

Involving patients in clinical research: the Telescot Patient Panel

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Abstract

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Background To date, patient involvement in the development of clinical research work has been limited. In 2011, the Telescot research team commenced work on a feasibility trial to investigate home telemonitoring of blood pressure for people who have experienced stroke or transient ischaemic attack (TIA). The team decided to involve patients in the development of the research.

Objectives To improve research design through patient involvement.

Method of patient involvement A modified form of the ‘Scrutiny Panel’ approach was used to involve people who had stroke in the research project.

Results The Patient Panel supported the research in three key ways: it informed patient communication; it presented patient perspectives on the applicability and usability of the intervention; and it guided the development of the qualitative study.

Discussion The initiative was considered a positive experience for all. However, challenges were identified in terms of the time and cost implications of undertaking patient involvement.

Implication for research practice Importance is attached to adequate project planning and development, partnership working with community-based organizations and the necessity for clear role delineation between patients and professionals to enable effective collaborative working.

Conclusions The Telescot Patient Panel was beneficial in supporting the development of the feasibility trial. The Panel approach was considered transferable to other clinical research contexts.

Introduction

In the UK, an increasing range of government initiatives are attempting to engage patients and carers as partners in service planning and development.^{1–4} Increasingly, health-care professionals are recognizing the value of involving patients and carers in research design and development.⁵ Most recently, guidance has been developed to support researchers seeking to take forward public involvement in clinical trials.⁶ However, to date, patient participation in the design and development of clinical research has been limited.⁷

In 2011, the Telescot research team⁸ commenced work on the development of a feasibility trial into the home telemonitoring of blood pressure by people who had experienced stroke or transient ischaemic attack (TIA).⁹ Prior to the study, two randomized control trials in stroke had involved patients in research development. The first sought to determine whether consumer involvement would help to solve some of the ethical problems associated with research into thrombolysis for acute ischaemic stroke, with its inherent risk of fatal intracranial haemorrhage.¹⁰ The second concerned consumer involvement in the design of a randomized controlled trial of routine oxygen supplementation after acute stroke.¹¹ Semi-structured interviews and questionnaires were used in both studies to acquire the views of patients on research design. In both studies, patient involvement was considered important in determining patient acceptability of the trial intervention. The Telescot team decided to involve patients in the development of its feasibility trial into telemonitoring in stroke, recognizing the value of patient perspectives on the acceptability of the proposed innovative intervention, the particular difficulties people with stroke may have in research participation, and what might work best in attempting to recruit people.

Objectives

This article outlines the approach taken to patient involvement in the Telescot feasibility

trial, considers the impact of the approach and presents some key learning points to assist clinical researchers who wish to engage patients in research development.

Although it is well established that effective control of blood pressure is the single most important controllable factor in the prevention of recurrent stroke,^{12–14} many stroke and TIA survivors do not have their blood pressure adequately controlled, despite the availability of effective medications. One reason for this is so-called therapeutic inertia^{15,16} where clinicians appear slow to intensify treatments. In a previous study by the research team, home telemonitoring as a means of supporting reduction in blood pressure amongst people with hypertension had reported positive outcomes,¹⁷ and this was thought to be due largely to overcoming therapeutic inertia. However, targets for blood pressure control in people with stroke/TIA are more challenging. The research team had concerns that this group, who are generally older and more frail, might have found telemonitoring technology more daunting and be less willing to participate in a trial. The decision was made to conduct a feasibility pilot trial before embarking on a substantive trial.

The trial protocol can be accessed on the Telescot website.⁹ The intervention consisted of the home use of an electronic sphygmomanometer to measure blood pressure on a weekly basis in patients in Lothian, Scotland. Readings from the sphygmomanometer were transmitted using Internet technology to the patients' practices where they would be accessed by GPs or practice nurses. Trial recruitment commenced in November 2011. Full recruitment was reached in March 2012 (55 participants). The trial collected quantitative data (at baseline and follow-up) and qualitative data (semi-structured interviews with patients and practitioners) to assess the feasibility of the intervention. The study has Research Ethics Committee Approval (ref: 11/SS/0023) and NHS Research Management Approval (ref: 2011/P/GP/09).

The patient panel approach

First steps

The Telescot team commenced patient involvement work in February 2011. The team comprised individuals who had experience of working with service users in previous research projects.¹⁸ The Telescot initiative was led by the team's qualitative researcher, who had previous experience in public consultation in health and social services. The project closely involved the Telescot programme manager and the trial manager. They reported to and consulted with the wider research team with regard to project development. Initial work focussed on the identification of the aims, parameters and desired outcomes of the project.

