Patient and public involvement in emergency care research

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ABSTRACT

Patients participate in emergency care research and are the intended beneficiaries of research findings. The public provide substantial funding for research through taxation and charitable donations. If we do research to benefit patients and the public are funding the research, then patients and the public should be involved in the planning, prioritisation, design, conduct and oversight of research, yet patient and public involvement (or more simply, public involvement, since patients are also members of the public) has only recently developed in emergency care research. In this article, we describe what public involvement is and how it can help emergency care research. We use the development of a pioneering public involvement group in emergency care, the Sheffield Emergency Care Forum, to provide insights into the potential and challenges of public involvement in emergency care research.

WHAT IS PUBLIC INVOLVEMENT AND WHY IS IT IMPORTANT?

Public involvement in research is defined as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.[1] Examples include members of the public identifying research priorities, acting as members of a project advisory or steering group, developing patient information leaflets or other research materials, or undertaking the research. It is distinct from public participation in research, where people take part as subjects of a research study, and public engagement, where information and knowledge about research is disseminated to the public.

Three levels of public involvement are defined as (1) consultation, where researchers seek the views of patients and members of the public about various aspects of the research; (2) collaborative, where an ongoing partnership is created between researchers and the patient group through the research; and (3) 'user-control', where the public design and undertake the research.[1] These levels are not fixed and public involvement may develop from consultation to collaboration and then user control.

Public involvement in research probably started in the USA in the 1970s, where Rose Kusher, a freelance writer who had breast cancer, wrote a book based on a thorough review of evidence of the effects of radical mastectomy and helped inspire the work of the US National Breast Cancer Coalition.[2] Public involvement is now recognised internationally and across all specialties. In the UK, it is Department of Health policy for patients and members of the public to be involved at every stage of the research process wherever possible. In 1996, the UK National Institute for Health Research (NIHR) established INVOLVE, a national advisory group with expertise and experience in the field of public involvement in research, to promote patient and public involvement in all areas of health research. All applications for NIHR funding are now expected to describe how patients and the public were involved in developing the research proposal and how they will be involved in delivering the research. In the USA, the Patient-Centered Outcomes Research Institute (PCORI) uses the term 'engagement in research' to promote meaningful involvement of patients, caregivers, clinicians and other healthcare stakeholders throughout the research process. All applications for PCORI funding must include an engagement plan that is evaluated in the review process.

Box 1 outlines reasons for involving the public in research. Evidence suggests that public involvement improves the quality, relevance and value of research.[3,4] A systematic review of studies exploring the impact of public involvement on health and/or social care research found that public involvement enhanced the quality and appropriateness of research, and reported positive impacts at all stages of research.[3] Another systematic review of studies exploring the impact of public involvement upon service users, researchers and communities found that service users reported feeling empowered and valued, researchers developed a greater understanding and insight into their research area, and the community became more aware and knowledgeable about their condition.[4]

PUBLIC INVOLVEMENT IN EMERGENCY CARE RESEARCH

The areas with the most well-established public involvement are those focusing on disease-specific patient groups, such as patients with cancer. Such groups are clearly defined by their patient population, and are often characterised by a long-term relationship between patients and healthcare services, allowing a high level of trust and engagement to develop. This leads to a largely positive attitude towards research within these specialties, which is reflected in high levels of public engagement. According to the UK National Cancer Research Network, approximately one in four new patients with cancer take part in clinical research.[5]

Emergency care, however, is defined by its short-term nature. There is no clearly definable patient group. Everyone is a potential user of emergency care but few people would identify themselves as regular users, and those who do may be atypical. Emergency care research can be a challenging area in which to involve the public if no one identifies

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Box 1 Reasons for involving the public in research

Democratic principles

- People who are affected by research have a right to have a say in what and how publicly funded research is undertaken

Providing a different perspective

- Members of the public might have personal knowledge and experience of the research topic

Improving the quality of the research

- Public involvement can make language and content more accessible and appropriate, ensure that methods are acceptable, ensure that outcomes are measured that are relevant to the public and increase participation in research

