used post-workshop to ensure that the

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feedback mechanism had accurately captured what the participants had discussed. Upon completion, the final design was circulated amongst all participants for verification that it was an accurate reflection of the discussions and proposed designs. More detail on the construction and content of the survey is provided in the findings section.

Phase 3: Cognitive Interviews

The survey was piloted within two NHS Trusts across two cycles each lasting six months, where staff were asked to distribute the survey to every patient discharged from wards participating in the study. Patients were given the survey and asked to complete it upon arrival at their next destination, and to return the survey to the research team using a pre-paid envelope. In total, 16 wards from four clinical areas (cardiology, care of older people, orthopaedics and stroke) were involved in the distribution of the survey. Patients deemed unable to give informed consent by their care team or were under the age of 18 were not eligible to participate.

Cognitive interviews were conducted by EH and JS with 28 patients (18 male, 10 female) in their place of residence who had completed the safety survey following discharge from hospital. Table 1 provides a summary of the distribution cycle recruited from, transport type, destination and clinical area. Participant ages ranged from 53 to 86 (mean=68, standard deviation=10). Cognitive interviews have proved useful in pre-testing of survey questions in a healthcare setting, particularly when they may be complex or of a sensitive nature,[31] as in this study.

Study ID	Cycle	Transport	Destination
Cardiology (n=13)			
980	1	Private Car	Hospital
462	1	Private Car	Home
2593	1	Ambulance	Hospital
2590	1	Ambulance	Hospital
4679	1	Private Car	Hospital
3954	1	Ambulance	Hospital
3319	1	Unknown	Hospital
5945	1	Unknown	Unknown
5583	1	Patient Transport	Hospital
4300	1	Private Car	Home
6227	2	Private Car	Home
6427	2	Private Car	Home

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11597	2	Taxi	Home
Care of Older People (n=3)			
104	1	Unknown	Unknown
1189	1	Ambulance	Home
7701	2	Private Car	Home
Orthopaedics (n=7)			
761	1	Ambulance	Home
1867	1	Private Car	Home
2494	1	Ambulance	Home
5853	1	Unknown	Home
6725	2	Private Car	Home
9748	2	Private Car	Home
11100	2	Walking	Home
Stroke (n=5)			
2450	1	Ambulance	Hospital
3445	1	Patient Transport	Hospital
3408	1	Private Car	Hospital
5767	1	Private Car	Home
8182	2	Private Car	Home

Table 1: Details of cognitive interview participants' care transfers.

Interviewees were invited to describe their thought processes in response to the survey questions, in order to identify any potential misunderstandings or other problems with those questions. We extended this beyond the questions to also ask about other components of the survey, including the introductory text, the description of different sections and the overall structure. Cognitive interviews were audio recorded and transcribed verbatim, then coded and analysed using NVivo qualitative analysis software. Interviews were thematically analysed using a deductive approach based on the structure and the questions asked in the survey by one researcher (EH), with codes and themes verified by JS, PD and JW.

Findings

The findings are reported in five sections. The first section summarises the findings of patient perceptions of safety that were published elsewhere.[8] The next two sections, *principles of patient feedback* and *integration with existing systems*, represent themes identified in the first workshop that should underpin the development of patient feedbackmechanisms applied specifically to capturing

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patient safety feedback. More specifically, *principles of patient feedback* represent the essential design principles of the patient feedback mechanisms, and *integration with existing systems* represents the acknowledgement by participants that where multiple organisations are involved in the care of the patient, particularly as patients cross organisational boundaries, feedback needs to be compatible with multiple patient safety and patient experience systems. The second two sections, *development of the safety survey* and *validation and refinement of the survey* report on the development and validation of the survey. These include why participants chose a safety survey as the most appropriate feedback mechanism, how the final design was developed by the participants and cognitive interview findings, including where confusion arose around the question format and the overall survey design.

Patient perceptions of safety

Semi-structured interviews with patients identified aspects of care that had made them feel safe. These included the ways in which staff communicated with patients and responded to the individual needs of the patient, for example by listening and adjusting the care provided. Interlinked with these themes was that of waiting times; where delays were not communicated to patients and patient requests were not listened to. Patients were also able to identify traditional safety issues, a catch-all term that included medications, falls and healthcare-acquired infections.[8]

Principles of patient feedback

Participants made recommendations and references to the principles on which the feedback mechanism should be based. There was agreement that the feedback mechanism needed to be short with options to expand on answers so that service users could report what was of most importance to them. This is highlighted in a conversation during a workshop between a community care team nurse and patient:

> "From a professional wanting to know what a patient would want, you'd want something that's short but open-ended…" [Community care team nurse]
>
> "Yes" [Patient]

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"… so it allows the patient to… discuss one aspect that you felt safe. That's a massive topic but if you had sort of four or five questions like, 'were you happy with that element of care?', 'did you find that was safe?', and that sort of thing" [Community care team nurse]

"Yeah, and, 'if not, why not?'" [Patient]

Participants also agreed that a short and concise feedback mechanism would increase response rates. A conversation between a community care team nurse, social care home manager and a patient highlights this agreement, and in doing so they begin to discuss the need for the feedback mechanism to be objective, or unbiased, through the presentation of positive (safe) and negative (unsafe) experiences.

"So to capture that [transfers of care are different], would we say that they would want the questionnaire to be sort of short and concise to encourage people to actually do it?" [Community care team nurse]

"Got to be fairly concise. The longer it is I think the less chance there is of getting involved with it, and especially if you're asking for positive as well as negative feedback or just general commentary" [Social care home manager]

"That's a very important point. It shouldn't all be whinging. You need to capture the positives as well" [Patient]

"So objective, yeah?" [Community care team nurse]

"Yeah" [Patient]

This unbiased approach was emphasised by both health care professionals and patients to emphasise the necessity to be appreciative. In a conversation between a social care home manager and a community care team nurse, the uneven balance of negative rather than positive feedback is discussed. Notably, it was perceived that this imbalance is caused by a lack of recording of positive feedback.

"You don't get much feedback unless it's a complaint" [Social care home manager]

"But I think, I think a lot of people do get feedback. I just think there's an emphasis on the negative. There's a lot of people, like I'm sure you've probably had a patient, where they feedback that you do a grand job. That never gets captured." [Community care team nurse]

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Participants felt that the feedback mechanism should have an option to be anonymous as some service users would want to avoid going through a formal complaints procedure. However there were concerns over the usability of patient feedback if it could not be traced to a particular incident, thus impacting on potential learning.

> "The only problem is with it being anonymous is... tracing it back because it's actually more effective when you can look. […] So you can improve practice generally, but for that specific case you might want to look at it in more detail." [Social care home manager]

Integration with existing systems

A number of discussion points arose that focused on how the potential feedback mechanism would fit with current feedback mechanisms. Firstly it was acknowledged that such a system for collecting patient feedback relating to admissions and discharge was required as there was no existing means for patients to provide feedback on this stage of their care, "what we haven't got is just before [service users] get to us, and just after we discharge them." [social care home manager]. A paramedic reported that feedback was limited to complaints or compliments, with a gap existing for the routine collection of patient feedback:

> "We've all got process in place that if there's something we're concerned about we can bring it up. But looking what feedback we get from patients, I know certainly on an ambulance point of view, we get no feedback. The only feedback we get is either a complaint coming in or a letter of thanks." [Ambulance service paramedic]

An additional consideration arose in the second workshop, where care home managers from both private and social care settings discussed utilising patient feedback when it relates to care delivered across organisational boundaries. In particular, it was reported and agreed that whilst patient feedback can be used to change practice, and systems can be changed to incorporate this feedback, they felt there was no opportunity to influence other parts of the health or social care systems. This resulted in a conflicting stance, with healthcare professionals wanting to receive meaningful feedback from patients, but knowing existing organisational structures prohibited being able to respond to this

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information and change practice. In turn this had the potential to impact upon the utility of any potential feedback mechanism for patients crossing organisational boundaries.

> "We want instant [patient] feedback to change our systems" [Social care home manager]
>
> "And so we can change the system within our environment but we can't change the system anywhere else" [Private nursing care home manager]

Development of the safety survey

In workshop 2, participants were given four Thinking Differently tools; 'fresh eyes, 'reframing by word play', 'pause, notice, observe' and 'random word, picture or object'.[29]. The use of 'fresh eyes' in particular encouraged participants to explore how non-healthcare organisations approach receiving feedback. These included some of the more traditional feedback mechanisms, such as noticeboards, postcards and questionnaires, and more novel methods, including an aviation-based reporting system, the Royal Society for the Protection of Birds' annual bird watch and supermarket tokens. Table 2 contains a brief description of each of the proposed feedback mechanisms.

Mechanism	Group	Explanation
Noticeboard	1	Provided in GP waiting rooms for patients to write comments about their recent experiences.
Postcard	1	Given to service users during every part of the journey to complete, capturing the wide range of organisational care transfers.
Post boxes	1	An alternative to the noticeboard which provides privacy for service users and confidentiality for healthcare professionals.
Thermometer scale	1	Service users are able to place stickers on a large thermometer relating to how safe or unsafe they felt. Proposed as it would be quick and easy for service users.
Questionnaire	1	A simple questionnaire sent to service users post-transfer.
Aviation Reporting Tool	2	Confidential Human factors Incident Reporting Programme is used in aviation. Suggested as an idea as it is confidential and had no blame attributed to the reports.
RSPB Bird Watch	2	A method of collecting a lot of data in a systematic way over a short period of time.
Gordon Ramsey approach	2	Communication in restaurants by waiters can reduce the impact that long waiting times have.
Supermarket tokens	2	System similar to supermarket charity donation tokens. Given to service users on discharge for them to place in a 'safe' or 'unsafe' box
Reverse transfer	2	Increase safety by reducing the number of organisational care transfers through increased care in the community.
Internet questionnaire	2	An automatic email sent to everyone that had gone through an organisational care transfer.

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Hospital waiting area information	2	Provide information, either in person or via electronic screens regarding length of wait and delays.
Discharge lounge	2	Place for service users to go prior to a discharge to free up a bed. Somebody could be there to coordinate transfers, provide information and receive feedback.

Table 2: Feedback mechanisms identified by workshop participants for patients to provide feedback on their experiences of safety

Each component of the feedback mechanism was designed by the participants using flipchart paper to draw examples to be discussed. One group decided that the postcard was the best feedback mechanism to take forward and develop due to its simplicity and applicability to a wide variety of settings. This included using a simple scoring system with a three-point scale that incorporated smiley faces: safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

> "One side with a smiley face and one side with a… [unhappy face]. And then straight away you can see" [Private care home manager]
>
> […]
>
> "Something simple. I think the most simple ideas are the most effective" [Patient safety team representative]

However, it was also recognised by participants that having an overly-simplistic system may result in data that lacked meaning, although participants did not stipulate the minimum or maximum amount of complexity or sensitivity required in order for the data to be meaningful. For example there was a debate whether a three-point Likert scale would produce results sensitive enough to identify outliers in safe or unsafe care.

> "As you were saying where you should have a red, a green, amber, and identifying how happy you were, but the detail this lady's describing would need to be addressed quite intricately" [Ambulance service safeguarding lead]

The other group chose to develop a leaflet-based feedback mechanism, split into three sections directed towards the discharge, transfer and admission of the service user. In particular, their decision

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to split the transfer into the three stages was summarised by a facilitator (DJ) when feeding back on behalf of the group.

> "We thought that most journeys, and I like your idea of defining a journey and what service user safety is, have a beginning, and a middle and an end. So, we would like to start with this panel, which is… we've got a day and a date… place of departure, so where did you depart from?" [Facilitator, DJ]

This three-stage structure was utilised in the final design, although transfer was changed to journey after the workshop, following feedback from one participant during verification of the design. Table 3 provides an overview of the survey structure and questions.

> *I'm never happy with transfer because people… some people, particularly the public, would automatically think you're talking about wheels, as opposed to the journey* [Email correspondence, community care team nurse]

Please tick which of the following affected how safe or unsafe you felt.

Discharge	Safe	Neutral	Unsafe	Journey	Safe	Neutral	Unsafe	Arrival or Admission	Safe	Neutral	Unsafe
Communication from staff				Communication from staff				Communication from staff			
Staff listening to you				Staff listening to you				Staff listening to you			
Departure running to schedule				Journey running to schedule				Waiting times			
Falling or potential falls				Falling or potential falls				Falling or potential falls			
Medication problems or concerns				Medication problems or concerns				Medication problems or concerns			
Hygiene				Hygiene				Hygiene			
Please use this space to tell us if there was another reason why you felt safe or unsafe or to expand on your answers above											
What could we have done to make you feel safer during your transfer?											

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Table 3: Structure and question format of the safety survey following initial development. Note that each response option was provided in the form of colour-coded smiley faces for safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

Validation and refinement of the survey through cognitive interviews

In the cognitive interviews, there was some diversity of opinion on the appropriateness of the paper format and the three-face design. While some participants suggested that an online or telephone survey might be easier to complete, there was a general consensus that varying access to computers, as well as time and cost restraints, meant that a paper version was more appropriate for most people. Patient 1867 summarised:

> "I would quite happily fill it in on an App, but [people] who are not computer literate would just back away from that. I think paperwork is probably the best way that would cover every age group." [Patient 1867]

Most participants found the three-point scale with smiley faces easy to use and understand. The statement from Patient 4300 makes this point, as well as reinforcing the workshop participants' preference for the survey to be concise:

> "Smiley faces and sad faces and things like that, you know red faces, it looked simple, it was easy, it caught your eye. It wasn't too wordy cos I think there's nothing worse than wordy surveys where you get half way through and you think, 'You know what, I can't be bothered'". [Patient 4300]

However, it should be noted that some participants expressed a preference for 'yes/no/maybe' style questions, with one suggesting that asking whether a patient felt safe, neutral, or unsafe was confusing and even "loaded" [Patient 3954]. Another participant suggested that three faces were not enough, and that there should be 5 in varying shades. Despite this diversity, there was general agreement that the paper survey with the three faces tick-box system was easy to use.

It was reported that two aspects of the survey design caused difficulties for many participants; the division into three stages of the care transfer (Departure, Journey, Arrival) and the way in which the

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questions were asked. For the stages of the transfer, patients were unclear about which departure, journey, and arrival they were being asked. Some interpreted the questions in the 'Journey' section to be relating to their journey *to* hospital rather than *from* hospital or thought they were being asked "to give an average" assessment of the two journeys (P1189); others though that 'Arrival' referred to their initial arrival on the ward, rather than at their next destination.

> "The format of that is not right. It needs drastically changing, I think you should keep 'your departure from' that needs to be explained really, from where?" [Patient 3954]

Second, some participants did not make the distinction between these three stages at all, instead answering questions in the three separate sections in relation to the entirety of the care transfer; these participants saw the three separate sections as merely repeating the same questions, without distinguishing between different transfer stages. For example, Patient 5853, when asked how they had interpreted a question relating to 'Arrival', stated

> "[The answer given does not relate to] when I was at home, I was talking probably, I thought this was probably an overall of those." *[Interviewer]: "'Your Arrival' as a summary of everything else?" [Patient 5853]:* Yeah.

On the basis of these findings, the survey was restructured into a two-page leaflet. The front and back pages provided additional information about the survey, and the middle two pages contained the survey questions (table 4). The survey still asked questions about each of the three stages of the transfer (departure, journey and arrival), however this was asked within each question. An additional explanation of the stages of the transfer was provided with increased clarity over which transfer was being referred to, and the survey questions were expanded to be more specific about what was being asked (see supplementary material for the wording). Space for free text comments was provided next to each question. Cognitive interviews with patients using the modified version of the survey suggested that the changes had resolved the original issues around question clarity and the type of transfer that was being asked about.