Conceptualizing engagement

The research team gave consideration to various approaches to patient involvement, noting three modes of engagement, as described by INVOLVE, the UK national advisory group that supports greater public involvement in NHS.¹⁹ They are as follows: a researcher-led approach involving *consultation* with patients in one or more elements of research development; a joint *collaborative approach* involving patients and professionals occupying equal but different roles in all aspects of project work; and/or a *patient/service user-led approach* to research design and implementation. It is recognized that the boundaries between the three approaches are not clear-cut and that patients and the public may be involved in more than one of these modes of engagement during project work. Different views were held within the research team on the merits and disadvantages of each approach and their applicability within the context of the research project. It was decided that patient involvement would take a consultative approach given that the design of the trial had been determined within the Telescot programme framework.⁸

It is recognized that there are two main ways of engaging patients in research consultation

work²⁰: through the inclusion of patients or their representatives on management boards/committees, or the use of 'satellite' or advisory groups where patients meet in structures separate to research management groups in order to discuss and advise on specific issues which are then reported back. The research team considered that the advisory group approach was advantageous in that it provided patients with the opportunity to advise and offer input outwith the constraints, pressures or influences of trial management group structures. This was considered a less disruptive way of instigating patient involvement given that the management structures underpinning the trial had been firmly established within the wider research programme. Some members of the research team had concerns that patients would find participation in a trial management group involving clinician-researchers, daunting and off-putting. Patient engagement with the complexity of subject matter discussed at such meetings, and the appropriateness of such content, was also raised as an issue.

The research team entered dialogue with a service user-led organization called VOCAL (Voice of Carers Across Lothian) on how best to involve patients in consultation work. They encouraged the research team to consider the 'scrutiny panel' approach. This model involves the formation of a small group of between four to six patients, intended to be typically representative of the wider stakeholder population, which would meet on a regular basis to review and give advice on aspects of research development. Scrutiny panels tend to work at arm's length to the service development initiatives which they were set-up to support, and whilst operating independently, provide regular feedback within project management and/or governance structures. The research team considered the Panel approach to be a pragmatic and flexible way of undertaking patient consultation along the lines earlier identified. However, the team felt uncomfortable with the identification of a 'scrutiny' role for the proposed Panel, considering this to have negative undertones. Consequently, the Patient

Panel, as it became known, operated in an advisory capacity to support research development.

The importance of partnership working

The development of the Panel approach was undertaken in partnership with Chest Heart & Stroke Scotland (CHSS), a non-governmental organization with expertise and experience in service user involvement work. The research team worked closely with staff from CHSS's Stroke Voices programme,²¹ an initiative designed to help individuals gain the skills and confidence to work in equal partnership with NHS Scotland on service improvement initiatives.²² The Stroke Voices staff provided practical advice and guidance to the research team on the development of the Patient Panel. This included support in refining the aims and objectives of the Panel; an understanding of the mechanics and practicalities of undertaking patient involvement work; the provision of CHSS training to the research team in supported communication skills; and assistance with the drafting of patient information materials to ensure adherence to the organization's information accessibility standards.²³

Preparing for panel

Recruitment to the Panel occurred through the CHSS network of stroke support groups in Lothian. Chest Heart & Stroke Scotland support group coordinators assisted with the dissemination of information about the Panel and provided opportunities for members of the Telescot team to meet with support group members to discuss the proposition of research involvement. As a result of this approach, eight people from support groups across the region came forward with an interest in participating in the Panel. Chest Heart & Stroke Scotland provided an induction course to prospective candidates to introduce the research work, the Panel approach and collaborative working. The researchers also attended the course. This presented both parties with the opportunity to

meet each other and to establish a pre-Panel dialogue about research engagement. This in itself was useful to the researchers in further developing the proposed role and function of the Panel, which was informed by those interested in participation.

The course was an adapted version of CHSS's 'Stroke Voices' training programme that had been designed to facilitate patient involvement in NHS service development. (Stroke Voices aims and objectives – Appendix S1.) Course content was modified in consultation with the Telescot team for the purposes of supporting patient involvement in *research* development. (Course outline – Appendix S2.) The course was provided over three half-day sessions and was delivered and facilitated by the CHSS Stroke Voices team. The structure was a mixture of interactive presentations and group work. Emphasis was placed on developing a safe environment for open dialogue and discussion between participants. Ground rules regarding terms of engagement were established from the outset. In recognition that stroke can lead to disability affecting an individual's capacity to communicate, an adapted version of Talking Mats,²⁴ a communication tool which uses a mat with symbols attached as the basis for communication, were used to ensure all participants had an opportunity to engage in group discussion. Participants discussed their experiences of using NHS services, aired and shared worries and apprehensions regarding working together, examined strategies to support successful team working and explored the possibilities and boundaries of what could be achieved by patient involvement in this context. The trial team provided an introduction to the research project and demonstrated use of the telemonitoring equipment. The course also explained some of the 'hidden' disabilities resulting from stroke and the impact of these on communication. The researchers found this part of the course particularly helpful as it highlighted some of the challenges, such as memory loss and visual impairment, which would need to be addressed in working with people who had been affected by stroke. The training course was evaluated by

questionnaire, which was completed by participants at the end of the last session (Fig. 1).