Improving the relevance of the research

- Public involvement can identify a wider set of research topics, suggest ideas for new research areas, ensure that research is focused on the public's interests, ensure that resources are used efficiently and help to clarify the research

Adapted from INVOLVE Briefing note three: Why involve members of the public in research?[1]

themselves as potential beneficiaries of such research. This may be reflected in the levels of engagement with clinical research and failure of emergency care trials to fulfil their recruitment targets.[6] Emergency care faces many challenges that may present a barrier to successful completion of valid and relevant research.[7] Public involvement can help to address these barriers and ensure that emergency care research is ethical, practical and acceptable to patients, but first we need to develop a public involvement group.

THE SHEFFIELD EMERGENCY CARE FORUM

The Sheffield Emergency Care Forum is a public involvement group that represents patients and the public in emergency care research in Sheffield and across the UK. It has 16 members and holds quarterly meetings to discuss new research proposals and review ongoing research. It has provided public involvement for a number of major evaluations in emergency care in the UK and provides advice to medical students undertaking research degrees and PhD students. It also provides opportunities for medical students and ambulance service personnel to learn about public involvement.

Development

The founding members of Sheffield Emergency Care Forum were formerly part of the Sheffield Community Health Council, Patient Forum and Sheffield Healthwatch. Through informal contacts with the School of Health and Related Research (ScHARR) in Sheffield, the founding members were asked to provide public representation to the UWAIT study of UK ED waiting times.[8] This led to the founding members providing public representation for other projects, such as the ESCAPE multicentre trial of chest pain units,[9] the National Evaluation of Emergency Care Practitioners schemes trial of emergency care practitioners[10] and evaluation of the National Infarct Angioplasty Pilots.[11] In 2010, the two founding members were joined by three more members and a formal public involvement group was created. The forum was officially launched at a public event and the first formal meeting of the group was on 30 April 2010. Since then the forum has provided public involvement as a formally constituted group.

The founding members of Sheffield Emergency Care Forum were a health service research assistant who was nearing retirement and a retired primary school science coordinator. They were already involved as public contributors to healthcare organisations when emergency care researchers in Sheffield asked them to provide public involvement to their projects. More recent members have been recruited because they, their partners or other family members had received emergency care and they wanted to contribute to research aimed at improving emergency care. In many cases, the forum member was a woman whose husband needed emergency care and their interest grew out of their role as a carer. As a consequence, the forum has a large number of women who are retired or working part time.

Table 1 summarises the main projects that the forum has been involved in and shows how the role of the group has developed. Public involvement was initially mainly limited to reviewing patient or public facing research materials and participating in a steering or advisory committee. It has increased over time and now includes active involvement in the design of the research, involvement in project management groups, co-design and co-facilitation of research events, involvement in analysis and interpretation of findings and dissemination of research findings to the public. Recognition of the role of public representatives has also increased. Initially public representatives were acknowledged in reports or included in group authorship as members of a steering or advisory committee. Increasingly they are being recognised as coauthors of publications and co-presenters at conferences.

The forum now has a website with information about the projects undertaken and top tips for researchers (http://www.secf.org.uk). It has hosted public meetings to disseminate the findings of projects and discuss general issues in emergency care research. It has also supported the development of research careers by providing advice to medical students, doctoral students and researchers undertaking educational projects.

What does the forum offer?

Box 2 outlines the services provided by the forum. Many of the services are provided in response to specific requests from researchers but the forum is now actively engaged in promoting research in emergency care and developing research ideas. The main aims of the forum are to improve the provision of emergency care, to provide a patient perspective and to look after the interests of patients during the research process. These aims are achieved by motivated and experienced members providing the services outlined.

Boxes 3 and 4 describe two case studies. These show how public involvement through the forum helped to deliver major research projects.

