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Can Consumer Research Panels form an effective part of the cancer research community?

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Abstract

The North Trent Cancer Research Network's Consumer Research Panel (NTCRN CRP) was

established in December 2001 by the Academic Unit of Supportive Care at the University of Sheffield. In three years, the CRP has succeeded in nurturing a climate of sustainable consumer involvement within the NTCRN and this has become embedded in the culture of the network. Furthermore, the panel have championed a sustainable development of consumer involvement in health and social care research by testing new ground and forging a new way of working between health professionals and patients and carers. The CRP model has been held up as an example to other cancer networks, with new panels being set up around the country to emulate its success. This paper describes the Sheffield model of patient and public involvement and using the eight key principles of successful consumer involvement in research, identified in a recent paper by Telford et al (2003), provides a useful framework for analysing the work of the Panel. This demonstrates how consumers and professionals can inform each other to work constructively and synergistically to achieve impressive research results. The need for measurable outcomes to assess the impact and effect of consumer involvement is finally explored.

Introduction

The recent consultation document issued by the Department of Health, 'Best Research for Best Health: A new National Health Research Strategy'[1], stressed that research should be patient-centred and more responsive to the needs of patients. The document was also highly supportive of increased public involvement in research, reinforcing a position expressed in many previous policy documents [2-5], including the Cancer Plan [6]. In addition, many organisations have advocated that the public should have a role in the research process – including the National Cancer Research Institute (www.ncri.org.uk), the Medical Research Council (www.mrc.ac.uk), the Health Technology Assessment Programme (www.nchta.org) and the Cochrane Collaboration(www.cochrane.no/consumers) Furthermore, the Research Governance Framework for Health and Social Care [7] also made explicit reference to consumer involvement and its continued importance in NHS R&D. Pragmatically, funding bodies like CTAAC (Clinical Trials Advisory and Awards Committee) and the Population and Behavioural Sciences Committee of Cancer Research UK have explicitly stated that consumer involvement is a key requisite of a successful application.

The North Trent Cancer Research Network Consumer Research Panel (NTCRN CRP)

In 2001, in response to the increasing policy initiatives to promote consumer involvement in research, the Academic Unit of Supportive Care (AUSC) based at the University of Sheffield was successful in securing £5,000 from the North Trent Cancer Research Network (NTCRN) to initiate funding of an innovative model of consumer involvement in health research. This initiative became known as the North Trent Cancer Research Network Consumer Research Panel (NTCRN CRP) and was the first of its kind in the UK. This panel has now been in operation for almost four years and it is made up of forty former and current cancer and palliative care patients and carers from diverse backgrounds. These patients and carers have a variety of different types of cancer including breast, lung, prostate, oesophageal, colorectal and myeloma, with some members having metastatic disease. Their ages range from 35 to 75 years and they come from all areas within North Trent. Due to increased expressions of interest to join the panel, an associate membership scheme has recently been included to ensure that patients and carers are able to provide 'virtual' input on the panel by written correspondence or email. The main aim of the CRP

is to increase, where appropriate, the engagement of consumers of cancer care in the whole research process – from generation of research questions, through protocol development and advice on issues such as ethics and patient recruitment, to actual consumer participation as researchers, presenters and co-authors of peer-reviewed papers.

The Work of the Panel

The eight key principles of successful consumer involvement in research, identified in a recent paper by Telford et al [8], provide a useful framework for analysing the work of the Panel and each principle will be discussed in turn.

Principles 1 – The roles of consumers are agreed between the researchers and consumers involved in the research.

There has been considerable commitment and enthusiasm towards the development of the CRP both from panel members and from the health professionals working in the AUSC and the NTCRN. The role of effective communication and information exchange between health professionals, researchers and the consumer panel members has been central to the work of the CRP. The effort by both parties to improve communication and information exchange has helped to create an environment of trust, mutual respect and understanding and has helped to minimise some of the challenges to consumer involvement in health research thus allowing new ideas to emerge and different ways of working to be implemented.