Participant selection

As the induction course progressed, the enthusiasm of participants became evident. In order to embrace the involvement of all those who wished to engage in supporting the project work, it was decided by the research team that course participants would be provided with a choice of two options at the end of the course: involvement in the Panel or participation in the study's focus group research. The last session of the induction course gave participants the opportunity to discuss these options. Further to the completion of the course, membership of the Panel was determined by the research team and CHSS colleagues. Four individuals were selected to participate in the Panel. Stroke had affected each Panel member differently, and the group contained a spread of representative disabilities. The remaining course participants took part in supporting the focus group research.

The panel at work

The Telescot Patient Panel commenced work in July 2011. The panel had an intended lifecycle of 9 months. Four meetings of the Panel were scheduled, the last of which occurred in March 2012. The Panel began work 3 months before

the commencement of trial recruitment in order to offer support and advice to the research team during project start-up. The last meeting occurred at the point of completion of recruitment and the start of analysis of the qualitative research work. Panel meetings had a thematic structure. Meetings were facilitated by the Telescot programme manager and the qualitative researcher. Meeting venues were varied to take account of the geographical spread of Panel participants, and venues were sought which were accessible for people with disability. Transport for Panel members was arranged by the research team so that participants did not incur expenses. Refreshments and lunch were also provided. Panel members were not paid for their time, and this decision was informed by resource constraints. The research team identified topics for consultation at Panel meetings based on issues arising at each point in the trial's lifecycle and from issues presented by Panel members. Advice and feedback was sought on a diverse range of issues, including strategies to support patient recruitment; operational issues regarding use of technology and the implementation of the research protocol; the preparation of patient information materials; involvement in the construction of the trial's qualitative study topic guides; feedback on preliminary analysis of the qualitative work; and strategies for dissemination. In addition to formal meetings, Panel members and the research team communicated by email.



Figure 1 Pictured: induction course participants, facilitated by Nicola Cotter, Chest Heart & Stroke Scotland.

Benefits

Within the context of this research project, the team considered the Panel beneficial in three key areas: with regard to patient communication issues, on practical issues relating to technology and the set-up of the trial intervention and in the development of the trial's qualitative research.

In the first of these areas, communication, the Panel's work was central in informing the research team's approach. The Panel advised on the merits and disadvantages of different modes of communication for people affected by stroke. They highlighted the difficulties that some people disabled by stroke experienced with communication by telephone, and the importance of a clear, patient and non-patronizing approach to verbal communication.

The Panel had considerable involvement in the development of the trial's printed materials. They critiqued the format of the research programme's standard information sheet and consent forms, identifying problems with presentation and layout, use of jargon and technical language, and with the density of information. The research team worked closely with the Panel, with the support and expertise of CHSS, to develop accessible patient information materials. Panel members were involved in the identification of key content, with the selection of pictures and simple diagrams used to illustrate central messages, and in reviewing the use of language and design in the revised leaflets.

The Panel's input on the usability of the technology and the accompanying telemonitoring set-up helped the research team understand and appreciate patient perspectives, which had not been previously considered. Initial feedback on the technology was acquired during induction (Appendix S3). It alerted the research team to difficulties people affected by stroke may have in fitting the cuff due to hemiparesis, and the impact of impaired vision on seeing readings taken by the equipment. This had a significant impact on the development of the research.

Panel members also drew to the researchers' attention how some physical disabilities resulting from stroke affected dexterity and the

impact of this on the use of mobile phones in the trial. Problems with using small keypads, difficulties with sending and retrieving/reading text messages, and the merits and disadvantages of using modem technology were all discussed by the Panel and reported back to the research team. However, the work of the Panel was not confined to identifying problems. Similar to other patient involvement initiatives,^{25,26} the Panel was involved in the resolution of practical problems which arose during the trial. One such issue related to how best to check that potential research participants had actually received the request to participate in the research from their practice. The panel suggested who they thought potential participants would find acceptable to receive contact from in general practice with regard to follow-up enquiries and what they considered to be the most applicable mode of communication in this context.