Challenges

The forum has faced a number of challenges:

- Funding: members are volunteers but costs are incurred by travel, meetings and clerical support. Furthermore, public representatives should be remunerated for time spent in research meetings. The forum receives support from research grants but lacks recurrent funding. It therefore relies upon successful research applications including subsistence costs to cover public involvement.
- Knowledge of research methods: public representatives should not be expected to have research expertise, but some knowledge and understanding can help with involvement and make the process more rewarding. Members of the forum have benefitted from training courses provided by the

Table 1 Projects involving the Sheffield Emergency Care Forum

Date	Project	Funding	Patient and public involvement	PPI recognition
07/2003 to 01/2007	UWAIT: What are the organisational factors that influence waiting times in emergency departments? http://www.nets.nihr.ac.uk/projects/hsdr/081310049	NIHR Health Service and Delivery Research Programme	Reviewing research materials Member of steering/advisory group Shadowing/observing data collection Contributing to the reporting of the research Dissemination of research findings	Representative acknowledged in published report[8]
01/2004 to 08/2007	ESCAPE: multicentre evaluation of chest pain units in the NHS http://www.nets.nihr.ac.uk/projects/hsdr/081304041	NIHR Health Service and Delivery Research Programme	Member of steering/advisory group Developing participant information resources	Representative named in group authorship[9]
09/2005 to 07/2009	NEECaP: National Evaluation of Emergency Care Practitioners schemes http://www.nets.nihr.ac.uk/projects/hsdr/08151998	NIHR Health Service and Delivery Research Programme	Member of steering/advisory group Developing participant information resource	Representative acknowledged in published report[10]
02/2006 to 09/2008	NIAP: evaluation of the National Infarct Angioplasty Pilots http://www.nets.nihr.ac.uk/projects/hsdr/081604120	NIHR Health Service and Delivery Research Programme	Member of steering/advisory group Organising stakeholder group Developing participant information resources Dissemination of research findings Presentation at public meeting	Representative acknowledged in published report[11]
11/2006 to 09/2011	DAVROS: Development and Validation of Risk-adjusted Outcomes for Systems of emergency care https://www.shef.ac.uk/scharr/sections/hsr/emris/davros	Medical Research Council	Member of steering/advisory group Developing participant information resources Presentation at public meeting	Representatives named in group authorship[12]
04/2007 to 05/2011	RATPAC: Randomised Assessment of Treatment using Panel Assay of Cardiac markers http://www.nets.nihr.ac.uk/projects/hta/0630219	NIHR Health Technology Assessment Programme	Design of the research Organising stakeholder group Member of steering/advisory group Developing participant information resources	Representative named in group authorship[13]
08/2008 to 12/2013	EDiT: National Evaluation of Junior Doctor Training in Emergency Departmentshttp://www.nets.nihr.ac.uk/projects/hsdr/081819221	NIHR Health Service and Delivery Research Programme	Design of the research Member of steering/advisory group	Representative acknowledged in published report[14]
10/2009 to 10/2010	PAINTED1: pandemic influenza triage in the emergency department http://www.nets.nihr.ac.uk/projects/hta/098466	NIHR Health Technology Assessment Programme	Design of the research Member of steering/advisory group Developing participant information resources Contributing to the reporting of the research Dissemination of research findings	Representative acknowledged in published report[15]
09/2010 to 01/2014	BYPASS: comparing triage and direct transfer to specialist centres with delivery to nearest hospital http://www.nets.nihr.ac.uk/projects/hsdr/09100137	NIHR Health Service and Delivery Research Programme	Member of steering/advisory group	Representative acknowledged in published report[16]
05/2011 to 10/2013	Decision making and safety in emergency care transition http://www.nets.nihr.ac.uk/projects/hsdr/10100753	NIHR Health Service and Delivery Research Programme	Coapplicant on research proposal Design of the research Member of steering/advisory group Developing participant information resources Contributing to the reporting of the research Dissemination of research findings	Representative named as an author on published paper[17] Representative co-presented at a conference and named as an author on the abstract[18]
07/2011 to 03/2013	AHEAD: monitoring anticoagulated patients who suffer head injury https://www.sheffield.ac.uk/scharr/sections/hsr/emris/ahead	NIHR Research for Patient Benefit Programme	Coapplicant on research proposal Member of steering/advisory group Developing participant information resources Contributing to the reporting of the research Dissemination of research findings	Representative to be acknowledged on paper for submission
11/2011 to 12/2014	EASy: identification of emergency and urgent care system characteristics affecting avoidable unplanned admission rates http://www.nets.nihr.ac.uk/projects/hsdr/10101008	NIHR Health Service and Delivery Research Programme	Design of the research Member of the project management group Member of steering / advisory group Contributing to interpretation of findings	Representative named as an author on published papers[19 20] Representative presented at national conference