Establishing the CRP gave rise to a number of challenges that initially inhibited effective working. For example, the principle of former and current patients and carers working alongside health professionals on research teams and committees was a new experience for both parties. There is some evidence that, at the outset, both groups were wary of working together, with neither sure of each other's roles and responsibilities or of the skills, expertise and understanding required to successfully establish consumer involvement in the research process. There were initial concerns by consumer members that they would not be able to contribute anything significant to the research process and some felt unable to vocalise their views in the presence of medical 'experts'. Some members were also concerned that their role was as a 'token' consumer. Not all health professionals welcomed consumer involvement in their work. Some felt that consumers were 'unrepresentative', they had 'their own agendas' and did not reflect the 'true' voice of the patient.

However, since the early days of the CRP, mechanisms have been put in place to understand and tackle such difficulties (including the provision of support and training, mentoring of new members, and role descriptions for consumers) that have helped to address some of the challenges of collaborative working. It has been essential to ensure members are carefully recruited onto the panel and they understand their roles and responsibilities as representatives of the panel. Having an understanding of medical language and terminology and the structure and role of the NTCRN has improved the confidence of consumer members to feel able to articulate their views and perspectives in medically dominated research or strategy meetings.

Principle 2 – Researchers budget appropriately for the costs of consumer involvement in research.

Members are paid £7 per hour for engaging in the research process (maximum £50 per day) although some members choose to work on the panel voluntarily. The budget for the panel has been small (2001/2 £5,000, 2002/3 £5,000, 2003/4 £5,000, 2004/5, £11,000, 2005/6 £11,000), and this has meant that the time required to facilitate and develop the panel has proved challenging with the limited resources allocated.

Principle 3 – Researchers respect the differing skills, knowledge and experience of consumers.

Health professionals have recognised that the language used within committee meetings and research project meetings may be a potential barrier to effective communication between the professional and the consumer and this has been overcome by the sensitive use of translating medical terms into non specialist language and by explaining specific procedures or technologies. The AUSC have worked to ensure that the health professionals clarify, at the outset, the role of consumer members on research projects, acknowledging that each consumer representative will bring a unique perspective and make explicit the roles that health professionals themselves have in guiding the consumer through the process. Professor Hancock (Yorkshire Cancer Research Director of Cancer Research) sums up his views of this aspect of the CRP's work:

“The CRP has achieved most by making clinicians aware of the important role of consumers on local, network and national committees. It has also helped to dispel the suspicion that research professionals have regarding what they see as ‘uninformed interference’ and personal agendas.”

Principle 4 – Consumers are offered training and personal support to enable them to be involved in research.

Training is one of the key elements in successful consumer involvement and from the inception of the panel in 2001, all new members joining the CRP attend a two-day induction research training programme. The aims of the training programme are to provide:

- an introduction and background to consumer involvement in health research
- an overview of the structure and role of the NTCRN and supportive and cancer research nationally
- an overview of the role of the CRP
- a basic grounding in research methodology (quantitative and qualitative) and terminology
- examples of funded research studies where consumers have been actively involved

Both the CRP training and the specifically produced supporting literature (*CRP Introduction Handbook* and *Overview of Cancer Research Handbook*) have proven very effective and requests for these documents have been received from many health care professionals working across the UK.

Principle 5 – Researchers ensure that they have the necessary skills to involve consumers in the research process.

Members of the CRP work alongside cancer and palliative care research teams, health professionals and professional bodies to provide a user perspective at any or all stages of research projects (including local and national clinical trials), where this is appropriate. This has necessitated a significant cultural change among health professionals:

“Members of the CRP contribute to every stage of research in our department. We no longer as clinicians have to imagine what our patients or their family would think about our studies and we can inform research ethics committees about the views of real consumers before we start. It works because they are with us at every step instead of passing judgement when plans for research are already worked up and changing them would be very wasteful of resources.” (Dr Noble Consultant Macmillan Physician and Senior Lecturer in Palliative Care, The University of Sheffield)

The involvement and integration of consumers into the NTCRN culture is an excellent demonstration of how a relatively simple model of involvement can result in effective communication and information exchange between health professionals and CRP members.