The Panel played an important role in the development of the qualitative work. For example, members were involved in reviewing the interview guides. The input of the Panel led to the inclusion of additional interview questions in the following areas: on carer involvement (an area that had been largely overlooked during the first iteration of the interview guides), on patient interaction with mobile phone technology (noting some of the concerns identified earlier) and on the acceptability and utility of the monitoring website for trial participants. In addition, the Panel was involved in data analysis. A Panel meeting was dedicated to a discussion of the coded data. The qualitative researcher presented a summary of the data to the Panel, using anonymized data extracts to illustrate key themes. Panel members reviewed these, providing insights and comments on the interpretation of the data. This information was then used by the qualitative researcher to inform the development of the coding framework.

Subsequent to the involvement of the Panel in data analysis, advice was also offered by members on dissemination of the trial's eventual findings. The Panel stressed the importance of communicating the findings to people with had experienced stroke, their friends/fam-

ily and carers and to the wider public. They proposed that an accessible summary of research findings should be created and distributed to community support groups, general practices and community centres to raise awareness of the research and its implications.

The involvement of the Panel in the development of the qualitative study was considerable, enabling the representation of a range of patient perspectives in all aspects of the research process. Given that qualitative research is sometimes viewed with scepticism within the medical research community, the research team considered that the extensive involvement of patients in the design and analysis of the qualitative study added extra credibility to the work, particularly in the eyes of both stakeholders and funders. (A benefit that has been identified by other researchers who have been similarly engaged in supporting patient involvement in research.^{27,28})

Discussion

Limitations and challenges

The team identified challenges in terms of time and cost implications of undertaking patient involvement work, and initial apprehensiveness from colleagues regarding how to best take forward the work.

It was a challenge implementing patient involvement work within the limited timeframe of a small-scale feasibility trial. The internal research governance arrangements within Telescot were not initially designed to incorporate patient involvement and although there were discussions to explore revisions to existing structures to incorporate Panel representation in groups such as the Independent Trial Steering Committee, for example, time constraints prevented these plans from being actualized. Equally, time constraints prevented Panel involvement in the development of the trial protocol (which had been formulated before Panel formation).

Issues related to cost often feature as a major concern in the evaluation of many patient involvement initiatives in research.²⁹ It

is important to acknowledge that the establishment of the Panel required dedicated time and effort. The workload involved in both developing and maintaining the Panel was borne by members of the Telescot research team and was incremental to the existing responsibilities of staff. Additional costs in patient involvement work (particularly with regard to training and support provided to the patients and professionals involved at the initial stages of Panel set-up, induction course and training) were minimal due to the generosity of the partner organization. However, the research team identified that costs related to staff time and resources would require consideration in any future grant applications to progress further patient involvement activity in this area.

The proposition of involving patients in research work required a lot of open and honest discussion at the outset as different members of the research team had different ideas about how best to approach and implement it. Some team members had met previous challenges when the expectations of service users did not align with those of the researchers in previous patient involvement initiatives. For this reason, careful planning was undertaken in the development of the Telescot approach to patient involvement. Time was required for researchers, who were used to working with other professionals in a research environment, to grow accustomed to receiving input from patients. This required a period of adjustment. To help manage this change, it was considered important that expectations regarding the purpose and function of the Panel were clearly outlined to all participants at the outset, both those directly involved with the Panel (including the Panel members themselves) and the wider research team. A great deal of care was taken to delineate and explain the different roles that patients held within the research process. Particular emphasis was placed on understanding the differences between the 'patient-as-research-participant' (as in the feasibility trial) and the 'patient-as-research-advisor' (as in the Patient Panel). Recognition of the importance of this distinction supported

8 Telescot patient panel, P Fairbrother *et al.*

the acceptance and understanding of the role of the Patient Panel within the research team.

A positive experience for all

As mentioned earlier, the Telescot team entered the arena of patient involvement work with some trepidation. Uncertain of the consequences of engagement, the initial approach taken by both the Panel and the research team was one of caution. However, such feelings started to dissolve as the work got underway. This was supported, in part, by the foundation laid during the earlier induction sessions which sought to establish mutually agreed terms of engagement between Panel members and researchers, built on a culture of openness and respect. The learning derived from the induction process provided a firm foundation for initial contact between both parties, and it proved helpful in supporting bonds of trust to develop. The positive working relationship between the Panel and the researchers enabled a friendly and frank dialogue to establish. It soon became apparent that all participants looked forward to the meetings. As the benefits arising from the work of the Panel started to emerge, so the research team's confidence in involving patients in research development began to grow. The researchers became increasingly comfortable in seeking advice from the group on emergent issues and problems during the course of the trial. The involvement of the Panel was transformative not only in terms of supporting development of the feasibility trial, but also with regard to the attitudes of some within the research team who had been initially hesitant about the initiative. The research team intend taking forward the Panel approach in future research projects and hope to extend the role of patient participation into the areas of project commissioning and management work.