How safe did communication from staff make you feel? For example giving you clear and timely information or being polite.
On your departure [Safe / Neutral / Unsafe]

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During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]
How safe did you feel with regards to staff listening to you and responding to your individual needs?
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]
Did you experience any delays? [Yes / No]
If yes, where was your longest delay? [Departure / Journey / Arrival]
How did this make you feel? [Safe / Neutral / Unsafe]
How safe did you feel about the possibility of falling? For example if you felt confident that you wouldn't fall or if you were concerned that you might.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]
How safe did you feel about your medication? For example receiving the correct medication, understanding the medication you were taking or delays in receiving your medication.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]
How safe did you feel about hygiene and cleanliness? For example if staff washed their hands and if the surroundings were clean.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]
Overall, how safe did you feel throughout the whole transfer including the departure, journey and arrival? [Safe / Neutral / Unsafe]

Table 4: Question format of the safety survey following cognitive interviews. Response options are provided in square brackets. Note that each response option was provided in the form of colour-coded smiley faces for safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

Discussion

A number of systematic reviews consider how patients can provide feedback on their safety,[14 16 17] however these focus on adverse events, typically within discrete care settings such as secondary care, rather than experiences of safety in the context of care transitions. Furthermore, there are relatively few studies reporting on the development of these feedback mechanisms. One notable study has reported on the development of a patient reporting tool, though again this is specific to secondary care settings.[11-13] Our study developed a mechanism for patients to provide feedback on their safety experiences following a transfer between organisations through a process of co-

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design. The transfer between organisations was chosen as it is a time in the patient's episode of care that is acknowledged to be particularly high in risk,[21 32] and when mistakes are likely to occur.[33]

The developed safety survey aims to capture patient experiences of safety, based on patients' definitions of what it is that makes them feel safe during a care transition.[8] This is a notable shift from some existing approaches to involving patients in reporting patient safety incidents, which have had limited success.[14] There has been a limited amount of work attempting to reconcile the differing perceptions of safety between clinicians and patients that result in a lack of a shared understanding about what it means to feel safe,[7 8] but the use of co-design approaches in developing feedback mechanisms can go some way to bringing together the different perceptions, particularly as it has been identified that patient experiences can be linked to clinical safety.[6]

By bringing together patients and healthcare professionals in tailored workshops within this study, we were able to identify principles that should underpin the feedback mechanism, including that it should be patient-centred, short, concise with clear signposting on how to complete it, optionally anonymous and be objective with a focus on both positive (safe) and negative (unsafe) care.

Within the principles of feedback mechanisms, the provision of patient-centred care refers to the location of the patient within their care. For a feedback mechanism to be patient-centred, this in turn requires the opportunity for patients to be involved and to play an active role, thereby placing their experience of care at the forefront. The length and structure of the feedback mechanism, in being short and concise with clear signposting on how to complete it, is already a feature of patient experience surveys and the benefits of brevity include increased response rates and greater acceptability and usability amongst patients.[34]

Giving patients the option to provide anonymous feedback is particularly important when considering and discussing safety. Existing evidence suggests that patients have concerns, whether founded or not, that challenging healthcare professionals can impact upon the care received and engender feelings of suspicion and mistrust,[35] and the concept of providing anonymous feedback was enshrined in participants' comments and the final feedback mechanism designed in this study. Finally, that both patients and healthcare professionals identified the need for feedback to be balanced

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between positive and negative experiences demonstrates that both groups were aware of criticisms of existing feedback mechanisms that focus on negative experiences alone, such as the use of complaints. The paradox of measuring safety by its absence was acknowledged early in the patient safety movement,[36] but this is now being reflected in proactive approaches to safety,[37] and the findings of this study suggest that the same principle should be applied to patient feedback mechanisms. The principles of being patient-centred, short, concise with clear signposting on how to complete the feedback mechanism, optionally anonymous and objective with a focus on both positive and negative care can be applied by others who are interested in developing feedback mechanisms for patients to provide feedback on their experiences of safety, and the generic nature of the principles can be applied to settings other than organisational care transfers.

Finally, the complexity associated with care being received across organisational boundaries was identified by participants and is recognised elsewhere in the literature.[20] In particular, healthcare professionals in this study acknowledged that they would be unable to implement change that impacts on or requires the input of other service providers as a result of patient feedback. This was a significant outcome, and an important consideration for future research that aims to involve the patient in their safety across organisational boundaries. Agreement between, or integration of, services may be necessary in order to promote organisational learning and change service delivery in response to patient feedback.

Use of co-design methods

We built upon the principles that should underpin a feedback mechanism by using participatory and co-design methods in the development of the survey, which are receiving increased attention in healthcare for their ability to increase participation and engagement,[26] and we used the Thinking Differently methodology[29] to provide a means by which to break out of existing schemas to encourage innovation.

Furthermore, co-designing a feedback mechanism ensures that it meets the requirements of different groups of users; in the case of this study, patients who are required to understand and complete the questions, and healthcare professionals who are required to collect and learn from the feedback

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provided. Co-design was particularly important given the differences that exist in patients' and healthcare professionals' understandings of safety, and provided an opportunity for shared learning. Despite these benefits of using co-design, we did encounter challenges associated with the approach, including personal agendas and dominant voices. Prior to the first workshop, we developed inclusive strategies such as post-it notes and flipchart paper that would enable both patient and healthcare professional participants to have their voice heard, even if it was not audible.[38] The issue of personal agendas amongst participants, where they would attempt to overly influence the direction of discussion, was a greater challenge. In a systematic review of the impact on patient involvement on research, personal experience stories that dominated discussions were identified to be a challenge.[39] In order to resolve this, we used the Thinking Differently toolkit in workshop 2 to provide focus for all participants by directing thoughts and discussions to situations equally familiar to all, thus reducing the available space in which individuals could dominate discussions.

Limitations

This study developed a safety survey using participatory and co-design methods, including the identification of underlying principles. Whilst the survey was co-designed by healthcare professionals and patients, including cognitive interviews to validate and further refine the survey, further research is required to pilot the developed feedback mechanism to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care. Furthermore, the participants involved in the development of the survey were recruited to represent a wide variety of health and social care services and patients. Due to the nature of organisational care transfers it is unlikely that they represented all possible types of transfers that patients experience. It was also not possible to explore further the governance relationships that exist between organisations, regardless of representation in this study, which could impact on the implementation of the survey into practice.

Future research

The use of participatory and co-design principles helped to overcome differences in the understanding of safety, to develop a feedback mechanism for patients to provide feedback on their experiences of safety relating to a care transfer. Further research is required before the survey is ready to be used in practice, including piloting in relevant clinical areas in order to determine its usability and acceptability

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to patients and healthcare professionals. This could include determining whether asking patients about safety experiences is likely to increase awareness of patient safety, and whether patient experiences of safety can lead to quality improvement in the complex area of care transfers.

Acknowledgements

We would like to thank all participants for their invaluable contribution to the study, the Safer Care North East Patient, Carer and Public Engagement group and the PRoSOCT advisory group for their support and guidance, and the NHS Trusts involved in the study for their ongoing support. We also thank The Health Foundation (an independent charity committed to bringing about better health and health care for people in the UK), Northumbria University and the former North East Strategic Health Authority, in particular the Patient Safety Action Team and the Safer Care North East programme, for funding the studies that contributed to this paper. The research team acknowledge the support of the National Institute for Health Research, through the Comprehensive Clinical Research Network.

Author contributions

Phases 1 and 2: JS, PD and DJ designed the phases, collected, analysed and interpreted the data. Phase 3: JS, JW and PD designed the phase. JS and EH collected, analysed and interpreted the data, with input from JW and PD. All authors contributed to the drafting of the manuscript.

Data sharing statement

No additional data are available.

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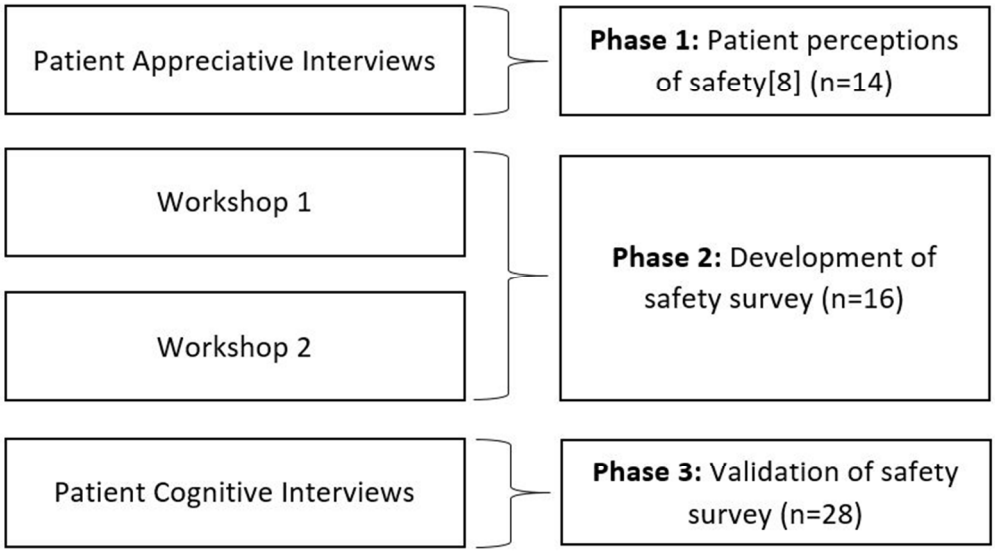

Figure 1: Process of development and validation of the patient feedback mechanism across three phases
70x40mm (300 x 300 DPI)

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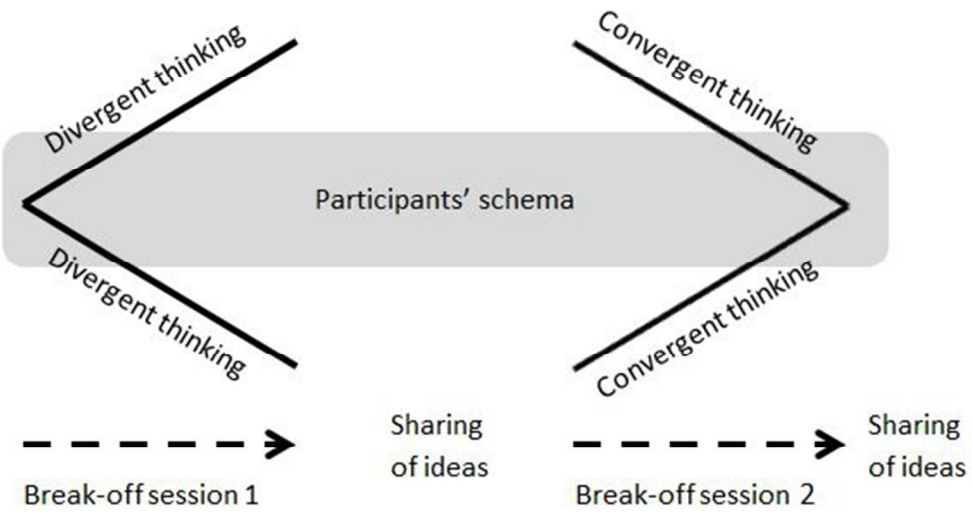

Figure 2: Divergent and convergent thinking strategies in Workshop 2 to encourage participants to think outside of their existing feedback mechanism schema
49x27mm (300 x 300 DPI)

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SAFE AND SURE

Safety Survey

Dear patient and / or carer,

This survey is for you to tell us how safe you felt during your most recent transfer out of hospital, and what made you feel this way. Anything that you tell us will remain confidential and will not affect the care that you receive.

It is important for us to find out about your experiences so that we can improve our services. **Please complete the survey and return it in the prepaid envelope provided**.

Contact Jason Scott or Emily Heavey if you have any questions, would like help completing the survey or if you would like to receive the survey in large print.

01904 876 376

j.scott@yorksj.ac.uk

e.heavey@yorksj.ac.uk

What does safety mean?

We believe that for you to feel safe, healthcare staff should communicate with you, respond to your individual needs and ensure you are physically safe and secure. We are also interested in finding out if there is anything else that makes you feel safe.

How do I complete the survey?

For each question, please tick the face that best represents how you felt. The **green face** means you had no worries or concerns about your safety, the **red face** means you were worried or concerned about your safety, and the **yellow face** means you felt somewhere between the two.

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York St John University · York Teaching Hospital NHS Foundation Trust · The University of Nottingham · Nottingham University Hospitals NHS Trust · The Health Foundation Inspiring Improvement · Yorkshire Ambulance Service NHS Trust

Departure means planning and preparing for, and leaving hospital.

Journey means travelling from hospital to your next location.

Arrival means settling in at your next location.

What is your NHS Number? (optional) _____

Are these the opinions of: patient ❑ carer ❑

What was the date of your departure? D D / M M / Y Y Y Y

Which ward did you depart from? _____

Where were you going to? _____

How did you get there? _____

Did someone go with you? Yes ❑ No ❑

If yes, who? Family / Friend ❑ Carer ❑ Member of Staff ❑

Only tick boxes for questions below that are relevant to you, for example the question on staff communication during your journey may not be applicable if you used your own transport.

How safe did the communication from staff make you feel? For example giving you clear and timely information or being polite.

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel with regards to staff listening to you and responding to your individual needs?

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

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Did you experience any delays? Yes ❑ No ❑

If yes, where was the longest delay during your transfer?

Departure ❑ Journey ❑ Arrival ❑ Comments: _____

How did this make you feel?

❑ ❑ ❑

_____

_____

How safe did you feel about the possibility of falling? For example if you felt confident that you wouldn't fall or if you were you concerned that you might

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel about your medication? For example receiving the correct medication, understanding the medication you were taking or delays in receiving your medication.

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel about hygiene and cleanliness? For example if staff washed their hands and if the surroundings were clean

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

Overall, how safe did you feel throughout the whole transfer including the departure, journey and arrival?

Comments: _____

❑ ❑ ❑

_____

_____

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Thank you for taking the time to complete this survey. Please return it in the freepost envelope provided.

What will we do with your answers to this survey?

We will bring together feedback from patients and provide this anonymously to healthcare teams involved in your transfer. The purpose of this is to identify what is being done well, and areas where the quality of care that you receive can be improved.

What should you do if you want to make a complaint about your care?

By completing this survey you are **not** making a complaint. If you have felt unsafe at any other point during your care or would like to raise a specific concern please contact the Patient Advice and Liaison Service. If you contact us we can give you information on how to do this.

Would you like to receive a summary of the research findings?

Yes ❑ No ❑

Please fill out your details below and we will send you this at the end of the study. All information will remain private and confidential in line with the Data Protection Act (1998), and will not be shared with anyone or used for any other purpose than to provide you feedback.

Name: _____

Address: _____

_____

Could you please tell us your gender, age and how you define your racial / ethnic origin. This will tell us if we're reaching a wide sample of people. If you are a carer, please tell us the patient's details. You do not have to complete this part if you do not want to.

