Making patient and public involvement in cancer and palliative research a reality: academic support is vital for success

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ABSTRACT

Objective Patient and public involvement (PPI) has become an established theme within the UK health research policy and is recognised as an essential force in the drive to improve the quality of services and research. These developments have been particularly rapid in the cancer field.

Methods This paper outlines a model of PPI in research (known as the North Trent Cancer Research Network Consumer Research Panel, NTCRN CRP; comprising 38 cancer and palliative care patients/carers) and the key benefits and challenges to effective PPI in cancer research.

Results The PPI model has become a sustainable, inclusive and effective way of implementing PPI within the cancer context. Challenges include (1) a lack of time and funding available to support the PPI model; (2) tensions between different stakeholder groups when developing and conducting health research; (3) panel members finding it difficult to effectively integrate into research meetings when their role and contribution is not made clear at the outset or when unfamiliar language and jargon are used and not explained; (4) some professionals remain unclear about the role and practical implications of PPI in research. However, notwithstanding its financial and organisational challenges, the way that the NTCRN CRP is supported has provided a solid base for it to flourish.

Conclusions PPI provides considerable opportunities for patients and the public to work collaboratively with professionals to influence the cancer research agenda, with the contribution of PPI to the research process being integral to the entire process from the outset, rather than appended to it.

PATIENT AND PUBLIC INVOLVEMENT IN HEALTH RESEARCH IN THE UK

Over the past 10–15 years, patient and public involvement (PPI) has become an established theme within the UK health research policy[1–3] with PPI being recognised as an essential force in the drive to improve the quality of services and research. These developments have been particularly rapid in the cancer field, where there have been several initiatives to promote PPI in cancer research.[4] [5] PPI in research can be conceptualised as, "doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public."[2] Three main levels of PPI have been identified:

1. Consultation (where researchers seek the views of the public on key aspects of the research);
2. Collaboration (an ongoing partnership between researchers and the public throughout the research process);
3. 'Publicly-led' (where the public designs and undertakes the research and where researchers are only invited to participate at the invitation of the public).[2]

The UK policy commitment to PPI in research can be seen in a number of respects: (1) the establishment of INVOLVE in 1996, to promote PPI in research in England[2]; (2) the requirement that researchers submitting bids to funders such as the National Institute for Health Research (NIHR) demonstrate that the public should be actively involved in any funded research[3] and (3) the establishment of regional NIHR Research Design Services that are responsible for bringing clinicians, academics and members of the public together to develop research ideas into fully developed protocols and grant applications.[3]

Underpinning this policy commitment, the case for PPI in research rests on three main arguments[4]—(1) it is morally and ethically correct; (2) it has potential benefits in terms of improving the quality, relevance and impact of health research; and (3) it is theoretically and practically justified.

The North Trent Cancer Research Network model of PPI

There are currently different models and approaches to PPI in research.[4] The model developed within the North Trent Cancer Research Network (NTCRN),[5 6] known as the North Trent Cancer Research Network Consumer Research Panel—NTCRN CRP, was the first of its kind to be established at the local level within the UK. This panel was instituted 12 years ago in order to: encourage cancer and palliative patients and carers to engage with health professionals and academics; and to provide the opportunity for patients to influence the research agenda and to contribute to the research process from the outset—from the generation of research questions, through protocol development and offering advice on issues such as ethics and patient recruitment, through full involvement as coresearchers, copresenters at conferences and coauthors of peer-reviewed papers.[5]

A feature of the NTCRN CRP's success has been its support from the outset by academia. It was originally developed by the Academic Unit of Supportive Care in the University of Sheffield's Medical School. It is now also supported by the Centre for Health and Social Care Research in the Faculty of Health and Wellbeing at Sheffield Hallam University. Thus the CRP is validated and nurtured, at professorial level, by both biomedical and health services research cultures.

Since its inception, the panel has grown and now undertakes PPI activities in four key domains which include Public Conferences and Engagement, Portfolio Management, Study Involvement and Research Governance (table 1 and http://www.ppihr.org.uk/).

This model has been replicated in other UK cancer networks and is currently held up as a beacon of good practice by the National Cancer Research Network and INVOLVE. Such panels provide an important