Implications for research practice

The research team learnt a great deal from the experience of involving patients in research

development and consider the Panel approach transferable to other clinical research contexts. It is hoped that the following key learning points, arising from reflections on the development of the Telescot patient involvement initiative, support researchers interested in undertaking patient involvement work.

Start at the beginning

Increasingly, research funders are asking for demonstrable commitment to patient involvement as part of grant applications. In the Telescot experience, patient involvement was initiated by the research team subsequent to project funding. Therefore, the overarching protocol governing trial work had already been determined by the time patient involvement work was initiated. Whilst patient input informed and influenced the implementation of the research work in the ways earlier outlined, it is acknowledged that involving patients in the pre-application process presents additional opportunities to improve research design. Increasingly, researchers are beginning to explore the involvement of service users as grant holders so that the perspectives of patients and carers inform initial project development and inform continual evaluation.

Partnership matters

The research team benefited from the expertise and experience of an established non-governmental organization in taking forward patient involvement work. It is recognized that many non-governmental organizations possess grassroots knowledge of service user populations, of issues affecting service user engagement in research involvement, and are often well placed to provide access to local networks of service users for the purposes of research work. In the Telescot context, partnership working also delivered considerable resource advantages. The support of CHSS minimized many of the costs associated with development work (notably with regard to recruitment and training).

Build together

Taking time to ensure the active support and engagement of all stakeholders is a vital prerequisite to the development of a shared common purpose in project work, which, in turn, enables effective collaborative working. Care was taken to ensure that all members of the research team and the Panel participants had an opportunity to express their views and provide input into the development of the Panel initiative. In particular, the Panel was constructed in collaboration with Panel members, to ensure the development of structures which were amenable to all involved. Chest Heart & Stroke Scotland played an important role in guiding the research team in this work and in establishing this approach during the Pre-Panel induction and training course.

Clarify roles

In the Telescot context, clear role delineation between patients and professionals helped dispel apprehensions and concerns from both parties regarding joint working. The training of patients and professionals, facilitated by CHSS, also helped identify and refine the terms of reference of the Panel.

Give time

Patient involvement work is time intensive. It took the Telescot research team 6 months from project initiation to the holding the first Panel meeting. In addition to the allocation of time for the development of tangible project deliverables such as recruitment and training, it is worth building in time to support organizational adjustment and culture change to ensure the work of the patient involvement initiative is fully understood and its contribution valued.

Consider costs

Costing patient involvement work is highly recommended. Financial considerations include the resourcing of staff time both in terms of development work and on-going facilitation,

costs associated with recruitment and training, expenses arising from venue hire and refreshments, transport costs for participants, honoraria for panel members and the cost of materials used during meetings (such as printed materials, use of equipment for presentations, tools for supported communication).

Celebrate success

Developing approaches to patient involvement in clinical research can be challenging. There are few quick fixes to the establishment of sustainable, meaningful methods of patient engagement and often unexpected complexities arise in the development of project work. In this context, it is important to maintain morale by celebrating success, however, big or small, along the journey. This may be the completion of patient information materials, a successful introductory session explaining the initiative to prospective participants or the recruitment of the first patient to the involvement initiative itself. Every step moves things forward.

Conclusion

The Patient Panel was beneficial in supporting development of the Telescot feasibility trial in three key ways: it informed approaches to patient communication at all stages in the research work; it presented patient perspectives on the usability of the technology and the accompanying telemonitoring set-up; and it played an important role in the development of the qualitative work.

As with similar initiatives reported in the literature, the team identified challenges in term of time and cost implications of undertaking the work. However, the project was greatly supported by the partner organization, Chest Heart & Stroke Scotland, which generously shared expertise and resources.

Patient involvement in research development was new to the research team. A great deal of care was taken to explain the Panel approach to all stakeholders and to make project development an inclusive experience for all involved. The involvement of the Panel was transforma-

10 Telescot patient panel, P Fairbrother *et al.*

tive in terms of building confidence within the research team on the value of patient involvement in research development. The Telescot team consider the Panel approach transferable to other clinical research contexts.

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Conflict of interest

No conflicts of interest have been declared.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Stroke Voices aims and objectives.

Appendix S2. Stroke Voices Course outline.

Appendix S3. Stroke Voices: induction.

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