Gender: Male ❑ Female ❑

Age: _____

Racial / ethnic origin: _____

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No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer / facilitator	Which author/s conducted the interview or focus group?	Pages 6, 7 and 8.
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	All researchers hold a PhD.
3.	Occupation	What was their occupation at the time of the study?	JS was a PhD candidate at the time of phases 1 and 2. JS and EH were research associates during phase 3. PD, AJ and JW were in academic positions during all phases.
4.	Gender	Was the researcher male or female?	Male and Female.
5.	Experience and training	What experience or training did the researcher have?	Experience conducting and analysing data from focus groups of patients and healthcare professionals.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No relationship was established prior to study commencement
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	This information was provided prior to data collection as part of the invitation and information leaflet
8.	Interviewer characteristics	What characteristics were reported about the interviewer / facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	No characteristics were reported about the researchers
Domain 2: study design			
Theoretical framework			

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No	Item	Guide questions/description	
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Page 5
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Pages 6, 7 and 8
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Pages 7 and 9
12.	Sample size	How many participants were in the study?	Pages 6, 7, 8 and 9, and figure 1
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	No participants dropped out. We are unaware of how many people refused to participate due to the way in which participants were invited to the study.
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Pages 7 and 9
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Nobody else was present during data collection
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Pages 6, 7, 8 and 9
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 6 and 9
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Repeat data collection was not conducted

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No	Item	Guide questions/description	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 8 and 9
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were not taken
21.	Duration	What was the duration of the interviews or focus group?	Page 7
22.	Data saturation	Was data saturation discussed?	For cognitive interviews, data saturation was discussed among those reviewing and coding the transcripts. Data saturation was not relevant for the co-design workshops
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 8
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Page 9
25.	Description of the coding tree	Did authors provide a description of the coding tree?	A summary of the coding tree is written on pages 9 and 10
26.	Derivation of themes	Were themes identified in advance or derived from the data?	For phases 1 and 2, themes were derived from the data (where applicable). For phase 3, themes were identified in advance based on the structure of the survey.
27.	Software	What software, if applicable, was used to manage the data?	Page 9
28.	Participant checking	Did participants provide feedback on the findings?	Participants provided real-time feedback during the co-design workshops.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Pages 10 - 17

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No	Item	Guide questions/description	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Pages 9 – 17. A summary of the major themes is presented at the start, and subheadings are used to present them in more detail.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Pages 10 – 12. In particular discussion about the integration with existing systems.

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BMJ Open

Healthcare professional and patient co-design and validation of a mechanism for service users to feedback patient safety experiences following a care transfer

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-011222.R2
Article Type:	Research
Date Submitted by the Author:	25-May-2016
Complete List of Authors:	Scott, Jason; Newcastle University, Institute of Health and Society Heavey, Emily; University of York, Social Policy Research Unit Waring, Justin; University of Nottingham, Centre for Health Innovation, Leadership & Learning / Nottingham University Business School Jones, Diana; Northumbria University, Dawson, Pamela; Northumbria University, Faculty of Health and Life Sciences
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Qualitative research
Keywords:	Patient safety, Patient experience, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH

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Healthcare professional and patient co-design and validation of a mechanism for service users to feedback patient safety experiences following a care transfer

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Funding: This research was funded by the North East Strategic Health Authority, Northumbria University and The Health Foundation (grant number 7204).

Number of tables: 4

Number of figures: 2

Key words: patient safety, patient experience, quality in health care, qualitative research

Word count: 5,574

Competing interests: The authors declare no competing interests.

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Abstract

Objective

To develop and validate a mechanism for patients to provide feedback on safety experiences following a care transfer between organisations.

Design

Qualitative study using participatory methods (co-design workshops) and cognitive interviews. Workshop data were analysed concurrently with participants and cognitive interviews were thematically analysed using a deductive approach based on the developed feedback mechanism.

Participants

Expert patients (n=5) and healthcare professionals (n=11) were recruited purposively to develop the feedback mechanism in two workshops. Workshop one explored principles underpinning safety feedback mechanisms, and workshop two included the practical development of the feedback mechanism. Final design and content of the feedback mechanism (a safety survey) were verified by workshop participants, and cognitive interviews (n=28) were conducted with patients.

Results

Workshop participants identified that safety feedback mechanisms should be patient-centred, short and concise with clear signposting on how to complete, with an option to be anonymous and balanced between positive (safe) and negative (unsafe) experiences. The agreed feedback mechanism consisted of a survey split across three stages of the care transfer; departure, journey and arrival. Care across organisational boundaries was recognised as being complex, with healthcare professionals acknowledging the difficulty implementing changes that impact other organisations. Cognitive interview participants agreed the content of the survey was relevant but identified barriers to completion relating to the survey formatting and understanding of a care transfer.

Conclusions

Participatory, co-design principles helped overcome differences in understandings of safety in the complex setting of care transfers when developing a safety survey. Practical barriers to the survey's

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usability and acceptability to patients were identified, resulting in a modified survey design. Further research is required to determine the usability and acceptability of the survey to patients and healthcare professionals, as well as identifying how governance structures should accommodate patient feedback when relating to multiple health or social care providers.

Strengths and limitations of the study:

- This study developed a safety survey using participatory and co-design methods to bring together patient and healthcare professional perspectives.
- Cognitive interviews with 28 patients were used to validate and further refine the survey format and questions.
- Further research is required to pilot the survey to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care.
- Due to the nature of organisational care transfers, which potentially include large numbers of organisations, it is unlikely that participants represented all possible types of transfers that patients experience.
- It was not possible to explore further the governance relationships that exist between different organisations responsible for patients' care, which could impact on the implementation of the survey into practice.

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Introduction

Progress in reducing patient harm from adverse incidents in healthcare remains slow.[1] Involving patients in understanding and commenting on their own safety may help organisations to identify poorly recognised safety issues, improve their learning and safety culture and reduce rates of avoidable harm.[2 3] While advocates of strict safety engineering suggest patients do not have a role to play in their own safety,[4] it is generally argued that, when willing and able, patients should be offered the opportunity to be involved, even though ultimate responsibility for safety rests with care providers.[5] A recent systematic review identified that patient experience data is positively associated with patient safety and clinical effectiveness.[6] However patients often perceive safety differently to clinicians, resulting in a lack of a shared understanding about what it means to feel safe.[7 8] In turn this may impact upon the ways in which patients can be involved in their safety.

Patients can be involved in the safety of their care in various ways, ranging from active participation in speaking up and challenging clinicians,[9 10] through to assessing factors that contribute to safety in hospital settings[11 12] and reporting safety incidents.[13] However it has been identified that formal incident report forms are not an appropriate mechanism for patients to report on their safety because patients were likely to report trivial matters and the process undermined trust in clinicians.[14] Another way of involving patients is to develop an understanding of, and to co-construct knowledge about safety.[15] A recent analysis of patient involvement in safety identified that a conjoint endeavour between patients and clinicians could reduce both parties' anxieties about patient involvement.[3]

Most efforts to involve patients in safety relate to care delivered in a relatively stable secondary care setting,[16 17] in which a single provider is responsible for patient safety. There has been less attention however, to patient experiences of safety in relation to a transition between organisations, defined as patients moving or being moved from one level of care to another or across different care settings.[18] The safety implications for care transitions are shown to be complex, resulting from the difficulties of working across organisational boundaries and leading to specific threats to safety and potential for re-admission.[19 20] With no one service having overall responsibility for the patient, existing safety systems are negated. In addition, with failures between organisations common,[21] organisational care transitions arguably increase the risk to patients due to deficits in communication

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and information transfer which negatively impact upon patients' continuity of care.[22] In Switzerland, it has been reported that poor coordination of care, albeit not necessarily directly related to care transitions, was the most important risk factor about which patients could provide feedback.[23] As the patient experiences the totality of the transition, there is an opportunity for patients to be involved in the safety of their care by providing a unique perspective on their transition and the continuity of care otherwise unavailable to healthcare professionals. Whilst there are an increasing number of international studies published that have sought to obtain patient perspectives on their transitions between organisations,[24 25] no known studies have developed, with patients and clinicians, a structured approach to collecting patient feedback on safety experiences in relation to organisational care transitions.

The aim of this study was to fill this knowledge gap by co-designing a mechanism with patients and clinicians for patients to provide feedback on their safety experiences following a transfer between organisations. To achieve this aim, specific objectives were to:

1. Identify principles that should underpin patient feedback on safety experiences following a transfer between organisations;
2. Co-design and construct a feedback mechanism based on these principles and patient perceptions of safety; and,
3. Determine the face validity of the survey design with patients who have recently been discharged from hospital.

Methods

This study was underpinned by Appreciative Inquiry (AI), which is a methodology that concentrates on identifying what works well in organisations and attempts to ascertain how these strengths can be built upon. [20]. AI is traditionally used as a method of organisational development and is closely aligned to action research, albeit with the emphasis of building upon what works well. When used in healthcare it is often adapted to the requirements of individual projects,[21] and can even be adapted to underpin specific methods such as appreciative interviews.[22] The development of the mechanism focussed upon the 'design' stage of AI, enabling an emphasis on safe rather than unsafe care, which

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is synonymous with a recent shift in the patient safety movement from what fails occasionally to what succeeds often.[23]

Data were collected across three phases (figure 1), including semi-structured interviews with patients that have been published elsewhere[8] (phase 1). The focus of phase 2 was the development of the feedback mechanism, with phase 3 acting as the validation process of the feedback mechanism. In phase 2, the primary method of developing the feedback mechanism was via two workshops using participatory and co-design methods, which are receiving increased attention in healthcare for their ability to increase participation and engagement.[26] The workshops were designed to bring together a wide variety of stakeholders, including patients and healthcare professionals, and afforded the opportunity for different stakeholders to present their unique experiences and perspectives. In phase 3, which was part of a larger feasibility project,[27] cognitive interviews were used to determine the face validity of the developed feedback mechanism. Patients were involved in choosing the focus on care transitions via the North East Strategic Health Authority's Patient, Carer and Public Engagement Network, who acted as a steering group for the study.

No incentives were provided for participation in any phase of the study. Approval for phases 1 and 2 was provided by Northumbria University School of Health, Community and Education Studies Ethics Committee, Sunderland Research Ethics Committee (reference: 09:H0904/57) and R&D departments at each of the included NHS sites. Approval for phase 3 was provided by Yorkshire & The Humber - Leeds West Research Ethics Committee (reference: 13/YH/0372) and R&D departments at each of the included NHS sites.

[Insert figure 1 around here]

Phase 1: Semi-Structured Interviews

Semi-structured interviews explored the concepts, explanations and terms used by patients when talking about safety in care transfers and how defences, barriers, and safeguards can be constructed through the provision of patient defined safe care. Fourteen participants were interviewed by JS, from three community care teams spanning two NHS Trusts (n=7), two City Council Resource Centres

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(n=3), two private nursing and residential care homes (n=3) and via snowball sampling (n=1) where the participant was not under the care of any organisation at the time of recruitment. A topic guide was used to provide structure to the interviews, with a focus on the types of transfers participants had experienced, whether participants had felt safe during the transfer, what safety meant to participants and what would make participants feel safer in the future. Full details are available in a separate paper.[8]

Phase 2: Workshops

Participants were sampled purposively using criterion sampling[28] for the two workshops, which were hosted at the Strategic Health Authority and lasted approximately two hours, to ensure that participants represented different types of organisations involved in the transfer of patients. The patients' voice was provided by five expert patients, identified as such due to their active involvement in either a Patient, Carer and Public Engagement (PCPE) network (n=3), which had also acted as a steering group for the study, or from the Northumbria University Service User Network (n=2), which consisted of service users who were involved in the education of pre- and post-registration healthcare professionals.

Eleven healthcare professionals also participated in the workshops. These included NHS community care team nurses (n=3), social care home managers (n=2) and a private nursing home manager (n=1) who were all involved in the identification and recruitment of participants to an earlier phase of the study where perceptions of safety were explored with patients who had recently completed an organisational care transfer.[8] Additional participants included ambulance service staff (n=4) and a representative of the Strategic Health Authority Patient Safety Team (n=1). Participants were provided with invitation letters and information sheets to explain the purpose of the study, and that participation was voluntary and could be withdrawn at any time.

The first workshop, facilitated by JS and PD, was used to explore the key principles of capturing patient feedback on their experiences of safety. Four questions were posed to the group to ascertain what the feedback mechanism should look like, the format of the feedback mechanism and how the feedback mechanism would fit with current systems. Participants were split into two mixed groups of

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healthcare professionals and expert patients to discuss answers to the questions. Numerous methods captured discussions to reduce the impact of potential power relationships between healthcare professionals and expert patients, including voice-recordings, flipchart paper, observations and notes from the facilitators and post-it notes.

The second workshop, facilitated by JS and DJ, was structured to have an emphasis on the practical outcome of designing a feedback mechanism, based in part on the results of the first workshop. Components of a Thinking Differently toolkit[29] were utilised to encourage creativity amongst participants when designing the feedback mechanism. Participants were split into two groups and given four Thinking Differently tools; 'fresh eyes, 'reframing by word play', 'pause, notice, observe' and 'random word, picture or object'.[29]. The fundamental basis of this toolkit is that individuals hold schemas, or mental structures of the world, through which thoughts are channelled. The schemas are separated from one another, meaning that it can be difficult to think outside of these mental structures, or to think differently. This in turn inhibits the potential for novel ways of doing something to be introduced into, or alongside, existing systems. Divergent thinking strategies (the Thinking Differently tools) were used in the first half of the workshop (break-out session 1) and participants were encouraged to converge their thinking in the second half of the workshop (break-out session 2; figure 2).

[Insert figure 2 around here]

As the workshop data were emergent it was not possible to plan the data analysis *a priori*. Instead, for the first workshop data were analysed inductively based upon the different themes and concepts that arose. For the second workshop, data analysis was conducted concurrently with participants drawing upon each other's ideas and working as individual groups via convergent thinking to assess these shared ideas and bring them into a tangible mechanism for patients to provide feedback on their safety experiences. A final discussion was held with all workshop participants about which parts of each group's chosen feedback mechanism were the strongest. This contributed to a process whereby the participants were involved as co-researchers in both data collection and analysis,[30] occurring in a participatory open forum.

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Following the second workshop, a researcher (JS) constructed the survey electronically using the final design agreed by the participants as a template. Additional data that were collected in the second workshop, such as voice recordings and flipcharts, were used post-workshop to ensure that the feedback mechanism had accurately captured what the participants had discussed. Upon completion, the final design was circulated amongst all participants for verification that it was an accurate reflection of the discussions and proposed designs. More detail on the construction and content of the survey is provided in the findings section.

Phase 3: Cognitive Interviews

Patients were recruited to cognitive interviews using convenience sampling after completing the safety survey and stating an interest in participating in an interview. Participants completed either the original tri-fold version of the survey (distribution cycle 1; n=20) or an updated bi-fold version of the survey (distribution cycle 2; n=8) following discharge from hospital and upon arrival at their next destination. Patients deemed unable to give informed consent by their care team or were under the age of 18 were not eligible to participate. Cognitive interviews were conducted by EH and JS with 28 patients (18 male, 10 female) in their place of residence who had completed the safety survey following discharge from hospital. Table 1 provides a summary of the clinical area that the patient was discharged from, distribution cycle recruited from, self-reported transport type, and self-reported destination. Participant ages ranged from 53 to 86 (mean=68, standard deviation=10). Cognitive interviews have proved useful in pre-testing of survey questions in a healthcare setting, particularly when they may be complex or of a sensitive nature,[31] as in this study.

Study ID	Cycle	Transport	Destination
Cardiology (n=13)			
980	1	Private Car	Hospital
462	1	Private Car	Home
2593	1	Ambulance	Hospital
2590	1	Ambulance	Hospital
4679	1	Private Car	Hospital
3954	1	Ambulance	Hospital
3319	1	Unknown	Hospital
5945	1	Unknown	Unknown

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5583	1	Patient Transport	Hospital
4300	1	Private Car	Home
6227	2	Private Car	Home
6427	2	Private Car	Home
11597	2	Taxi	Home
Care of Older People (n=3)			
104	1	Unknown	Unknown
1189	1	Ambulance	Home
7701	2	Private Car	Home
Orthopaedics (n=7)			
761	1	Ambulance	Home
1867	1	Private Car	Home
2494	1	Ambulance	Home
5853	1	Unknown	Home
6725	2	Private Car	Home
9748	2	Private Car	Home
11100	2	Walking	Home
Stroke (n=5)			
2450	1	Ambulance	Hospital
3445	1	Patient Transport	Hospital
3408	1	Private Car	Hospital
5767	1	Private Car	Home
8182	2	Private Car	Home

Table 1: Details of cognitive interview participants' care transfers.

