Patient and public involvement in emergency care research

Enid Hirst,1 Andy Irving,2 Steve Goodacre2

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
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

---

**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

---

Table 1  Projects involving the Sheffield Emergency Care Forum

<table>
<thead>
<tr>
<th>Date</th>
<th>Project</th>
<th>Funding</th>
<th>Patient and public involvement</th>
<th>PPI recognition</th>
</tr>
</thead>
<tbody>
<tr>
<td>07/2003 to 01/2007</td>
<td>UWAIT: What are the organisational factors that influence waiting times in emergency departments? <a href="http://www.nets.nihr.ac.uk/projects/hsdr/081310049">http://www.nets.nihr.ac.uk/projects/hsdr/081310049</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>Reviewing research materials Member of steering/advisory group Shadowing/oberving data collection Contributing to the reporting of the research Dissemination of research findings</td>
<td>Representative acknowledged in published report&lt;sup&gt;8&lt;/sup&gt;</td>
</tr>
<tr>
<td>01/2004 to 08/2007</td>
<td>ESCAPE: multicentre evaluation of chest pain units in the NHS <a href="http://www.nets.nihr.ac.uk/projects/hsdr/081304041">http://www.nets.nihr.ac.uk/projects/hsdr/081304041</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>Member of steering/advisory group Developing participant information resources</td>
<td>Representative named in group authorship&lt;sup&gt;9&lt;/sup&gt;</td>
</tr>
<tr>
<td>09/2005 to 07/2009</td>
<td>NEECaP: National Evaluation of Emergency Care Practitioners schemes <a href="http://www.nets.nihr.ac.uk/projects/hsdr/08151998">http://www.nets.nihr.ac.uk/projects/hsdr/08151998</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>Member of steering/advisory group Developing participant information resource</td>
<td>Representative acknowledged in published report&lt;sup&gt;10&lt;/sup&gt;</td>
</tr>
<tr>
<td>02/2006 to 09/2008</td>
<td>NIAP: evaluation of the National Infarct Angioplasty Pilots <a href="http://www.nets.nihr.ac.uk/projects/hsdr/081604120">http://www.nets.nihr.ac.uk/projects/hsdr/081604120</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>Member of steering/advisory group Organising stakeholder group Developing participant information resources Dissemination of research findings Presentation at public meeting</td>
<td>Representative acknowledged in published report&lt;sup&gt;11&lt;/sup&gt;</td>
</tr>
<tr>
<td>11/2006 to 09/2011</td>
<td>DAVROS: Development and Validation of Risk-adjusted Outcomes for Systems of emergency care <a href="https://www.shef.ac.uk/scharr/sections/hsr/emris/davros">https://www.shef.ac.uk/scharr/sections/hsr/emris/davros</a></td>
<td>Medical Research Council</td>
<td>Member of steering/advisory group Developing participant information resources Presentation at public meeting</td>
<td>Representatives named in group authorship&lt;sup&gt;12&lt;/sup&gt;</td>
</tr>
<tr>
<td>04/2007 to 05/2011</td>
<td>RATPAC: Randomised Assessment of Treatment using Panel Assay of Cardiac markers <a href="http://www.nets.nihr.ac.uk/projects/hta/0630219">http://www.nets.nihr.ac.uk/projects/hta/0630219</a></td>
<td>NIHR Health Technology Assessment Programme</td>
<td>Design of the research Organising stakeholder group Member of steering/advisory group Developing participant information resources</td>
<td>Representative named in group authorship&lt;sup&gt;13&lt;/sup&gt;</td>
</tr>
<tr>
<td>08/2008 to 12/2013</td>
<td>EDIT: National Evaluation of Junior Doctor Training in Emergency Departments <a href="http://www.nets.nihr.ac.uk/projects/hsdr/081819221">http://www.nets.nihr.ac.uk/projects/hsdr/081819221</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>Design of the research Member of steering/advisory group</td>
<td>Representative acknowledged in published report&lt;sup&gt;14&lt;/sup&gt;</td>
</tr>
<tr>
<td>10/2009 to 10/2010</td>
<td>PAINTED1: pandemic influenza triage in the emergency department <a href="http://www.nets.nihr.ac.uk/projects/hta/098466">http://www.nets.nihr.ac.uk/projects/hta/098466</a></td>
<td>NIHR Health Technology Assessment Programme</td>
<td>Design of the research Member of steering/advisory group Developing participant information resources Contributing to the reporting of the research Dissemination of research findings</td>
<td>Representative acknowledged in published report&lt;sup&gt;15&lt;/sup&gt;</td>
</tr>
<tr>
<td>09/2010 to 01/2014</td>
<td>BYPASS: comparing triage and direct transfer to specialist centres with delivery to nearest hospital <a href="http://www.nets.nihr.ac.uk/projects/hsdr/09100137">http://www.nets.nihr.ac.uk/projects/hsdr/09100137</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>Member of steering/advisory group</td>
<td>Representative acknowledged in published report&lt;sup&gt;16&lt;/sup&gt;</td>
</tr>
<tr>
<td>05/2011 to 10/2013</td>
<td>Decision making and safety in emergency care transition <a href="http://www.nets.nihr.ac.uk/projects/hsdr/10100753">http://www.nets.nihr.ac.uk/projects/hsdr/10100753</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>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</td>
<td>Representative named as an author on published paper&lt;sup&gt;17&lt;/sup&gt; Representative co-presented at a conference and named as an author on the abstract&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>07/2011 to 03/2013</td>
<td>AHEAD: monitoring anticoagulated patients who suffer head injury <a href="https://www.sheffield.ac.uk/scharr/sections/hsr/emris/ahead">https://www.sheffield.ac.uk/scharr/sections/hsr/emris/ahead</a></td>
<td>NIHR Research for Patient Benefit Programme</td>
<td>Coapplicant on research proposal Member of steering/advisory group Developing participant information resources Contributing to the reporting of the research Dissemination of research findings</td>
<td>Representative to be acknowledged on paper for submission</td>
</tr>
<tr>
<td>11/2011 to 12/2014</td>
<td>EASY: identification of emergency and urgent care system characteristics affecting avoidable unplanned admission rates <a href="http://www.nets.nihr.ac.uk/projects/hsdr/10101008">http://www.nets.nihr.ac.uk/projects/hsdr/10101008</a></td>
<td>NIHR Health Service and Delivery Research Programme</td>
<td>Design of the research Member of the project management group Member of steering / advisory group Contributing to interpretation of findings</td>
<td>Representative named as an author on published papers&lt;sup&gt;19, 20&lt;/sup&gt; Representative presented at national conference</td>
</tr>
</tbody>
</table>