Continued

Table 1 Continued

Date	Project	Funding	Patient and public involvement	PPI recognition
			Contributing to the reporting of the research Dissemination of research findings Lay summary produced for public dissemination	
06/2011 to date	PhOEBE: Pre-Hospital Outcomes for Evidence Based Evaluation http://www.nihr.ac.uk/funding/fundingdetails.htm?postid=2196	NIHR Programme Grants for Applied Research	Design of the research Member of steering/advisory group Developing participant information resources Contributing to the reporting of the research Dissemination of research findings Co-designed and facilitated a PPI event	Representative presented at national conference Representative named as an author on conference presentation[21] Representative to be coauthor on paper for submission
08/2012 to date	PAINTED2: PAndemic INfluenza Triage in the Emergency Department http://www.nets.nihr.ac.uk/projects/hta/114607	NIHR Health Technology Assessment Programme	Design of the research Member of steering/advisory group Developing participant information resources Contributing to the reporting of the research	PPI representative acknowledged in published report[22]

NIHR, National Institute for Health Research; PPI, patient & public involvement.

Box 2 What does Sheffield Emergency Care Forum provide?

The principal aims of the forum are to gain improvements in health services for all patients and carers, to provide a patient perspective and to look after the interests of patients during the whole of the research process.

These are achieved by providing:

- Enthusiastic and committed members with wide-ranging knowledge of local health services, particularly in prehospital and emergency care
- Experience in the reviewing of funding proposals as lay people
- Members with links with other public involvement groups
- Ideas of how to involve more public and patients in clinical research
- Ideas for the dissemination of findings to the general public to create more interest in health service research
- Review of research proposals to determine feasibility, acceptability and relevance to patients and the public
- Review of patient and public materials, such as plain language summaries, consent forms and information sheets
- Patient and public perspectives on ethical issues
- Public representation on steering committees or management groups
- Involvement in research processes, such as identifying study participants, helping to facilitate focus groups and involvement in prioritisation or consensus processes
- Dissemination of research findings, including distributing leaflets, public meetings and media contact

local hospital and have been trained ‘on the job’ by researchers when necessary. Acquiring funding for formal training courses remains a challenge.

- Clerical work: organising meetings, maintaining the website, answering queries from researchers and providing input to grant applications all require substantial clerical work and coordination of the group. This represents a substantial burden for a volunteer coordinator. Clerical support can be provided by academic or healthcare organisations but formal adoption by an organisation could threaten the group's independence.
- Equality and diversity: the forum tries to recruit members from a diverse local population but ensuring representation from the younger, male or non-white population is challenging. The reasons for this are not clear but similar demographics are common in other voluntary organisations. The relative lack of male members may reflect more limited opportunities for men due to poorer health, later age of retirement or less involvement in part-time work.
- Communication: research is very dependent upon electronic communication and is usually undertaken by academics in institutions with excellent information technology (IT) support. Public representatives with limited IT support or literacy may struggle to engage with communication.
- Freedom of expression: public representatives need to be independent of researchers and the interventions or services they are evaluating. They expect to be able to express their opinions of research, healthcare and health services. This could be problematic if researchers were unwilling to accept criticism or organisations were concerned about bad publicity.