Interviewees were invited to describe their thought processes in response to the survey questions, in order to identify any potential misunderstandings or other problems with those questions. We extended this beyond the questions to also ask about other components of the survey, including the introductory text, the description of different sections and the overall structure. Cognitive interviews were audio recorded and transcribed verbatim, then coded and analysed using NVivo qualitative analysis software. Interviews were thematically analysed using a deductive approach based on the structure and the questions asked in the survey by one researcher (EH), with codes and themes verified by JS, PD and JW.

Findings

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The findings are reported in five sections. The first section summarises the findings of patient perceptions of safety that were published elsewhere.[8] The next two sections, *principles of patient feedback* and *integration with existing systems*, represent themes identified in the first workshop that should underpin the development of patient feedback mechanisms applied specifically to capturing patient safety feedback. More specifically, *principles of patient feedback* represent the essential design principles of the patient feedback mechanisms, and *integration with existing systems* represents the acknowledgement by participants that where multiple organisations are involved in the care of the patient, particularly as patients cross organisational boundaries, feedback needs to be compatible with multiple patient safety and patient experience systems. The last two sections, *development of the safety survey* and *validation and refinement of the survey* report on the development and validation of the survey. These include why participants chose a safety survey as the most appropriate feedback mechanism, how the final design was developed by the participants and cognitive interview findings, including where confusion arose around the question format and the overall survey design.

Patient perceptions of safety

Semi-structured interviews with patients identified aspects of care that had made them feel safe. These included the ways in which staff communicated with patients and responded to the individual needs of the patient, for example by listening and adjusting the care provided. Interlinked with these themes was that of waiting times; where delays were not communicated to patients and patient requests were not listened to. Patients were also able to identify traditional safety issues, a catch-all term that included medications, falls and healthcare-acquired infections.[8]

Principles of patient feedback

Participants made recommendations and references to the principles on which the feedback mechanism should be based. There was agreement that the feedback mechanism needed to be short with options to expand on answers so that service users could report what was of most importance to them. This is highlighted in a conversation during a workshop between a community care team nurse and patient:

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"From a professional wanting to know what a patient would want, you'd want something that's short but open-ended…" [Community care team nurse]

"Yes" [Patient]

"… so it allows the patient to… discuss one aspect that you felt safe. That's a massive topic but if you had sort of four or five questions like, 'were you happy with that element of care?', 'did you find that was safe?', and that sort of thing" [Community care team nurse]

"Yeah, and, 'if not, why not?'" [Patient]

Participants also agreed that a short and concise feedback mechanism would increase response rates. A conversation between a community care team nurse, social care home manager and a patient highlights this agreement, and in doing so they begin to discuss the need for the feedback mechanism to be objective, or unbiased, through the presentation of positive (safe) and negative (unsafe) experiences.

"So to capture that [transfers of care are different], would we say that they would want the questionnaire to be sort of short and concise to encourage people to actually do it?" [Community care team nurse]

"Got to be fairly concise. The longer it is I think the less chance there is of getting involved with it, and especially if you're asking for positive as well as negative feedback or just general commentary" [Social care home manager]

"That's a very important point. It shouldn't all be whinging. You need to capture the positives as well" [Patient]

"So objective, yeah?" [Community care team nurse]

"Yeah" [Patient]

This unbiased approach was emphasised by both health care professionals and patients to emphasise the necessity to be appreciative. In a conversation between a social care home manager and a community care team nurse, the uneven balance of negative rather than positive feedback is discussed. Notably, it was perceived that this imbalance is caused by a lack of recording of positive feedback.

"You don't get much feedback unless it's a complaint" [Social care home manager]

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> "But I think, I think a lot of people do get feedback. I just think there's an emphasis on the negative. There's a lot of people, like I'm sure you've probably had a patient, where they feedback that you do a grand job. That never gets captured." [Community care team nurse]

Participants felt that the feedback mechanism should have an option to be anonymous as some service users would want to avoid going through a formal complaints procedure. However there were concerns over the usability of patient feedback if it could not be traced to a particular incident, thus impacting on potential learning.

> "The only problem is with it being anonymous is... tracing it back because it's actually more effective when you can look. […] So you can improve practice generally, but for that specific case you might want to look at it in more detail." [Social care home manager]

Integration with existing systems

A number of discussion points arose that focused on how the potential feedback mechanism would fit with current feedback mechanisms. Firstly it was acknowledged that such a system for collecting patient feedback relating to admissions and discharge was required as there was no existing means for patients to provide feedback on this stage of their care, "what we haven't got is just before [service users] get to us, and just after we discharge them." [social care home manager]. A paramedic reported that feedback was limited to complaints or compliments, with a gap existing for the routine collection of patient feedback:

> "We've all got process in place that if there's something we're concerned about we can bring it up. But looking what feedback we get from patients, I know certainly on an ambulance point of view, we get no feedback. The only feedback we get is either a complaint coming in or a letter of thanks." [Ambulance service paramedic]

An additional consideration arose in the second workshop, where care home managers from both private and social care settings discussed utilising patient feedback when it relates to care delivered across organisational boundaries. In particular, it was reported and agreed that whilst patient feedback can be used to change practice, and systems can be changed to incorporate this feedback, they felt there was no opportunity to influence other parts of the health or social care systems. This

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resulted in a conflicting stance, with healthcare professionals wanting to receive meaningful feedback from patients, but knowing existing organisational structures prohibited being able to respond to this information and change practice. In turn this had the potential to impact upon the utility of any potential feedback mechanism for patients crossing organisational boundaries.

> "We want instant [patient] feedback to change our systems" [Social care home manager]
>
> "And so we can change the system within our environment but we can't change the system anywhere else" [Private nursing care home manager]

Development of the safety survey

In workshop 2, participants were given four Thinking Differently tools; 'fresh eyes, 'reframing by word play', 'pause, notice, observe' and 'random word, picture or object'.[29]. The use of 'fresh eyes' in particular encouraged participants to explore how non-healthcare organisations approach receiving feedback. These included some of the more traditional feedback mechanisms, such as noticeboards, postcards and questionnaires, and more novel methods, including an aviation-based reporting system, the Royal Society for the Protection of Birds' annual bird watch and supermarket tokens. Table 2 contains a brief description of each of the proposed feedback mechanisms.

Mechanism	Group	Explanation
Noticeboard	1	Provided in GP waiting rooms for patients to write comments about their recent experiences.
Postcard	1	Given to service users during every part of the journey to complete, capturing the wide range of organisational care transfers.
Post boxes	1	An alternative to the noticeboard which provides privacy for service users and confidentiality for healthcare professionals.
Thermometer scale	1	Service users are able to place stickers on a large thermometer relating to how safe or unsafe they felt. Proposed as it would be quick and easy for service users.
Questionnaire	1	A simple questionnaire sent to service users post-transfer.
Aviation Reporting Tool	2	Confidential Human factors Incident Reporting Programme is used in aviation. Suggested as an idea as it is confidential and had no blame attributed to the reports.
RSPB Bird Watch	2	A method of collecting a lot of data in a systematic way over a short period of time.
Gordon Ramsey approach	2	Communication in restaurants by waiters can reduce the impact that long waiting times have.
Supermarket tokens	2	System similar to supermarket charity donation tokens. Given to service users on discharge for them to place in a 'safe' or 'unsafe' box

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Reverse transfer	2	Increase safety by reducing the number of organisational care transfers through increased care in the community.
Internet questionnaire	2	An automatic email sent to everyone that had gone through an organisational care transfer.
Hospital waiting area information	2	Provide information, either in person or via electronic screens regarding length of wait and delays.
Discharge lounge	2	Place for service users to go prior to a discharge to free up a bed. Somebody could be there to coordinate transfers, provide information and receive feedback.

Table 2: Feedback mechanisms identified by workshop participants for patients to provide feedback on their experiences of safety

Each component of the feedback mechanism was designed by the participants using flipchart paper to draw examples to be discussed. One group decided that the postcard was the best feedback mechanism to take forward and develop due to its simplicity and applicability to a wide variety of settings. This included using a simple scoring system with a three-point scale that incorporated smiley faces: safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

> "One side with a smiley face and one side with a… [unhappy face]. And then straight away you can see" [Private care home manager]
>
> […]
>
> "Something simple. I think the most simple ideas are the most effective" [Patient safety team representative]

However, it was also recognised by participants that having an overly-simplistic system may result in data that lacked meaning, although participants did not stipulate the minimum or maximum amount of complexity or sensitivity required in order for the data to be meaningful. For example there was a debate whether a three-point Likert scale would produce results sensitive enough to identify outliers in safe or unsafe care.

> "As you were saying where you should have a red, a green, amber, and identifying how happy you were, but the detail this lady's describing would need to be addressed quite intricately" [Ambulance service safeguarding lead]

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The other group chose to develop a leaflet-based feedback mechanism, split into three sections directed towards the discharge, transfer and admission of the service user. In particular, their decision to split the transfer into the three stages was summarised by a facilitator (DJ) when feeding back on behalf of the group.

> "We thought that most journeys, and I like your idea of defining a journey and what service user safety is, have a beginning, and a middle and an end. So, we would like to start with this panel, which is… we've got a day and a date… place of departure, so where did you depart from?" [Facilitator, DJ]

This three-stage structure was utilised in the final design, although transfer was changed to journey after the workshop, following feedback from one participant during verification of the design. Table 3 provides an overview of the survey structure and questions.

> *I'm never happy with transfer because people… some people, particularly the public, would automatically think you're talking about wheels, as opposed to the journey* [Email correspondence, community care team nurse]

Please tick which of the following affected how safe or unsafe you felt.

Discharge	Safe	Neutral	Unsafe	Journey	Safe	Neutral	Unsafe	Arrival or Admission	Safe	Neutral	Unsafe
Communication from staff				Communication from staff				Communication from staff			
Staff listening to you				Staff listening to you				Staff listening to you			
Departure running to schedule				Journey running to schedule				Waiting times			
Falling or potential falls				Falling or potential falls				Falling or potential falls			
Medication problems or concerns				Medication problems or concerns				Medication problems or concerns			
Hygiene				Hygiene				Hygiene			
Please use this space to tell us if there was another reason why you felt safe or unsafe or to expand on your answers above											
What could we have done to make you feel safer during your transfer?											

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Table 3: Structure and question format of the safety survey following initial development. Note that each response option was provided in the form of colour-coded smiley faces for safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

Validation and refinement of the survey through cognitive interviews

Twenty participants provided feedback on an original tri-fold version of the survey. There was some diversity of opinion on the appropriateness of the paper format and the three-face design. While some participants suggested that an online or telephone survey might be easier to complete, there was a general consensus that varying access to computers, as well as time and cost restraints, meant that a paper version was more appropriate for most people. Patient 1867 summarised:

> "I would quite happily fill it in on an App, but [people] who are not computer literate would just back away from that. I think paperwork is probably the best way that would cover every age group." [Patient 1867]

Most participants found the three-point scale with smiley faces easy to use and understand. The statement from Patient 4300 makes this point, as well as reinforcing the workshop participants' preference for the survey to be concise:

> "Smiley faces and sad faces and things like that, you know red faces, it looked simple, it was easy, it caught your eye. It wasn't too wordy cos I think there's nothing worse than wordy surveys where you get half way through and you think, 'You know what, I can't be bothered'". [Patient 4300]

However, it should be noted that some participants expressed a preference for 'yes/no/maybe' style questions, with one suggesting that asking whether a patient felt safe, neutral, or unsafe was confusing and even "loaded" [Patient 3954]. Another participant suggested that three faces were not enough, and that there should be 5 in varying shades. Despite this diversity, there was general agreement that the paper survey with the three faces tick-box system was easy to use.

It was reported that two aspects of the survey design caused difficulties for many participants; the division into three stages of the care transfer (Departure, Journey, Arrival) and the way in which the

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questions were asked. For the stages of the transfer, patients were unclear about which departure, journey, and arrival they were being asked. Some interpreted the questions in the 'Journey' section to be relating to their journey *to* hospital rather than *from* hospital or thought they were being asked "to give an average" assessment of the two journeys (P1189); others though that 'Arrival' referred to their initial arrival on the ward, rather than at their next destination.

> "The format of that is not right. It needs drastically changing, I think you should keep 'your departure from' that needs to be explained really, from where?" [Patient 3954]

Second, some participants did not make the distinction between these three stages at all, instead answering questions in the three separate sections in relation to the entirety of the care transfer; these participants saw the three separate sections as merely repeating the same questions, without distinguishing between different transfer stages. For example, Patient 5853, when asked how they had interpreted a question relating to 'Arrival', stated

> "[The answer given does not relate to] when I was at home, I was talking probably, I thought this was probably an overall of those." *[Interviewer]: "'Your Arrival' as a summary of everything else?" [Patient 5853]:* Yeah.

On the basis of these findings, the survey was restructured into a two-page leaflet. The front and back pages provided additional information about the survey, and the middle two pages contained the survey questions (table 4). The survey still asked questions about each of the three stages of the transfer (departure, journey and arrival), however this was asked within each question. An additional explanation of the stages of the transfer was provided with increased clarity over which transfer was being referred to, and the survey questions were expanded to be more specific about what was being asked (see supplementary material for the wording). Space for free text comments was provided next to each question. Cognitive interviews with eight additional patients using the modified version of the survey suggested that the changes had resolved the original issues around question clarity and the type of transfer that was being asked about. Participants suggested that some sections of the survey were not of relevance to them, which was either due to patients feeling safe, or because parts of their transfer did not involve healthcare staff, such as when transported by private car.

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> "[The only difficulty completing it was] knowing what on earth to put sometimes, because I kept thinking, 'I don't think, I don't think that applies.'[…] I couldn't decide whether I was putting the right thing sometimes, because I didn't feel unsafe and y'know, everything was kind of looked after okay" [Patient 6227]

Similar to the original tri-fold design, patients also reported that they considered the survey to be capturing their experiences of safety across their entire episode of care, rather than an individual transfer. For example, patient 6725 reflected, "this felt as though it was reflecting on my three day stay in hospital", and patient 8182 provided a similar reflection.

> "I wasn't sure that it was that that they were asking the question for or that it was a general safety survey of the whole experience of going to hospital, being a patient." [Patient 8182]

How safe did communication from staff make you feel? For example giving you clear and timely information or being polite.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

How safe did you feel with regards to staff listening to you and responding to your individual needs?
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

Did you experience any delays? [Yes / No]
If yes, where was your longest delay? [Departure / Journey / Arrival]
How did this make you feel? [Safe / Neutral / Unsafe]

How safe did you feel about the possibility of falling? For example if you felt confident that you wouldn't fall or if you were concerned that you might.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

How safe did you feel about your medication? For example receiving the correct medication, understanding the medication you were taking or delays in receiving your medication.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

How safe did you feel about hygiene and cleanliness? For example if staff washed their hands and if the surroundings were clean.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

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Overall, how safe did you feel throughout the whole transfer including the departure, journey and arrival? [Safe / Neutral / Unsafe]

Table 4: Question format of the safety survey following cognitive interviews. Response options are provided in square brackets. Note that each response option was provided in the form of colour-coded smiley faces for safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

Discussion

A number of systematic reviews consider how patients can provide feedback on their safety,[14 16 17] however these focus on adverse events, typically within discrete care settings such as secondary care, rather than experiences of safety in the context of care transitions. Furthermore, there are relatively few studies reporting on the development of these feedback mechanisms. One notable study has reported on the development of a patient reporting tool, though again this is specific to secondary care settings.[11-13] Our study developed a mechanism for patients to provide feedback on their safety experiences following a transfer between organisations through a process of co-design. The transfer between organisations was chosen as it is a time in the patient's episode of care that is acknowledged to be particularly high in risk,[21 32] and when mistakes are likely to occur.[33]

The developed safety survey aims to capture patient experiences of safety, based on patients' definitions of what it is that makes them feel safe during a care transition.[8] This is a notable shift from some existing approaches to involving patients in reporting patient safety incidents, which have had limited success.[14] There has been a limited amount of work attempting to reconcile the differing perceptions of safety between clinicians and patients that result in a lack of a shared understanding about what it means to feel safe,[7 8] but the use of co-design approaches in developing feedback mechanisms can go some way to bringing together the different perceptions, particularly as it has been identified that patient experiences can be linked to clinical safety.[6]

By bringing together patients and healthcare professionals in tailored workshops within this study, we were able to identify principles that should underpin the feedback mechanism, including that it should

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be patient-centred, short, concise with clear signposting on how to complete it, optionally anonymous and be objective with a focus on both positive (safe) and negative (unsafe) care.