The CRP has become a sustainable part of the NTCRN's core work. Indeed the NTCRN in their Annual Report [9] to the National Cancer Research Network stated that *‘the involvement of consumers in North Trent has been the biggest initiative in the last 12 months, building on the solid foundations laid over the last two years...Consumers are now an integral part of the network. We consider ourselves to be the leaders in consumer involvement.’* Professor Coleman, Clinical Lead for Research, North Trent Cancer Research Network has argued that:

“The CRP has provided an important additional dimension to the vision of our network in ensuring that the opportunity to participate in clinical trials becomes a standard of care across the range of tumour types. The patient perspective and advice from CRP members on communicating the aims of individual trials through clearly written protocols and appropriately written patient information have been invaluable.” [9]

Principle 6 – Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research.

Two CRP members are currently involved in a Cancer Research UK study ‘Patient and professional factors influencing choice of surgery in the management of breast cancer.’ These members have worked alongside breast surgeons and researchers and have been involved in all stages of the study, and recommended several modifications to the way that patients were recruited into the study. Members have also collaborated with the research team to design patient information sheets, interview schedules and questionnaires. They have recently been assisting the team in analysing and interpreting qualitative data gained during the study.

Principle 7 – Consumer involvement is described in research reports.

Consumers have presented papers at local, regional and national conferences. Consumers are assisting in analysis and dissemination and have contributed to publications [10,11]

Principle 8 – Research findings are available to consumers, in formats and a language they can easily understand.

CRP members have been involved in the editing and review of reports prior to publication. They have also been co-authors of research publications and presentations. Given the expansion of the panels activities and the need to disseminate information the CRP have designed their own website (ntcrp.org.uk) and have recently launched their first quarterly newsletter. The aim of this newsletter to promote communication and effective information exchange between health professionals, researchers and consumers

As well as individual members being involved in a number of research projects (see below), members are also asked to attend the CRP ‘business meeting’ four times a year. This meeting provides a forum for members to meet and share the work they are undertaking on behalf of the panel, to discuss particular successes or difficulties relating to being involved as consumers on research projects, to generate new research ideas, discuss further training needs and it also acts as a forum for the research fellow from the AUSC to disseminate information about new research projects or activities where CRP input is being sought. The CRP uses three main tools of communication to further its purpose –

1. Consumer-chaired meetings to discuss business, research proposals and to plan an annual national conference
2. A consumer-designed website and newsletter which are supported by the academic unit
3. Many local, regional and national representations and talks involving consumers, health professionals and academics.

One of the panel members summarises what the panel means to its members:

“The formation of the Consumer Research Panel has enabled patients/carers to become more involved in different areas of cancer care and research by giving the group and individuals the confidence, information and opportunities to be able to contribute at all levels. There are enormous benefits of being part of a panel rather than being an individual representative. The training and support are invaluable creating a very professional team who have the ability to share their skills and experiences in areas they did not previously have access to. Consumers have responded very positively and enthusiastically to invitations to join project teams. We have been made to feel very welcome and a valued member of any team. It is a wonderful opportunity to give something back and hopefully make a difference” (CRP member).

CRP involvement on research studies

Within the North Trent Cancer Research Network, CRP members have been involved in many projects, and at different stages. Examples are provided below.

1. Identifying and prioritising research topics

Two CRP members represent the CRP at the Supportive and Primary Care Oncology Research Group (SPORG) (which is funded by the NTCRN). SPORG is a funding forum for the exchange of views about research projects on supportive and primary care research. The projects focus on all aspects of communication process between patients and health professionals and determination of the extent that this process influences treatment decisions, entry into clinical trials, clinical outcomes and patient enablement. For example, members of the CRP identified the need for a study that explored ways of improving clinical consultations in order to help patients to cope and understand their illness. This idea was put to the Supportive and Primary Care Oncology Research Group (which is funded by the NTCRN) by two CRP members and this was taken up by the group. Thereafter, CRP members worked alongside a palliative care consultant to develop the proposal. ‘Improving clinical consultations: a survey of clinics in the North Trent Cancer

Research Network.’ This was subsequently funded by SPORG in 2003 and is currently being written up. Two CRP members have been actively involved in this study as members of the steering group.