Box 3 Public involvement in EASy (the Emergency Admissions Study)

The EASy was funded by the UK National Institute for Health Research to explore variation in avoidable emergency admissions between different emergency and urgent care systems in England. It used mixed methods to seek explanations for variation in potentially avoidable emergency admissions. A regression model was used to identify predictors of admission rate and then in-depth case studies were undertaken in six systems to identify factors that might explain variation that was not accounted for by the model.

Members of Sheffield Emergency Care Forum:

- Commented and advised upon the initial proposal and ethical issues
- Joined the project management group
- Joined the study advisory group
- Coauthored published papers from the study[19 20]
- Wrote a plain language summary of the study findings
- Distributed the plain language summary to over 200 locations in Sheffield (medical centres, pharmacies, libraries, waiting rooms, public organisations and the Clinical Commissioning Group)
- Gave a service user presentation to a national conference on emergency admissions

Involvement in EASy went beyond the advisory role and involved delivery of the study, drawing conclusions and disseminating findings. This required different members of the forum to take on different roles. One member became part of the research team (joining the project management group, coauthoring papers and disseminating findings), while another remained independent as a member of the study advisory group.

The future

Having been successfully established the forum now faces the challenge of ensuring that it is sustainable. This will require new members joining the group and existing members taking active roles in running of the group. Funding will be required to ensure that members are not left out of pocket, which in turn requires the forum to continue to be involved in successful funding applications. Training will be required to ensure new and existing members continue to find involvement fulfilling and worthwhile. The most important requirement, however, is likely to be an emergency care research community that values and respects the role of patient and public representatives, and recognises the importance of public involvement in research.

THE FUTURE OF PUBLIC INVOLVEMENT IN EMERGENCY CARE RESEARCH

The development of the Sheffield Emergency Care Forum reflects increasing public involvement in emergency care research. Similar groups are being developed at other research centres in the UK, while priority setting in emergency medicine research in the UK involves a partnership between a professional association (the Royal College of Emergency Medicine) and a public organisation (the James Lind Alliance).[23] Many research funders expect proposals to include the public perspective and ideally to be based upon public perception of priority and need. Research regulators often regard public involvement as necessary to show evidence of respect for the dignity and autonomy of patients. Research impact may be judged in terms of public engagement and understanding of the findings. These are all good reasons why researchers increasingly need to develop ways of involving the public in their research, but the main reason is that public involvement results in better quality research.[3 4] To do so it needs to be more than just a 'tick box' exercise. It needs to ensure that members of the public are fully engaged and supported. This requires researchers to commit time and ensure appropriate support, especially in terms of funding and training. This article hopefully shows the benefits that can be achieved when public representatives are fully engaged and supported.

Box 4 Public involvement in PhOEBE (Pre-hospital Outcomes for Evidence Based Evaluation)

The PhOEBE project is a 5-year research programme which aims to develop new ways of measuring the quality, performance and impact of prehospital care provided by ambulance services. Public representatives were involved with the initial study design and were coapplicants on the funding application. A patient and public reference group was created at the outset to independently consider relevant issues and advise the research team. The public and patient reference group has three patient representatives; two from the Sheffield Emergency Care Forum and an expert patient advisor.

Members of Sheffield Emergency Care Forum (as part of the reference group):

- Commented and advised upon the initial proposal and ethical issues
- Joined the project management group
- Joined the study steering committee
- Co-designed and co-facilitated a patient and public consensus event
- Co-designed a study poster—published conference abstract[21]
- Coauthored a paper from the study (submitted)
- Wrote a plain language summary of the study findings
- Gave a service user poster presentation to a national conference

Involvement in the PhOEBE programme went beyond consultation and collaboration towards partially user-lead public involvement. The reference group worked with the research team to co-design an event to obtain public feedback on complex, little known aspects of ambulance service performance measurement. This required public representatives to use their own networks to recruit wider public participants and write a 'jargon busting' glossary of research terms and lay summaries of the performance measures. Public representatives co-facilitated small group discussions helping participants understand and engage in the event. The co-designed public event demonstrated the public representatives' high level of commitment and willingness to take on new design, facilitation and dissemination activities.

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Notes