Within the principles of feedback mechanisms, the provision of patient-centred care refers to the location of the patient within their care. For a feedback mechanism to be patient-centred, this in turn requires the opportunity for patients to be involved and to play an active role, thereby placing their experience of care at the forefront. The length and structure of the feedback mechanism, in being short and concise with clear signposting on how to complete it, is already a feature of patient experience surveys and the benefits of brevity include increased response rates and greater acceptability and usability amongst patients.[34]

Giving patients the option to provide anonymous feedback is particularly important when considering and discussing safety. Existing evidence suggests that patients have concerns, whether founded or not, that challenging healthcare professionals can impact upon the care received and engender feelings of suspicion and mistrust,[35] and the concept of providing anonymous feedback was enshrined in participants' comments and the final feedback mechanism designed in this study. That both patients and healthcare professionals identified the need for feedback to be balanced between positive and negative experiences demonstrates that both groups were aware of criticisms of existing feedback mechanisms that focus on negative experiences alone, such as the use of complaints. The paradox of measuring safety by its absence was acknowledged early in the patient safety movement,[36] but this is now being reflected in proactive approaches to safety,[37] and the findings of this study suggest that the same principle should be applied to patient feedback mechanisms. The principles of being patient-centred, short, concise with clear signposting on how to complete the feedback mechanism, optionally anonymous and objective with a focus on both positive and negative care can be applied by others who are interested in developing feedback mechanisms for patients to provide feedback on their experiences of safety, and the generic nature of the principles can be applied to settings other than organisational care transfers.

Finally, the complexity associated with care being received across organisational boundaries was identified by participants and is recognised elsewhere in the literature.[20] In particular, healthcare

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professionals in this study acknowledged that they would be unable to implement change that impacts on or requires the input of other service providers as a result of patient feedback. This was a significant outcome, and an important consideration for future research that aims to involve the patient in their safety across organisational boundaries. Agreement between, or integration of, services may be necessary in order to promote organisational learning and change service delivery in response to patient feedback.

Use of co-design methods

We built upon the principles that should underpin a feedback mechanism by using participatory and co-design methods in the development of the survey, which are receiving increased attention in healthcare for their ability to increase participation and engagement,[26] and we used the Thinking Differently methodology[29] to provide a means by which to break out of existing schemas to encourage innovation.

Furthermore, co-designing a feedback mechanism ensures that it meets the requirements of different groups of users; in the case of this study, patients who are required to understand and complete the questions, and healthcare professionals who are required to collect and learn from the feedback provided. Co-design was particularly important given the differences that exist in patients' and healthcare professionals' understandings of safety, and provided an opportunity for shared learning. Despite these benefits of using co-design, we did encounter challenges associated with the approach, including personal agendas and dominant voices. Prior to the first workshop, we developed inclusive strategies such as post-it notes and flipchart paper that would enable both patient and healthcare professional participants to have their voice heard, even if it was not audible.[38] The issue of personal agendas amongst participants, where they would attempt to overly influence the direction of discussion, was a greater challenge. In a systematic review of the impact on patient involvement on research, personal experience stories that dominated discussions were identified to be a challenge.[39] In order to resolve this, we used the Thinking Differently toolkit in workshop 2 to provide focus for all participants by directing thoughts and discussions to situations equally familiar to all, thus reducing the available space in which individuals could dominate discussions.

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Limitations

This study developed a safety survey using participatory and co-design methods, including the identification of underlying principles. Whilst the survey was co-designed by healthcare professionals and patients, including cognitive interviews to validate and further refine the survey, further research is required to pilot the developed feedback mechanism to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care. Furthermore, the participants involved in the development of the survey were recruited to represent a wide variety of health and social care services and patients. Due to the nature of organisational care transfers it is unlikely that they represented all possible types of transfers that patients experience. It was also not possible to explore further the governance relationships that exist between organisations, regardless of representation in this study, which could impact on the implementation of the survey into practice. Finally, the self-reported destination of the cognitive interview participants was not directly explored, and so it was not possible to validate or determine the accuracy of this information.

Future research

The use of participatory and co-design principles helped to overcome differences in the understanding of safety, to develop a feedback mechanism for patients to provide feedback on their experiences of safety relating to a care transfer. Additional research is required before the survey is ready to be used in practice, including piloting in further clinical areas in order to determine its usability and acceptability to patients and healthcare professionals. Patient cognitive interviews indicated confusion between whether patients were being asked to provide feedback solely on their care transfer or their whole episode of care, indicating that it may be difficult to solicit feedback on experiences of care relating to one aspect of an episode of care. Further research is required to explore this, which could include determining whether asking patients about safety experiences is likely to increase awareness of patient safety, and whether patient experiences of safety can lead to quality improvement in the complex area of care transfers.

Acknowledgements

We would like to thank all participants for their invaluable contribution to the study, the Safer Care North East Patient, Carer and Public Engagement group and the PRoSOCT advisory group for their

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support and guidance, and the NHS Trusts involved in the study for their ongoing support. We also thank The Health Foundation (an independent charity committed to bringing about better health and health care for people in the UK), Northumbria University and the former North East Strategic Health Authority, in particular the Patient Safety Action Team and the Safer Care North East programme, for funding the studies that contributed to this paper. The research team acknowledge the support of the National Institute for Health Research, through the Comprehensive Clinical Research Network.

Author contributions

Phases 1 and 2: JS, PD and DJ designed the phases, collected, analysed and interpreted the data. Phase 3: JS, JW and PD designed the phase. JS and EH collected, analysed and interpreted the data, with input from JW and PD. All authors contributed to the drafting of the manuscript.

Data sharing statement

No additional data are available.

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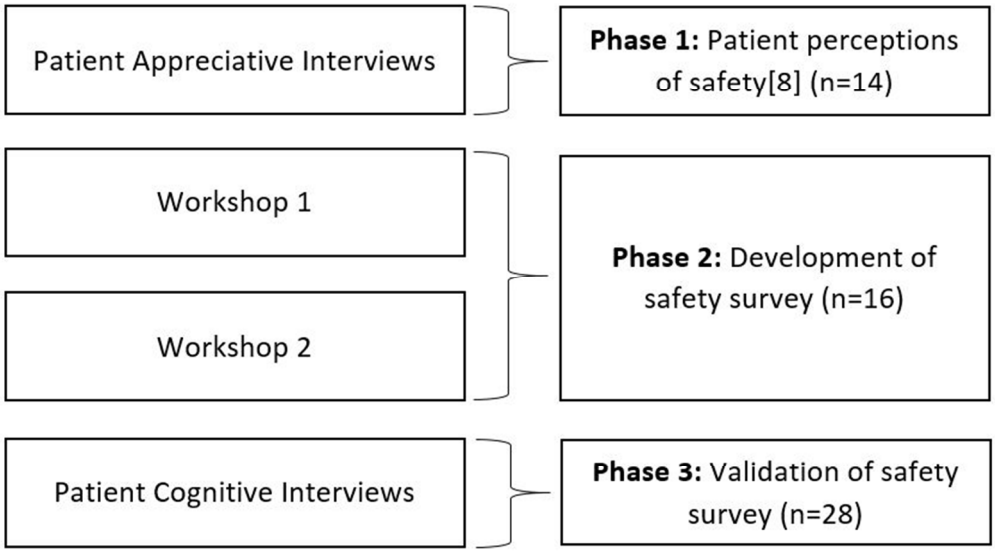

Figure 1: Process of development and validation of the patient feedback mechanism across three phases
70x40mm (300 x 300 DPI)

review only

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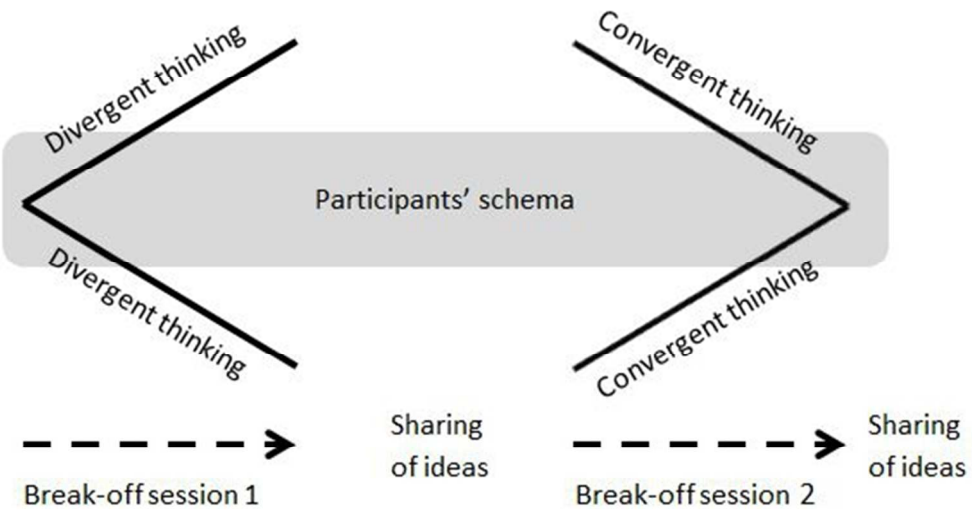

Figure 2: Divergent and convergent thinking strategies in Workshop 2 to encourage participants to think outside of their existing feedback mechanism schema
49x27mm (300 x 300 DPI)

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SAFE AND SURE

Safety Survey

Dear patient and / or carer,

This survey is for you to tell us how safe you felt during your most recent transfer out of hospital, and what made you feel this way. Anything that you tell us will remain confidential and will not affect the care that you receive.

It is important for us to find out about your experiences so that we can improve our services. **Please complete the survey and return it in the prepaid envelope provided**.

Contact Jason Scott or Emily Heavey if you have any questions, would like help completing the survey or if you would like to receive the survey in large print.

01904 876 376

j.scott@yorksj.ac.uk

e.heavey@yorksj.ac.uk

What does safety mean?

We believe that for you to feel safe, healthcare staff should communicate with you, respond to your individual needs and ensure you are physically safe and secure. We are also interested in finding out if there is anything else that makes you feel safe.

How do I complete the survey?

For each question, please tick the face that best represents how you felt. The **green face** means you had no worries or concerns about your safety, the **red face** means you were worried or concerned about your safety, and the **yellow face** means you felt somewhere between the two.

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York St John University York Teaching Hospital NHS Foundation Trust The University of Nottingham Nottingham University Hospitals NHS The Health Foundation Inspiring Improvement Yorkshire Ambulance Service NHS

Departure means planning and preparing for, and leaving hospital.

Journey means travelling from hospital to your next location.

Arrival means settling in at your next location.

What is your NHS Number? (optional) _____

Are these the opinions of: patient ❑ carer ❑

What was the date of your departure? D D / M M / Y Y Y Y

Which ward did you depart from? _____

Where were you going to? _____

How did you get there? _____

Did someone go with you? Yes ❑ No ❑

If yes, who? Family / Friend ❑ Carer ❑ Member of Staff ❑

Only tick boxes for questions below that are relevant to you, for example the question on staff communication during your journey may not be applicable if you used your own transport.

How safe did the communication from staff make you feel? For example giving you clear and timely information or being polite.

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel with regards to staff listening to you and responding to your individual needs?

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

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Did you experience any delays? Yes ❑ No ❑

If yes, where was the longest delay during your transfer?

Departure ❑ Journey ❑ Arrival ❑ Comments: _____

How did this make you feel?

❑ ❑ ❑

_____

_____

How safe did you feel about the possibility of falling? For example if you felt confident that you wouldn't fall or if you were you concerned that you might

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel about your medication? For example receiving the correct medication, understanding the medication you were taking or delays in receiving your medication.

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel about hygiene and cleanliness? For example if staff washed their hands and if the surroundings were clean

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

Overall, how safe did you feel throughout the whole transfer including the departure, journey and arrival?

Comments: _____

❑ ❑ ❑

_____

_____

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Thank you for taking the time to complete this survey. Please return it in the freepost envelope provided.

What will we do with your answers to this survey?

We will bring together feedback from patients and provide this anonymously to healthcare teams involved in your transfer. The purpose of this is to identify what is being done well, and areas where the quality of care that you receive can be improved.

What should you do if you want to make a complaint about your care?

By completing this survey you are **not** making a complaint. If you have felt unsafe at any other point during your care or would like to raise a specific concern please contact the Patient Advice and Liaison Service. If you contact us we can give you information on how to do this.

Would you like to receive a summary of the research findings?

Yes ❑ No ❑

Please fill out your details below and we will send you this at the end of the study. All information will remain private and confidential in line with the Data Protection Act (1998), and will not be shared with anyone or used for any other purpose than to provide you feedback.

Name: _____

Address: _____

_____

Could you please tell us your gender, age and how you define your racial / ethnic origin. This will tell us if we're reaching a wide sample of people. If you are a carer, please tell us the patient's details. You do not have to complete this part if you do not want to.

Gender: Male ❑ Female ❑

Age: _____

Racial / ethnic origin: _____

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No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer / facilitator	Which author/s conducted the interview or focus group?	Pages 6, 7 and 8.
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	All researchers hold a PhD.
3.	Occupation	What was their occupation at the time of the study?	JS was a PhD candidate at the time of phases 1 and 2. JS and EH were research associates during phase 3. PD, AJ and JW were in academic positions during all phases.
4.	Gender	Was the researcher male or female?	Male and Female.
5.	Experience and training	What experience or training did the researcher have?	Experience conducting and analysing data from focus groups of patients and healthcare professionals.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No relationship was established prior to study commencement
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	This information was provided prior to data collection as part of the invitation and information leaflet
8.	Interviewer characteristics	What characteristics were reported about the interviewer / facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	No characteristics were reported about the researchers
Domain 2: study design			
Theoretical framework			

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No	Item	Guide questions/description	
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Page 5
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Pages 6, 7 and 8
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Pages 7 and 9
12.	Sample size	How many participants were in the study?	Pages 6, 7, 8 and 9, and figure 1
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	No participants dropped out. We are unaware of how many people refused to participate due to the way in which participants were invited to the study.
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Pages 7 and 9
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Nobody else was present during data collection
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Pages 6, 7, 8 and 9
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 6 and 9
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Repeat data collection was not conducted

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No	Item	Guide questions/description	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 8 and 9
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were not taken
21.	Duration	What was the duration of the interviews or focus group?	Page 7
22.	Data saturation	Was data saturation discussed?	For cognitive interviews, data saturation was discussed among those reviewing and coding the transcripts. Data saturation was not relevant for the co-design workshops
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 8
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Page 9
25.	Description of the coding tree	Did authors provide a description of the coding tree?	A summary of the coding tree is written on pages 9 and 10
26.	Derivation of themes	Were themes identified in advance or derived from the data?	For phases 1 and 2, themes were derived from the data (where applicable). For phase 3, themes were identified in advance based on the structure of the survey.
27.	Software	What software, if applicable, was used to manage the data?	Page 9
28.	Participant checking	Did participants provide feedback on the findings?	Participants provided real-time feedback during the co-design workshops.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Pages 10 - 17

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No	Item	Guide questions/description	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Pages 9 – 17. A summary of the major themes is presented at the start, and subheadings are used to present them in more detail.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Pages 10 – 12. In particular discussion about the integration with existing systems.