2. Commissioning research projects

Two CRP members represent the CRP at a monthly NTCRN Clinical Trials Executive. This is a forum for the presentation of new trials and research studies which are presented by principle investigators. The CRP member role is to work alongside health professionals and academic researchers to peer review and discuss research proposals in light of their understanding from the perspective of a patient or carer, before deciding as a group whether approval is or is not given for the trial to go forward for ethics and research and development approval

3. Designing and managing projects

CRP members are involved in a project ‘Patient-led Integrated Supportive Care Evaluation Study’ funded from the Department of Health that originated in response to Guidance on Supportive Care Services recently published in the National Institute for Clinical Excellence. Its purpose is to map the provision of supportive care services in Sheffield and assess the extent to which they fulfil the requirements of the NICE guidance. The project steering group comprises of consumers, clinicians/researchers. Consumer members have been involved in every stages of the research process including data collection and analysis and they are currently involved in writing up the study.

CRP members are also working together on developing a ‘user led’ project, with a specific research question – the costs of cancer treatments borne by patients.

“We are currently embarking on the ultimate step which would be for consumer research ideas to be fully worked up into research projects and clinical trials. We would hope that in the near future, some of the research ideas which have come from our members will be fully investigated and result in positive help and support for the dedicated staff and deserving patients in the health service.” (David Ardron, CRP Vice Chair)

As noted above, consumers have also been involved in analysing and interpreting data, and contributing to articles that have been subsequently published in peer-reviewed journals.

4. Disseminating and implementing research findings

Consumer members are also involved in the organisation and planning of a unique national annual consumer conference held in Sheffield on all aspects of cancer and supportive and palliative care. This event is always well attended (in excess of 200 delegates). It is unique in that it brings together health professionals, researchers and members of the public. The aim of the conference is to increase the profile of consumer involvement in health and social care in research nationally and to enhance communication and information exchange between health professionals and the public to ensure that people who use services are involved in and can influence the development of cancer services, practices and research in North Trent.

“The Research Open-Days held annually in Sheffield provide an almost unique opportunity in this country where users and professionals demonstrate an openness and transparency that is both refreshing and exciting.” (Derek Stewart, former Chair of NCRI Consumer Liaison Group)

The themes that arise from the sessions between health professionals/researchers and the public are thereafter used to inform the research agenda within the Cancer Network [12]. For example, as a result of a call from consumers at this conference for patients’ consultations to be audio taped, three consultants working in North Trent took action at once and were among the first consultants to meet the demand for recordings of their consultations. The availability of taped recordings of consultations has since been added to the guide (Your Guide to Cancer Services in Sheffield: information for patients, their families, carers and friends, 2nd edition, June 2003) given to all patients receiving cancer treatment within North Trent.

Links with other organisations

Panel members are frequently asked to provide their views and expertise as panel members on their experiences of being involved in health research at local and national research forums and conferences. In order to take consumer involvement in cancer and supportive care research forward and contribute at a broader level, the CRP has established and strengthened links with a number of national and regional cancer organisations and groups across the UK. CRP members have been invited to join a number of influential groups as consumer members (such as the National Cancer Research Institute Breast Cancer Clinical Studies Group, the National Cancer Research Institute Lung Cancer Clinical Studies Group, **the National Cancer Research Institute Palliative Care Studies Development Group** and the National Cancer Research Institute **Strategic Planning Group on PET Scanning**, NCRN Macmillan Steering Group and the National Translational Cancer Research Co-ordinating Centre (NTRAC). The research fellow (Dr Karen Collins) who voluntarily (facilitator post non funded) provides support, guidance and training to panel members is also regularly contacted by health professionals and academic researchers working across the UK and asked to present to health professionals on the process of setting up consumer research panels and to explain what training is required in order that health professionals and patients/carers can meaningfully engage in constructive dialogue in order to enhance consumer involvement in health research (e.g. Sheffield Health and Social Research Consortium, Trent Research Development Support Unit). Further more, national pharmaceutical companies are aware of the profile of the panel and have contacted the panel facilitator to request advice on involving consumers in the pharmaceutical industry to initiate meetings between the panel and these companies to set up exploratory meetings on potential collaborative working and incorporate the panel into their work. As a result of Dr Collins’ work on the panel, in 2004 she was appointed to INVOLVE (an advisory body to the Department of Health to promote consumer involvement in health , social care and public health research) and also encouraged panel members to participate in the conference held by INVOLVE in order to maximise good working practice within the panel.

What have been the measurable outcomes?