Continued
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.

### Table 1

<table>
<thead>
<tr>
<th>Date</th>
<th>Project Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>06/2011 to date</td>
<td>Contributing to the reporting of the research</td>
</tr>
<tr>
<td></td>
<td>Lay summary produced for public dissemination</td>
</tr>
<tr>
<td></td>
<td>Design of the research</td>
</tr>
<tr>
<td></td>
<td>Member of steering/advisory group</td>
</tr>
<tr>
<td></td>
<td>Co-designed and facilitated a PPI</td>
</tr>
<tr>
<td>08/2012 to date</td>
<td>Contributing to the reporting of the research</td>
</tr>
<tr>
<td></td>
<td>Lay summary produced for public dissemination</td>
</tr>
<tr>
<td></td>
<td>Design of the research</td>
</tr>
<tr>
<td></td>
<td>Member of steering/advisory group</td>
</tr>
<tr>
<td></td>
<td>Contributing to the reporting of the research</td>
</tr>
</tbody>
</table>

### 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

▸ Public representation 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

<table>
<thead>
<tr>
<th>Date</th>
<th>Project Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>06/2011 to date</td>
<td>Contributing to the reporting of the research</td>
</tr>
<tr>
<td></td>
<td>Lay summary produced for public dissemination</td>
</tr>
<tr>
<td></td>
<td>Design of the research</td>
</tr>
<tr>
<td></td>
<td>Member of steering/advisory group</td>
</tr>
<tr>
<td></td>
<td>Co-designed and facilitated a PPI</td>
</tr>
<tr>
<td>08/2012 to date</td>
<td>Contributing to the reporting of the research</td>
</tr>
<tr>
<td></td>
<td>Lay summary produced for public dissemination</td>
</tr>
<tr>
<td></td>
<td>Design of the research</td>
</tr>
<tr>
<td></td>
<td>Member of steering/advisory group</td>
</tr>
<tr>
<td></td>
<td>Contributing to the reporting of the research</td>
</tr>
</tbody>
</table>

NIHR, National Institute for Health Research; PPI, patient & public involvement.
Recognises the importance of public involvement in research and respects the role of patient and public representatives, and likely to be an emergency care research community that values worthwhile. The most important requirement, however, is ideally to be based upon public perception of priority and need.

Funders expect proposals to include the public perspective and requires the forum to continue to be involved in successful funding applications. Training will be required to ensure that members are not left out of pocket, which in turn ensures that members of the public are fully engaged and supported. 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). 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. 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.

**Twitter** Follow Andy Irving at @irvingad82

**Acknowledgements** We thank Alicia O’Cathain, Janette Turner and Sue Mason for their comments on this paper.

**Contributors** SG conceived the idea for the paper. EH collected information about SECF. All three authors contributed to writing the paper and approved the final draft.
Competing interests None declared.

Provenance and peer review Not commissioned; internally peer reviewed.

REFERENCES
Patient and public involvement in emergency care research

Enid Hirst, Andy Irving and Steve Goodacre

Emerg Med J published online April 4, 2016

Updated information and services can be found at: http://emj.bmj.com/content/early/2016/04/04/emermed-2016-205700

These include:

References

This article cites 16 articles, 10 of which you can access for free at: http://emj.bmj.com/content/early/2016/04/04/emermed-2016-205700#BIBL

Email alerting service

Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Notes

To request permissions go to: http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to: http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to: http://group.bmj.com/subscribe/