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Healthcare professional and patient co-design and validation of a mechanism for service users to feedback patient safety experiences following a care transfer

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-011222.R3
Article Type:	Research
Date Submitted by the Author:	10-Jun-2016
Complete List of Authors:	Scott, Jason; Newcastle University, Institute of Health and Society Heavey, Emily; University of York, Social Policy Research Unit Waring, Justin; University of Nottingham, Centre for Health Innovation, Leadership & Learning / Nottingham University Business School Jones, Diana; Northumbria University, Dawson, Pamela; Northumbria University, Faculty of Health and Life Sciences
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Qualitative research
Keywords:	Patient safety, Patient experience, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH

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Healthcare professional and patient co-design and validation of a mechanism for service users to feedback patient safety experiences following a care transfer

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Funding: This research was funded by the North East Strategic Health Authority, Northumbria University and The Health Foundation (grant number 7204).

Number of tables: 4

Number of figures: 2

Key words: patient safety, patient experience, quality in health care, qualitative research

Word count: 5,621

Competing interests: The authors declare no competing interests.

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Abstract

Objective

To develop and validate a mechanism for patients to provide feedback on safety experiences following a care transfer between organisations.

Design

Qualitative study using participatory methods (co-design workshops) and cognitive interviews. Workshop data were analysed concurrently with participants and cognitive interviews were thematically analysed using a deductive approach based on the developed feedback mechanism.

Participants

Expert patients (n=5) and healthcare professionals (n=11) were recruited purposively to develop the feedback mechanism in two workshops. Workshop one explored principles underpinning safety feedback mechanisms, and workshop two included the practical development of the feedback mechanism. Final design and content of the feedback mechanism (a safety survey) were verified by workshop participants, and cognitive interviews (n=28) were conducted with patients.

Results

Workshop participants identified that safety feedback mechanisms should be patient-centred, short and concise with clear signposting on how to complete, with an option to be anonymous and balanced between positive (safe) and negative (unsafe) experiences. The agreed feedback mechanism consisted of a survey split across three stages of the care transfer; departure, journey and arrival. Care across organisational boundaries was recognised as being complex, with healthcare professionals acknowledging the difficulty implementing changes that impact other organisations. Cognitive interview participants agreed the content of the survey was relevant but identified barriers to completion relating to the survey formatting and understanding of a care transfer.

Conclusions

Participatory, co-design principles helped overcome differences in understandings of safety in the complex setting of care transfers when developing a safety survey. Practical barriers to the survey's

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usability and acceptability to patients were identified, resulting in a modified survey design. Further research is required to determine the usability and acceptability of the survey to patients and healthcare professionals, as well as identifying how governance structures should accommodate patient feedback when relating to multiple health or social care providers.

Strengths and limitations of the study:

- This study developed a safety survey using participatory and co-design methods to bring together patient and healthcare professional perspectives.
- Cognitive interviews with 28 patients were used to validate and further refine the survey format and questions.
- Further research is required to pilot the survey to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care.
- Due to the nature of organisational care transfers, which potentially include large numbers of organisations, it is unlikely that participants represented all possible types of transfers that patients experience.
- It was not possible to explore further the governance relationships that exist between different organisations responsible for patients' care, which could impact on the implementation of the survey into practice.

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Introduction

Progress in reducing patient harm from adverse incidents in healthcare remains slow.[1] Involving patients in understanding and commenting on their own safety may help organisations to identify poorly recognised safety issues, improve their learning and safety culture and reduce rates of avoidable harm.[2 3] While advocates of strict safety engineering suggest patients do not have a role to play in their own safety,[4] it is generally argued that, when willing and able, patients should be offered the opportunity to be involved, even though ultimate responsibility for safety rests with care providers.[5] A recent systematic review identified that patient experience data is positively associated with patient safety and clinical effectiveness.[6] However patients often perceive safety differently to clinicians, resulting in a lack of a shared understanding about what it means to feel safe.[7 8] In turn this may impact upon the ways in which patients can be involved in their safety.

Patients can be involved in the safety of their care in various ways, ranging from active participation in speaking up and challenging clinicians,[9 10] through to assessing factors that contribute to safety in hospital settings[11 12] and reporting safety incidents.[13] However it has been identified that formal incident report forms are not an appropriate mechanism for patients to report on their safety because patients were likely to report trivial matters and the process undermined trust in clinicians.[14] Another way of involving patients is to develop an understanding of, and to co-construct knowledge about safety.[15] A recent analysis of patient involvement in safety identified that a conjoint endeavour between patients and clinicians could reduce both parties' anxieties about patient involvement.[3]

Most efforts to involve patients in safety relate to care delivered in a relatively stable secondary care setting,[16 17] in which a single provider is responsible for patient safety. There has been less attention however, to patient experiences of safety in relation to a transition between organisations, defined as patients moving or being moved from one level of care to another or across different care settings.[18] The safety implications for care transitions are shown to be complex, resulting from the difficulties of working across organisational boundaries and leading to specific threats to safety and potential for re-admission.[19 20] With no one service having overall responsibility for the patient, existing safety systems are negated. In addition, with failures between organisations common,[21] organisational care transitions arguably increase the risk to patients due to deficits in communication

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and information transfer which negatively impact upon patients' continuity of care.[22] In Switzerland, it has been reported that poor coordination of care, albeit not necessarily directly related to care transitions, was the most important risk factor about which patients could provide feedback.[23] As the patient experiences the totality of the transition, there is an opportunity for patients to be involved in the safety of their care by providing a unique perspective on their transition and the continuity of care otherwise unavailable to healthcare professionals. Whilst there are an increasing number of international studies published that have sought to obtain patient perspectives on their transitions between organisations,[24 25] no known studies have developed, with patients and clinicians, a structured approach to collecting patient feedback on safety experiences in relation to organisational care transitions.

The aim of this study was to fill this knowledge gap by co-designing a mechanism with patients and clinicians for patients to provide feedback on their safety experiences following a transfer between organisations. To achieve this aim, specific objectives were to:

1. Identify principles that should underpin patient feedback on safety experiences following a transfer between organisations;
2. Co-design and construct a feedback mechanism based on these principles and patient perceptions of safety; and,
3. Determine the face validity of the survey design with patients who have recently been discharged from hospital.

Methods

This study was underpinned by Appreciative Inquiry (AI), which is a methodology that concentrates on identifying what works well in organisations and attempts to ascertain how these strengths can be built upon. [20]. AI is traditionally used as a method of organisational development and is closely aligned to action research, albeit with the emphasis of building upon what works well. When used in healthcare it is often adapted to the requirements of individual projects,[21] and can even be adapted to underpin specific methods such as appreciative interviews.[22] The development of the mechanism focussed upon the 'design' stage of AI, enabling an emphasis on safe rather than unsafe care, which

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is synonymous with a recent shift in the patient safety movement from what fails occasionally to what succeeds often.[23]

Data were collected across three phases (figure 1), including semi-structured interviews with patients that have been published elsewhere[8] (phase 1). The focus of phase 2 was the development of the feedback mechanism, with phase 3 acting as the validation process of the feedback mechanism. In phase 2, the primary method of developing the feedback mechanism was via two workshops using participatory and co-design methods, which are receiving increased attention in healthcare for their ability to increase participation and engagement.[26] The workshops were designed to bring together a wide variety of stakeholders, including patients and healthcare professionals, and afforded the opportunity for different stakeholders to present their unique experiences and perspectives. In phase 3, which was part of a larger feasibility project,[27] cognitive interviews were used to determine the face validity of the developed feedback mechanism. Patients were involved in choosing the focus on care transitions via the North East Strategic Health Authority's Patient, Carer and Public Engagement Network, who acted as a steering group for the study.

No incentives were provided for participation in any phase of the study. Approval for phases 1 and 2 was provided by Northumbria University School of Health, Community and Education Studies Ethics Committee, Sunderland Research Ethics Committee (reference: 09:H0904/57) and R&D departments at each of the included NHS sites. Approval for phase 3 was provided by Yorkshire & The Humber - Leeds West Research Ethics Committee (reference: 13/YH/0372) and R&D departments at each of the included NHS sites.

[Insert figure 1 around here]

Phase 1: Semi-Structured Interviews

Semi-structured interviews explored the concepts, explanations and terms used by patients when talking about safety in care transfers and how defences, barriers, and safeguards can be constructed through the provision of patient defined safe care. Fourteen participants were interviewed by JS, from three community care teams spanning two NHS Trusts (n=7), two City Council Resource Centres

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(n=3), two private nursing and residential care homes (n=3) and via snowball sampling (n=1) where the participant was not under the care of any organisation at the time of recruitment. A topic guide was used to provide structure to the interviews, with a focus on the types of transfers participants had experienced, whether participants had felt safe during the transfer, what safety meant to participants and what would make participants feel safer in the future. Full details are available in a separate paper.[8]

Phase 2: Workshops

Participants were sampled purposively using criterion sampling[28] for the two workshops, which were hosted at the Strategic Health Authority and lasted approximately two hours, to ensure that participants represented different types of organisations involved in the transfer of patients. The patients' voice was provided by five expert patients, identified as such due to their active involvement in either a Patient, Carer and Public Engagement (PCPE) network (n=3), which had also acted as a steering group for the study, or from the Northumbria University Service User Network (n=2), which consisted of service users who were involved in the education of pre- and post-registration healthcare professionals.

Eleven healthcare professionals also participated in the workshops. These included NHS community care team nurses (n=3), social care home managers (n=2) and a private nursing home manager (n=1) who were all involved in the identification and recruitment of participants to an earlier phase of the study where perceptions of safety were explored with patients who had recently completed an organisational care transfer.[8] Additional participants included ambulance service staff (n=4) and a representative of the Strategic Health Authority Patient Safety Team (n=1). Participants were provided with invitation letters and information sheets to explain the purpose of the study, and that participation was voluntary and could be withdrawn at any time.

The first workshop, facilitated by JS and PD, was used to explore the key principles of capturing patient feedback on their experiences of safety. Four questions were posed to the group to ascertain what the feedback mechanism should look like, the format of the feedback mechanism and how the feedback mechanism would fit with current systems. Participants were split into two mixed groups of

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healthcare professionals and expert patients to discuss answers to the questions. Numerous methods captured discussions to reduce the impact of potential power relationships between healthcare professionals and expert patients, including voice-recordings, flipchart paper, observations and notes from the facilitators and post-it notes.

The second workshop, facilitated by JS and DJ, was structured to have an emphasis on the practical outcome of designing a feedback mechanism, based in part on the results of the first workshop. Components of a Thinking Differently toolkit[29] were utilised to encourage creativity amongst participants when designing the feedback mechanism. Participants were split into two groups and given four Thinking Differently tools; 'fresh eyes, 'reframing by word play', 'pause, notice, observe' and 'random word, picture or object'.[29]. The fundamental basis of this toolkit is that individuals hold schemas, or mental structures of the world, through which thoughts are channelled. The schemas are separated from one another, meaning that it can be difficult to think outside of these mental structures, or to think differently. This in turn inhibits the potential for novel ways of doing something to be introduced into, or alongside, existing systems. Divergent thinking strategies (the Thinking Differently tools) were used in the first half of the workshop (break-out session 1) and participants were encouraged to converge their thinking in the second half of the workshop (break-out session 2; figure 2).

[Insert figure 2 around here]

As the workshop data were emergent it was not possible to plan the data analysis *a priori*. Instead, for the first workshop data were analysed inductively based upon the different themes and concepts that arose. For the second workshop, data analysis was conducted concurrently with participants drawing upon each other's ideas and working as individual groups via convergent thinking to assess these shared ideas and bring them into a tangible mechanism for patients to provide feedback on their safety experiences. A final discussion was held with all workshop participants about which parts of each group's chosen feedback mechanism were the strongest. This contributed to a process whereby the participants were involved as co-researchers in both data collection and analysis,[30] occurring in a participatory open forum.

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Following the second workshop, a researcher (JS) constructed the survey electronically using the final design agreed by the participants as a template. Additional data that were collected in the second workshop, such as voice recordings and flipcharts, were used post-workshop to ensure that the feedback mechanism had accurately captured what the participants had discussed. Upon completion, the final design was circulated amongst all participants for verification that it was an accurate reflection of the discussions and proposed designs. More detail on the construction and content of the survey is provided in the findings section.

Phase 3: Cognitive Interviews

Patients were recruited to cognitive interviews using convenience sampling after completing the safety survey and stating an interest in participating in an interview. Participants completed either the original tri-fold version of the survey (distribution cycle 1; n=20) or an updated bi-fold version of the survey (distribution cycle 2; n=8) following discharge from hospital and upon arrival at their next destination. Patients deemed unable to give informed consent by their care team or were under the age of 18 were not eligible to participate. Cognitive interviews were conducted by EH and JS with 28 patients (18 male, 10 female) in their place of residence who had completed the safety survey following discharge from hospital. Table 1 provides a summary of the clinical area that the patient was discharged from, distribution cycle recruited from, self-reported transport type, and self-reported destination. Participant ages ranged from 53 to 86 (mean=68, standard deviation=10). Cognitive interviews have proved useful in pre-testing of survey questions in a healthcare setting, particularly when they may be complex or of a sensitive nature,[31] as in this study.

Study ID	Cycle	Transport*	Destination*
Cardiology (n=13)			
980	1	Private Car	Hospital
462	1	Private Car	Home
2593	1	Ambulance	Hospital
2590	1	Ambulance	Hospital
4679	1	Private Car	Hospital
3954	1	Ambulance	Hospital
3319	1	Unknown	Hospital
5945	1	Unknown	Unknown

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5583	1	Patient Transport	Hospital
4300	1	Private Car	Home
6227	2	Private Car	Home
6427	2	Private Car	Home
11597	2	Taxi	Home
Care of Older People (n=3)			
104	1	Unknown	Unknown
1189	1	Ambulance	Home
7701	2	Private Car	Home
Orthopaedics (n=7)			
761	1	Ambulance	Home
1867	1	Private Car	Home
2494	1	Ambulance	Home
5853	1	Unknown	Home
6725	2	Private Car	Home
9748	2	Private Car	Home
11100	2	Walking	Home
Stroke (n=5)			
2450	1	Ambulance	Hospital
3445	1	Patient Transport	Hospital
3408	1	Private Car	Hospital
5767	1	Private Car	Home
8182	2	Private Car	Home

* Transport and destination were self-reported. It was not possible to validate or determine the accuracy of this information

Table 1: Details of cognitive interview participants' care transfers.

Interviewees were invited to describe their thought processes in response to the survey questions, in order to identify any potential misunderstandings or other problems with those questions. We extended this beyond the questions to also ask about other components of the survey, including the introductory text, the description of different sections and the overall structure. Cognitive interviews were audio recorded and transcribed verbatim, then coded and analysed using NVivo qualitative analysis software. Interviews were thematically analysed using a deductive approach based on the structure and the questions asked in the survey by one researcher (EH), with codes and themes verified by JS, PD and JW.

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Findings

The findings are reported in five sections. The first section summarises the findings of patient perceptions of safety that were published elsewhere.[8] The next two sections, *principles of patient feedback* and *integration with existing systems*, represent themes identified in the first workshop that should underpin the development of patient feedback mechanisms applied specifically to capturing patient safety feedback. More specifically, *principles of patient feedback* represent the essential design principles of the patient feedback mechanisms, and *integration with existing systems* represents the acknowledgement by participants that where multiple organisations are involved in the care of the patient, particularly as patients cross organisational boundaries, feedback needs to be compatible with multiple patient safety and patient experience systems. The last two sections, *development of the safety survey* and *validation and refinement of the survey* report on the development and validation of the survey. These include why participants chose a safety survey as the most appropriate feedback mechanism, how the final design was developed by the participants and cognitive interview findings, including where confusion arose around the question format and the overall survey design.