It is difficult to assess objectively the impact of the CRP on the nature, quality and extent of cancer research within the NTCRN. Many commentators have noted that there has to date been no systematic evaluation of the benefits or otherwise of consumer involvement in research, and this is urgently required. Key questions, which as yet remain unanswered, include defining the policy

drivers for consumer involvement in research, ascertaining the relative significance of each and identifying outcome measures to assess the impact and effect of participation.

The ethical argument that consumers should be involved in the research processes – as such studies may have an impact upon their own and others health, has often been stated. However, such an argument implies that it is already known that all consumer involvement is a good thing – whereas there is some evidence for example, to show that participation can be disempowering for consumers, and that some consumers have overly high expectations about the effects of their input and about outcomes from single studies and are dissatisfied with the process [11].

There is a temptation to say that the gathering evidence based upon specific criteria is neither necessary nor sufficient. If there is only concern about process factors (such as openness, accountability, numbers of consumers involved), then any subsequent effects on research outcomes are irrelevant. Similarly, if it is accepted that the drivers are essentially political in nature, then the requirements for evidence are similarly reduced. Finally, in regard to ethics, some commentators have suggested that it is not within the remit of a scientific enquiry to investigate ethically driven policies such as the involvement of consumers in research.

Despite these challenges, the CRP is now attempting to assess and evaluate the changes resulting in cancer and palliative research studies and advisory group meetings occurring as a direct result of consumer involvement and to map, using specifically designed evaluation forms the perceived role, expectations and activities of the consumer members against those of the health professionals/researchers. This work will provide essential information on the value of incorporating consumers in various stages of the research process. The process serves as a useful tool to identify any difficulties as they arise from health professionals and consumers working together. Furthermore, since, these evaluation and feedback forms were introduced, a number of organisations have requested permission to adapt the evaluation tool for their own use (e.g. The Sheffield Health and Social Research Consortium (a collaboration between Sheffield's two Universities, four Primary Care Trusts, Social Services and Trent Focus which exist to ensure scientific research is well supported within social services and the NHS outside hospitals). Thus, the CRP has been effective in sharing and disseminating information about the process of consumer involvement in health research and such sharing of ideas across organisations has resulted in the NTCRN CRP becoming recognised as a panel promoting good practice in consumer involvement.

However, CRP members are now seen as essential representatives of local research teams and on local and national strategic groups and committees, with a standing equivalent to the health professionals on those bodies. The CRP model is being replicated in other cancer networks across the UK; and is viewed as a model of good practice by national consumer advisory group (INVOLVE). NTCRN CRP training packs are being used across the UK, members of the CRP have been invited to conduct presentations at local and national events, and there have been five successful annual CRP national conferences. Development of the CRP website, newsletters, logos, initiation of user led projects, dissemination of CRP guides and annual reports to all cancer networks across the UK to assist with development of consumer involvement initiatives, collaboration with national bodies including NCRI, NTRAC, INVOLVE). The AUSC and CRP members have remained committed and enthusiastic to the developments of the panel and

frequently work voluntarily to promote the concept of consumer involvement in cancer and palliative care research across the UK. The panel are now very keen to move forward 'user led' research projects in cancer and palliative care and additional resources are required to support the development of such initiatives.

Conclusions

The NTCRN CRP is an excellent demonstration of how patients/carers and health professionals can work together to increase effective consumer involvement in health and social care research. It has increased the dialogue and communication between health professionals and patients and carers, and engendered significant cultural and organisational change. The CRP has succeeded in providing a forum for cancer and palliative care users and carers who are wishing to become actively involved in cancer and palliative research. It has given a real 'voice' to users of the health service, enabling their opinions to be fully considered and fed into the research process. It has also provided a unique resource for health professionals and researchers who wish to involve consumers in any or all stages of the research process. It has also empowered patients and carers to take on new responsibilities outside of North Trent and into national organisations, with the result that the NTCRN CRP is now at the forefront of consumer involvement developments in cancer and palliative care research nationally.

Practice Implications

The CRP model of consumer involvement in health research has become a flagship for the development and implementation of other panels in other Cancer Networks across the UK. This initiative is currently being developed by the National Cancer Research Network and Macmillan Cancer Relief, and aims to fully integrate consumers and the cancer research community, and to develop CRPs as a national resource using information and communication technology.

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I confirm that the patient/person(s) have read this manuscript and given their permission for it to be published in PEC

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