Table 1 Examples illustrating panel member current involvement and activities

European Union (EU)	
Study Involvement	INTEGRATE-EU, re palliative care across the EU
National	
Public Conferences and Engagement	NCRI conference Liverpool INVOLVE conference
Portfolio Management	James Lind Priority Setting Partnership NHS Head and Neck Oncology Group (DAHNO) NHS England Clinical Reference Group for Chemotherapy
Study Involvement	National Cancer Survivorship Initiative (NCSI) NIHR Programme Grant 'Bridging the Age Gap in Breast Cancer' MRC QUARTZ Trial (Quality of Life and Whole Brain Radiotherapy-for Multiple Brain Metastases) ENT-UK and Head and Neck 5000 working with the James Lind Alliance SMP2 National Matrix Study Review Panel And others
Research Governance	Stratified Medicines Governance Board MRC Review Body for use of Human Biological Material HRA consultation process on research governance HRA consultation on use of NHS data Breast Cancer Campaign Tissue Bank
Regional	
Public Conferences and Engagement	BME Network and Transformational Survivorship Project Focus Group
Portfolio Management	North Trent Network Site Specific Group (BC NSSG) North Trent Network Site Specific Group (Head and Neck NSSG)
Study Involvement	Studies both local, regional and national funded by the NIHR, Charities and local funding bodies
Research Governance	Trent Cancer Registry management group North Trent Cancer Network Patient Partnership Group South Yorkshire Patient and Public Strategic Planning Group. CLRN, CLAHRC and RDS Collaborative YCR/CRUK Sheffield Cancer Research Centre Steering Group
Local	
Public Conferences and Engagement	Sheffield University School of Law—consultation about use of data
Portfolio Management	North Trent Cancer Research Network Clinical Trials Executive
Study Involvement	SarCaBon—Saracatanib as a novel analgesic for cancer-induced bone pain FOCCUS—Focus on Cancer Chemotherapy and Unwanted SideEffects (London) And others
Research Governance	Sheffield Experimental Cancer Medicine Centre (ECMC) Executive Committee Sheffield Cancer Biobank Sheffield Ethics Committee

opportunity for the public to get actively involved in the design and delivery of health research projects by way of being 'experts by experience'.[6]

Benefits and challenges of PPI

A key challenge for those engaged in PPI is to demonstrate the value-added nature of its impact on research processes and outcomes. It is difficult to assess objectively the impact of PPI on the nature, quality, relevance and effectiveness of health research.[7–9] Findings from a recent systematic review of PPI[7] reported that although the evidence comprised mainly of qualitative or case study reflections and cross-sectional studies reporting individual or organisational views of PPI but with relatively little critical evaluation. Nevertheless, positive PPI impacts on research were apparent such as the importance of PPI in identification and prioritisation of research, developing patient-focused research questions, commenting on research protocols, developing research instruments, adapting and improving the sensitivity of research language in patient information sheets and invitation letters, and identifying poor logic and poorly worded questions in draft questionnaires.[7] Additionally, the review found that PPI helped to foster important links with the community, which in turn helped researchers to access participants and improve response rates (including recruitment rates from seldom heard groups).[7]

Challenges faced by the NTCRN CRP model of PPI

Challenges specific to the NTCRN CRP can be summarised as follows:

1. A lack of time and funding available to both the academics facilitating the panel (KC/SHA) and panel members themselves. In recent years the panel has had to make annual pleas to different sources to support panellist work. The panel has relied primarily on the altruism of patients to undertake numerous panel-related activities on a voluntary basis. One would argue that this particular panel has been fortunate as several similar panels have folded due to the lack of financial support. However, the authors argue that if PPI is central to our current UK government health research agenda, funding should be made available to enable many other successful initiatives nationally following the model outlined, so that patient involvement can be sustained, valued and recognised;
2. Although there has been a gradual recognition of the value of PPI within cancer research, tensions still remain between different stakeholder groups when developing and conducting health research; furthermore, researchers have reported concerns about the level of understanding of the public of certain health research methods (in particular the rationale for including PPI in biomedical, especially preclinical, research;
3. Members of the panel find it difficult to effectively integrate into research meetings when their role and contribution is not made clear at the outset or when unfamiliar language and jargon are used and not explained;
4. Some professionals are still unclear about the practical implications of involving the public in research; and researchers may voice concerns that those members of the public who get involved in research may not necessarily be representative of potential research participants. However, lay advocates correspondingly argue that individual professionals who take part in research are not representative of their professions or disciplines.

Additionally, several commentators are critical of the ability of patients, carers and service users to provide objective scientific critiques of research, arguing that they can only provide a non-scientific subjective view, based on their individual, highly variable experiences, which runs counter to the medico-scientific paradigm of knowledge development.[10] Addressing the issue of representativeness, Boote *et al*[4] argue that although individual patients or the public cannot be assumed to represent the views of all members of a particular patient group, their incorporation into a research team can provide an added dimension to the conduct and outcome of a research project which would otherwise be lacking and possibly ineffective. The challenges to PPI raised in this paper can be addressed by professionals and academic researchers providing the following to patients and service users: an outline of what contribution to the study that the PPI member can make; a lay summary of the planned research project at the start of their involvement; a glossary of key terms; ongoing guidance and support; and an environment of mutual respect.[4]

SUMMARY

In conclusion, PPI in research is now an established theme within the UK health research policy, with a number of different models and approaches to PPI emergent. Despite its challenges, PPI provides considerable opportunities for cancer and palliative care patients, carers and the public to work collaboratively with professionals and researchers to influence the research agenda, with the contribution of PPI to the research process being integral to the entire process from the outset, rather than appended to it. It is also important that professionals and researchers who are considering PPI in their research should seek guidance from professionals and organisations who have substantial expertise in this field (eg, INVOLVE, the NIHR Research Design Services) to ensure good practice and to optimise mutual benefit from all PPI activity. Finally we commend the NTCRN CRP model as a sustainable, inclusive and satisfying way of implementing PPI, at least in a cancer context. Notwithstanding its financial and organisational challenges, the way that the NTCRN CRP has continuing academic support in the city's two universities has provided a solid base for it to flourish.

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