Patient perceptions of safety

Semi-structured interviews with patients identified aspects of care that had made them feel safe. These included the ways in which staff communicated with patients and responded to the individual needs of the patient, for example by listening and adjusting the care provided. Interlinked with these themes was that of waiting times; where delays were not communicated to patients and patient requests were not listened to. Patients were also able to identify traditional safety issues, a catch-all term that included medications, falls and healthcare-acquired infections.[8]

Principles of patient feedback

Participants made recommendations and references to the principles on which the feedback mechanism should be based. There was agreement that the feedback mechanism needed to be short with options to expand on answers so that service users could report what was of most importance to them. This is highlighted in a conversation during a workshop between a community care team nurse and patient:

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"From a professional wanting to know what a patient would want, you'd want something that's short but open-ended…" [Community care team nurse]

"Yes" [Patient]

"… so it allows the patient to… discuss one aspect that you felt safe. That's a massive topic but if you had sort of four or five questions like, 'were you happy with that element of care?', 'did you find that was safe?', and that sort of thing" [Community care team nurse]

"Yeah, and, 'if not, why not?'" [Patient]

Participants also agreed that a short and concise feedback mechanism would increase response rates. A conversation between a community care team nurse, social care home manager and a patient highlights this agreement, and in doing so they begin to discuss the need for the feedback mechanism to be objective, or unbiased, through the presentation of positive (safe) and negative (unsafe) experiences.

"So to capture that [transfers of care are different], would we say that they would want the questionnaire to be sort of short and concise to encourage people to actually do it?" [Community care team nurse]

"Got to be fairly concise. The longer it is I think the less chance there is of getting involved with it, and especially if you're asking for positive as well as negative feedback or just general commentary" [Social care home manager]

"That's a very important point. It shouldn't all be whinging. You need to capture the positives as well" [Patient]

"So objective, yeah?" [Community care team nurse]

"Yeah" [Patient]

This unbiased approach was emphasised by both health care professionals and patients to emphasise the necessity to be appreciative. In a conversation between a social care home manager and a community care team nurse, the uneven balance of negative rather than positive feedback is discussed. Notably, it was perceived that this imbalance is caused by a lack of recording of positive feedback.

"You don't get much feedback unless it's a complaint" [Social care home manager]

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> "But I think, I think a lot of people do get feedback. I just think there's an emphasis on the negative. There's a lot of people, like I'm sure you've probably had a patient, where they feedback that you do a grand job. That never gets captured." [Community care team nurse]

Participants felt that the feedback mechanism should have an option to be anonymous as some service users would want to avoid going through a formal complaints procedure. However there were concerns over the usability of patient feedback if it could not be traced to a particular incident, thus impacting on potential learning.

> "The only problem is with it being anonymous is... tracing it back because it's actually more effective when you can look. […] So you can improve practice generally, but for that specific case you might want to look at it in more detail." [Social care home manager]

Integration with existing systems

A number of discussion points arose that focused on how the potential feedback mechanism would fit with current feedback mechanisms. Firstly it was acknowledged that such a system for collecting patient feedback relating to admissions and discharge was required as there was no existing means for patients to provide feedback on this stage of their care, "what we haven't got is just before [service users] get to us, and just after we discharge them." [social care home manager]. A paramedic reported that feedback was limited to complaints or compliments, with a gap existing for the routine collection of patient feedback:

> "We've all got process in place that if there's something we're concerned about we can bring it up. But looking what feedback we get from patients, I know certainly on an ambulance point of view, we get no feedback. The only feedback we get is either a complaint coming in or a letter of thanks." [Ambulance service paramedic]

An additional consideration arose in the second workshop, where care home managers from both private and social care settings discussed utilising patient feedback when it relates to care delivered across organisational boundaries. In particular, it was reported and agreed that whilst patient feedback can be used to change practice, and systems can be changed to incorporate this feedback, they felt there was no opportunity to influence other parts of the health or social care systems. This

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resulted in a conflicting stance, with healthcare professionals wanting to receive meaningful feedback from patients, but knowing existing organisational structures prohibited being able to respond to this information and change practice. In turn this had the potential to impact upon the utility of any potential feedback mechanism for patients crossing organisational boundaries.

> "We want instant [patient] feedback to change our systems" [Social care home manager]
>
> "And so we can change the system within our environment but we can't change the system anywhere else" [Private nursing care home manager]

Development of the safety survey

In workshop 2, participants were given four Thinking Differently tools; 'fresh eyes, 'reframing by word play', 'pause, notice, observe' and 'random word, picture or object'.[29]. The use of 'fresh eyes' in particular encouraged participants to explore how non-healthcare organisations approach receiving feedback. These included some of the more traditional feedback mechanisms, such as noticeboards, postcards and questionnaires, and more novel methods, including an aviation-based reporting system, the Royal Society for the Protection of Birds' annual bird watch and supermarket tokens. Table 2 contains a brief description of each of the proposed feedback mechanisms.

Mechanism	Group	Explanation
Noticeboard	1	Provided in GP waiting rooms for patients to write comments about their recent experiences.
Postcard	1	Given to service users during every part of the journey to complete, capturing the wide range of organisational care transfers.
Post boxes	1	An alternative to the noticeboard which provides privacy for service users and confidentiality for healthcare professionals.
Thermometer scale	1	Service users are able to place stickers on a large thermometer relating to how safe or unsafe they felt. Proposed as it would be quick and easy for service users.
Questionnaire	1	A simple questionnaire sent to service users post-transfer.
Aviation Reporting Tool	2	Confidential Human factors Incident Reporting Programme is used in aviation. Suggested as an idea as it is confidential and had no blame attributed to the reports.
RSPB Bird Watch	2	A method of collecting a lot of data in a systematic way over a short period of time.
Gordon Ramsey approach	2	Communication in restaurants by waiters can reduce the impact that long waiting times have.
Supermarket tokens	2	System similar to supermarket charity donation tokens. Given to service users on discharge for them to place in a 'safe' or 'unsafe' box

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Reverse transfer	2	Increase safety by reducing the number of organisational care transfers through increased care in the community.
Internet questionnaire	2	An automatic email sent to everyone that had gone through an organisational care transfer.
Hospital waiting area information	2	Provide information, either in person or via electronic screens regarding length of wait and delays.
Discharge lounge	2	Place for service users to go prior to a discharge to free up a bed. Somebody could be there to coordinate transfers, provide information and receive feedback.

Table 2: Feedback mechanisms identified by workshop participants for patients to provide feedback on their experiences of safety

Each component of the feedback mechanism was designed by the participants using flipchart paper to draw examples to be discussed. One group decided that the postcard was the best feedback mechanism to take forward and develop due to its simplicity and applicability to a wide variety of settings. This included using a simple scoring system with a three-point scale that incorporated smiley faces: safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

> "One side with a smiley face and one side with a… [unhappy face]. And then straight away you can see" [Private care home manager]
>
> […]
>
> "Something simple. I think the most simple ideas are the most effective" [Patient safety team representative]

However, it was also recognised by participants that having an overly-simplistic system may result in data that lacked meaning, although participants did not stipulate the minimum or maximum amount of complexity or sensitivity required in order for the data to be meaningful. For example there was a debate whether a three-point Likert scale would produce results sensitive enough to identify outliers in safe or unsafe care.

> "As you were saying where you should have a red, a green, amber, and identifying how happy you were, but the detail this lady's describing would need to be addressed quite intricately" [Ambulance service safeguarding lead]

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The other group chose to develop a leaflet-based feedback mechanism, split into three sections directed towards the discharge, transfer and admission of the service user. In particular, their decision to split the transfer into the three stages was summarised by a facilitator (DJ) when feeding back on behalf of the group.

> "We thought that most journeys, and I like your idea of defining a journey and what service user safety is, have a beginning, and a middle and an end. So, we would like to start with this panel, which is… we've got a day and a date… place of departure, so where did you depart from?" [Facilitator, DJ]

This three-stage structure was utilised in the final design, although transfer was changed to journey after the workshop, following feedback from one participant during verification of the design. Table 3 provides an overview of the survey structure and questions.

> *I'm never happy with transfer because people… some people, particularly the public, would automatically think you're talking about wheels, as opposed to the journey* [Email correspondence, community care team nurse]

Please tick which of the following affected how safe or unsafe you felt.

Discharge	Safe	Neutral	Unsafe	Journey	Safe	Neutral	Unsafe	Arrival or Admission	Safe	Neutral	Unsafe
Communication from staff				Communication from staff				Communication from staff			
Staff listening to you				Staff listening to you				Staff listening to you			
Departure running to schedule				Journey running to schedule				Waiting times			
Falling or potential falls				Falling or potential falls				Falling or potential falls			
Medication problems or concerns				Medication problems or concerns				Medication problems or concerns			
Hygiene				Hygiene				Hygiene			
Please use this space to tell us if there was another reason why you felt safe or unsafe or to expand on your answers above											
What could we have done to make you feel safer during your transfer?											

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Table 3: Structure and question format of the safety survey following initial development. Note that each response option was provided in the form of colour-coded smiley faces for safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

Validation and refinement of the survey through cognitive interviews

Twenty participants provided feedback on an original tri-fold version of the survey. There was some diversity of opinion on the appropriateness of the paper format and the three-face design. While some participants suggested that an online or telephone survey might be easier to complete, there was a general consensus that varying access to computers, as well as time and cost restraints, meant that a paper version was more appropriate for most people. Patient 1867 summarised:

> "I would quite happily fill it in on an App, but [people] who are not computer literate would just back away from that. I think paperwork is probably the best way that would cover every age group." [Patient 1867]

Most participants found the three-point scale with smiley faces easy to use and understand. The statement from Patient 4300 makes this point, as well as reinforcing the workshop participants' preference for the survey to be concise:

> "Smiley faces and sad faces and things like that, you know red faces, it looked simple, it was easy, it caught your eye. It wasn't too wordy cos I think there's nothing worse than wordy surveys where you get half way through and you think, 'You know what, I can't be bothered'". [Patient 4300]

However, it should be noted that some participants expressed a preference for 'yes/no/maybe' style questions, with one suggesting that asking whether a patient felt safe, neutral, or unsafe was confusing and even "loaded" [Patient 3954]. Another participant suggested that three faces were not enough, and that there should be 5 in varying shades. Despite this diversity, there was general agreement that the paper survey with the three faces tick-box system was easy to use.

It was reported that two aspects of the survey design caused difficulties for many participants; the division into three stages of the care transfer (Departure, Journey, Arrival) and the way in which the

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questions were asked. For the stages of the transfer, patients were unclear about which departure, journey, and arrival they were being asked. Some interpreted the questions in the 'Journey' section to be relating to their journey *to* hospital rather than *from* hospital or thought they were being asked "to give an average" assessment of the two journeys (P1189); others though that 'Arrival' referred to their initial arrival on the ward, rather than at their next destination.

> "The format of that is not right. It needs drastically changing, I think you should keep 'your departure from' that needs to be explained really, from where?" [Patient 3954]

Second, some participants did not make the distinction between these three stages at all, instead answering questions in the three separate sections in relation to the entirety of the care transfer; these participants saw the three separate sections as merely repeating the same questions, without distinguishing between different transfer stages. For example, Patient 5853, when asked how they had interpreted a question relating to 'Arrival', stated:

> "[The answer given does not relate to] when I was at home, I was talking probably, I thought this was probably an overall of those." *[Interviewer]: "'Your Arrival' as a summary of everything else?" [Patient 5853]:* Yeah.

On the basis of these findings, the survey was restructured into a two-page leaflet. The front and back pages provided additional information about the survey, and the middle two pages contained the survey questions (table 4). The survey still asked questions about each of the three stages of the transfer (departure, journey and arrival), however this was asked within each question. An additional explanation of the stages of the transfer was provided with increased clarity over which transfer was being referred to, and the survey questions were expanded to be more specific about what was being asked (see supplementary material for the wording). Space for free text comments was provided next to each question. Cognitive interviews with eight additional patients using the modified version of the survey suggested that the changes had resolved the original issues around question clarity and the type of transfer that was being asked about. Participants suggested that some sections of the survey were not of relevance to them, which was either due to patients feeling safe, or because parts of their transfer did not involve healthcare staff, such as when transported by private car.

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> "[The only difficulty completing it was] knowing what on earth to put sometimes, because I kept thinking, 'I don't think, I don't think that applies.'[…] I couldn't decide whether I was putting the right thing sometimes, because I didn't feel unsafe and y'know, everything was kind of looked after okay" [Patient 6227]

Similar to the original tri-fold design, patients also reported that they considered the survey to be capturing their experiences of safety across their entire episode of care, rather than an individual transfer. For example, patient 6725 reflected, "this felt as though it was reflecting on my three day stay in hospital", and patient 8182 provided a similar reflection. This suggests that the description of the stages of the transfer was not sufficient in explaining to patients that the survey was focusing only upon the transfer, and not their entire episode of care, and future iterations would require this distinction to be explicit.

> "I wasn't sure that it was [the transfer] that they were asking the question for, or that it was a general safety survey of the whole experience of going to hospital, being a patient." [Patient 8182]

How safe did communication from staff make you feel? For example giving you clear and timely information or being polite.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

How safe did you feel with regards to staff listening to you and responding to your individual needs?
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

Did you experience any delays? [Yes / No]
If yes, where was your longest delay? [Departure / Journey / Arrival]
How did this make you feel? [Safe / Neutral / Unsafe]

How safe did you feel about the possibility of falling? For example if you felt confident that you wouldn't fall or if you were concerned that you might.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

How safe did you feel about your medication? For example receiving the correct medication, understanding the medication you were taking or delays in receiving your medication.
On your departure [Safe / Neutral / Unsafe]
During your journey [Safe / Neutral / Unsafe]
On arrival at your next destination [Safe / Neutral / Unsafe]

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How safe did you feel about hygiene and cleanliness? For example if staff washed their hands and if the surroundings were clean.

On your departure [Safe / Neutral / Unsafe]

During your journey [Safe / Neutral / Unsafe]

On arrival at your next destination [Safe / Neutral / Unsafe]

Overall, how safe did you feel throughout the whole transfer including the departure, journey and arrival? [Safe / Neutral / Unsafe]

Table 4: Question format of the safety survey following cognitive interviews. Response options are provided in square brackets. Note that each response option was provided in the form of colour-coded smiley faces for safe (green smiling face), neutral (yellow impassive face) and unsafe (red frowning face).

Discussion

A number of systematic reviews consider how patients can provide feedback on their safety,[14 16 17] however these focus on adverse events, typically within discrete care settings such as secondary care, rather than experiences of safety in the context of care transitions. Furthermore, there are relatively few studies reporting on the development of these feedback mechanisms. One notable study has reported on the development of a patient reporting tool, though again this is specific to secondary care settings.[11-13] Our study developed a mechanism for patients to provide feedback on their safety experiences following a transfer between organisations through a process of co-design. The transfer between organisations was chosen as it is a time in the patient's episode of care that is acknowledged to be particularly high in risk,[21 32] and when mistakes are likely to occur.[33]

The developed safety survey aims to capture patient experiences of safety, based on patients' definitions of what it is that makes them feel safe during a care transition.[8] This is a notable shift from some existing approaches to involving patients in reporting patient safety incidents, which have had limited success.[14] There has been a limited amount of work attempting to reconcile the differing perceptions of safety between clinicians and patients that result in a lack of a shared understanding about what it means to feel safe,[7 8] but the use of co-design approaches in developing feedback mechanisms can go some way to bringing together the different perceptions, particularly as it has been identified that patient experiences can be linked to clinical safety.[6]

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By bringing together patients and healthcare professionals in tailored workshops within this study, we were able to identify principles that should underpin the feedback mechanism, including that it should be patient-centred, short, concise with clear signposting on how to complete it, optionally anonymous and be objective with a focus on both positive (safe) and negative (unsafe) care.

Within the principles of feedback mechanisms, the provision of patient-centred care refers to the location of the patient within their care. For a feedback mechanism to be patient-centred, this in turn requires the opportunity for patients to be involved and to play an active role, thereby placing their experience of care at the forefront. The length and structure of the feedback mechanism, in being short and concise with clear signposting on how to complete it, is already a feature of patient experience surveys and the benefits of brevity include increased response rates and greater acceptability and usability amongst patients.[34]

Giving patients the option to provide anonymous feedback is particularly important when considering and discussing safety. Existing evidence suggests that patients have concerns, whether founded or not, that challenging healthcare professionals can impact upon the care received and engender feelings of suspicion and mistrust,[35] and the concept of providing anonymous feedback was enshrined in participants' comments and the final feedback mechanism designed in this study. That both patients and healthcare professionals identified the need for feedback to be balanced between positive and negative experiences demonstrates that both groups were aware of criticisms of existing feedback mechanisms that focus on negative experiences alone, such as the use of complaints. The paradox of measuring safety by its absence was acknowledged early in the patient safety movement,[36] but this is now being reflected in proactive approaches to safety,[37] and the findings of this study suggest that the same principle should be applied to patient feedback mechanisms. The principles of being patient-centred, short, concise with clear signposting on how to complete the feedback mechanism, optionally anonymous and objective with a focus on both positive and negative care can be applied by others who are interested in developing feedback mechanisms for patients to provide feedback on their experiences of safety, and the generic nature of the principles can be applied to settings other than organisational care transfers.

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Finally, the complexity associated with care being received across organisational boundaries was identified by participants and is recognised elsewhere in the literature.[20] In particular, healthcare professionals in this study acknowledged that they would be unable to implement change that impacts on or requires the input of other service providers as a result of patient feedback. This was a significant outcome, and an important consideration for future research that aims to involve the patient in their safety across organisational boundaries. Agreement between, or integration of, services may be necessary in order to promote organisational learning and change service delivery in response to patient feedback.

Use of co-design methods

We built upon the principles that should underpin a feedback mechanism by using participatory and co-design methods in the development of the survey, which are receiving increased attention in healthcare for their ability to increase participation and engagement,[26] and we used the Thinking Differently methodology[29] to provide a means by which to break out of existing schemas to encourage innovation.

Furthermore, co-designing a feedback mechanism ensures that it meets the requirements of different groups of users; in the case of this study, patients who are required to understand and complete the questions, and healthcare professionals who are required to collect and learn from the feedback provided. Co-design was particularly important given the differences that exist in patients' and healthcare professionals' understandings of safety, and provided an opportunity for shared learning. Despite these benefits of using co-design, we did encounter challenges associated with the approach, including personal agendas and dominant voices. Prior to the first workshop, we developed inclusive strategies such as post-it notes and flipchart paper that would enable both patient and healthcare professional participants to have their voice heard, even if it was not audible.[38] The issue of personal agendas amongst participants, where they would attempt to overly influence the direction of discussion, was a greater challenge. In a systematic review of the impact on patient involvement on research, personal experience stories that dominated discussions were identified to be a challenge.[39] In order to resolve this, we used the Thinking Differently toolkit in workshop 2 to

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provide focus for all participants by directing thoughts and discussions to situations equally familiar to all, thus reducing the available space in which individuals could dominate discussions.

Limitations

This study developed a safety survey using participatory and co-design methods, including the identification of underlying principles. Whilst the survey was co-designed by healthcare professionals and patients, including cognitive interviews to validate and further refine the survey, further research is required to pilot the developed feedback mechanism to determine whether patients would be willing to be engaged in reporting their experiences of safety following a transfer in care. Furthermore, the participants involved in the development of the survey were recruited to represent a wide variety of health and social care services and patients. Due to the nature of organisational care transfers it is unlikely that they represented all possible types of transfers that patients experience. It was also not possible to explore further the governance relationships that exist between organisations, regardless of representation in this study, which could impact on the implementation of the survey into practice. Finally, the self-reported transport and destination of the cognitive interview participants was not directly explored, and so it was not possible to validate or determine the accuracy of this information.

Future research

The use of participatory and co-design principles helped to overcome differences in the understanding of safety, to develop a feedback mechanism for patients to provide feedback on their experiences of safety relating to a care transfer. Additional research is required before the survey is ready to be used in practice, including piloting in further clinical areas in order to determine its usability and acceptability to patients and healthcare professionals. Patient cognitive interviews indicated confusion between whether patients were being asked to provide feedback solely on their care transfer or their whole episode of care, indicating that it may be difficult to solicit feedback on experiences of care relating to one aspect of an episode of care. Further research is required to explore this, which could include determining whether asking patients about safety experiences is likely to increase awareness of patient safety, and whether patient experiences of safety can lead to quality improvement in the complex area of care transfers.

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Acknowledgements

We would like to thank all participants for their invaluable contribution to the study, the Safer Care North East Patient, Carer and Public Engagement group and the PRoSOCT advisory group for their support and guidance, and the NHS Trusts involved in the study for their ongoing support. We also thank The Health Foundation (an independent charity committed to bringing about better health and health care for people in the UK), Northumbria University and the former North East Strategic Health Authority, in particular the Patient Safety Action Team and the Safer Care North East programme, for funding the studies that contributed to this paper. The research team acknowledge the support of the National Institute for Health Research, through the Comprehensive Clinical Research Network.

Author contributions

Phases 1 and 2: JS, PD and DJ designed the phases, collected, analysed and interpreted the data. Phase 3: JS, JW and PD designed the phase. JS and EH collected, analysed and interpreted the data, with input from JW and PD. All authors contributed to the drafting of the manuscript.

Data sharing statement

No additional data are available.

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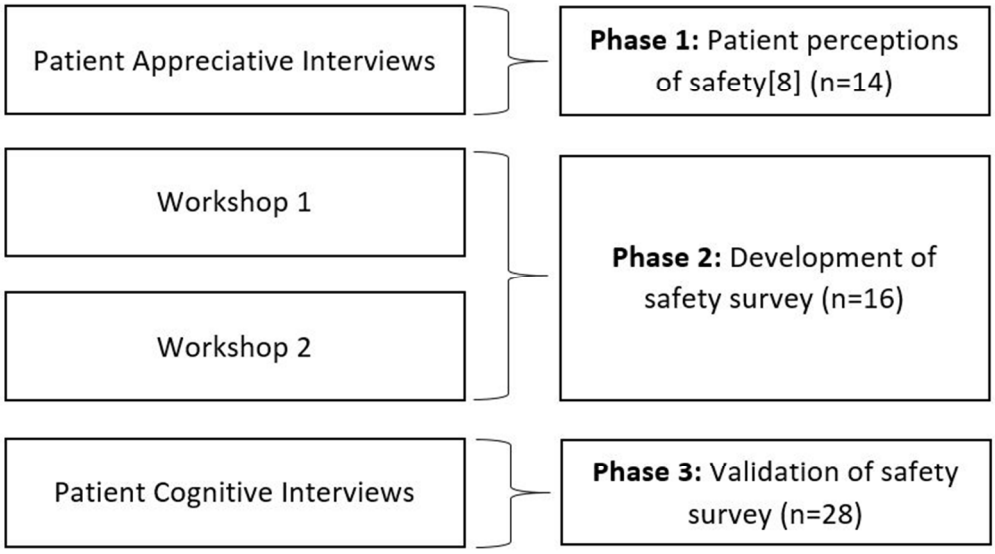

Figure 1: Process of development and validation of the patient feedback mechanism across three phases
70x40mm (300 x 300 DPI)

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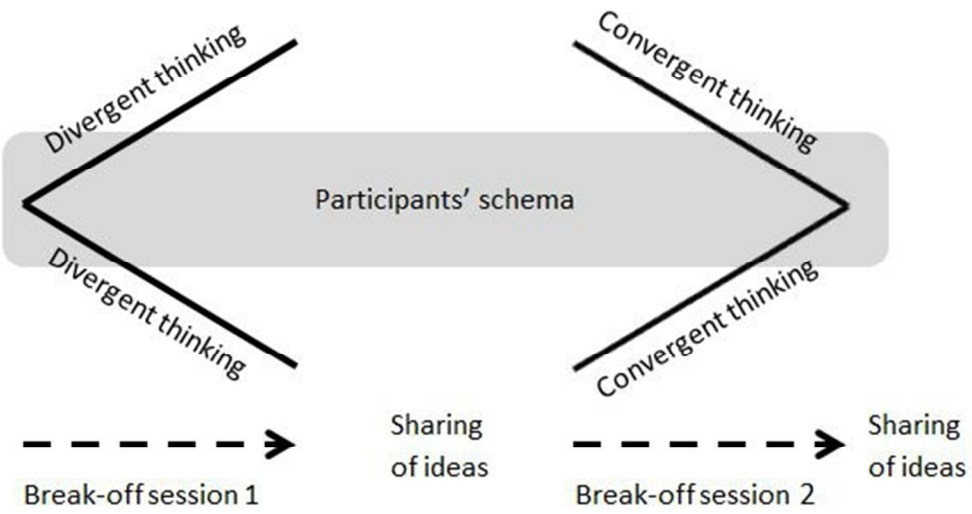

Figure 2: Divergent and convergent thinking strategies in Workshop 2 to encourage participants to think outside of their existing feedback mechanism schema
49x27mm (300 x 300 DPI)

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SAFE AND SURE

Safety Survey

Dear patient and / or carer,

This survey is for you to tell us how safe you felt during your most recent transfer out of hospital, and what made you feel this way. Anything that you tell us will remain confidential and will not affect the care that you receive.

It is important for us to find out about your experiences so that we can improve our services. **Please complete the survey and return it in the prepaid envelope provided**.

Contact Jason Scott or Emily Heavey if you have any questions, would like help completing the survey or if you would like to receive the survey in large print.

01904 876 376

j.scott@yorksj.ac.uk

e.heavey@yorksj.ac.uk

What does safety mean?

We believe that for you to feel safe, healthcare staff should communicate with you, respond to your individual needs and ensure you are physically safe and secure. We are also interested in finding out if there is anything else that makes you feel safe.

How do I complete the survey?

For each question, please tick the face that best represents how you felt. The **green face** means you had no worries or concerns about your safety, the **red face** means you were worried or concerned about your safety, and the **yellow face** means you felt somewhere between the two.

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York St John University York Teaching Hospital NHS Foundation Trust The University of Nottingham Nottingham University Hospitals NHS The Health Foundation Inspiring Improvement Yorkshire Ambulance Service NHS

Departure means planning and preparing for, and leaving hospital.

Journey means travelling from hospital to your next location.

Arrival means settling in at your next location.

What is your NHS Number? (optional) _____

Are these the opinions of: patient ❑ carer ❑

What was the date of your departure? D D / M M / Y Y Y Y

Which ward did you depart from? _____

Where were you going to? _____

How did you get there? _____

Did someone go with you? Yes ❑ No ❑

If yes, who? Family / Friend ❑ Carer ❑ Member of Staff ❑

Only tick boxes for questions below that are relevant to you, for example the question on staff communication during your journey may not be applicable if you used your own transport.

How safe did the communication from staff make you feel? For example giving you clear and timely information or being polite.

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel with regards to staff listening to you and responding to your individual needs?

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

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Did you experience any delays? Yes ❑ No ❑

If yes, where was the longest delay during your transfer?

Departure ❑ Journey ❑ Arrival ❑ Comments: _____

How did this make you feel?

❑ ❑ ❑

_____

_____

How safe did you feel about the possibility of falling? For example if you felt confident that you wouldn't fall or if you were you concerned that you might

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel about your medication? For example receiving the correct medication, understanding the medication you were taking or delays in receiving your medication.

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

How safe did you feel about hygiene and cleanliness? For example if staff washed their hands and if the surroundings were clean

				Comments: _____
On your departure	❑	❑	❑	_____
During your journey	❑	❑	❑	_____
On arrival at your next location	❑	❑	❑	_____

Overall, how safe did you feel throughout the whole transfer including the departure, journey and arrival?

Comments: _____

❑ ❑ ❑

_____

_____

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Thank you for taking the time to complete this survey. Please return it in the freepost envelope provided.

What will we do with your answers to this survey?

We will bring together feedback from patients and provide this anonymously to healthcare teams involved in your transfer. The purpose of this is to identify what is being done well, and areas where the quality of care that you receive can be improved.

What should you do if you want to make a complaint about your care?

By completing this survey you are **not** making a complaint. If you have felt unsafe at any other point during your care or would like to raise a specific concern please contact the Patient Advice and Liaison Service. If you contact us we can give you information on how to do this.

Would you like to receive a summary of the research findings?

Yes ❑ No ❑

Please fill out your details below and we will send you this at the end of the study. All information will remain private and confidential in line with the Data Protection Act (1998), and will not be shared with anyone or used for any other purpose than to provide you feedback.

Name: _____

Address: _____

_____

Could you please tell us your gender, age and how you define your racial / ethnic origin. This will tell us if we're reaching a wide sample of people. If you are a carer, please tell us the patient's details. You do not have to complete this part if you do not want to.

Gender: Male ❑ Female ❑

Age: _____

Racial / ethnic origin: _____

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No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer / facilitator	Which author/s conducted the interview or focus group?	Pages 6, 7 and 8.
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	All researchers hold a PhD.
3.	Occupation	What was their occupation at the time of the study?	JS was a PhD candidate at the time of phases 1 and 2. JS and EH were research associates during phase 3. PD, AJ and JW were in academic positions during all phases.
4.	Gender	Was the researcher male or female?	Male and Female.
5.	Experience and training	What experience or training did the researcher have?	Experience conducting and analysing data from focus groups of patients and healthcare professionals.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No relationship was established prior to study commencement
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	This information was provided prior to data collection as part of the invitation and information leaflet
8.	Interviewer characteristics	What characteristics were reported about the interviewer / facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	No characteristics were reported about the researchers
Domain 2: study design			
Theoretical framework			

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No	Item	Guide questions/description	
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Page 5
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Pages 6, 7 and 8
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Pages 7 and 9
12.	Sample size	How many participants were in the study?	Pages 6, 7, 8 and 9, and figure 1
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	No participants dropped out. We are unaware of how many people refused to participate due to the way in which participants were invited to the study.
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Pages 7 and 9
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Nobody else was present during data collection
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Pages 6, 7, 8 and 9
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 6 and 9
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Repeat data collection was not conducted

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No	Item	Guide questions/description	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 8 and 9
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were not taken
21.	Duration	What was the duration of the interviews or focus group?	Page 7
22.	Data saturation	Was data saturation discussed?	For cognitive interviews, data saturation was discussed among those reviewing and coding the transcripts. Data saturation was not relevant for the co-design workshops
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 8
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Page 9
25.	Description of the coding tree	Did authors provide a description of the coding tree?	A summary of the coding tree is written on pages 9 and 10
26.	Derivation of themes	Were themes identified in advance or derived from the data?	For phases 1 and 2, themes were derived from the data (where applicable). For phase 3, themes were identified in advance based on the structure of the survey.
27.	Software	What software, if applicable, was used to manage the data?	Page 9
28.	Participant checking	Did participants provide feedback on the findings?	Participants provided real-time feedback during the co-design workshops.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Pages 10 - 17

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No	Item	Guide questions/description	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Pages 9 – 17. A summary of the major themes is presented at the start, and subheadings are used to present them in more detail.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Pages 10 – 12. In particular discussion about the integration with existing systems.

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