Patient and Public Involvement in cancer and palliative care research

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

The North Trent Cancer Network Consumer Research Panel (NTCN CRP) was developed against a backdrop of an evolving interest and trend towards patient and public involvement in health and social care research. The panel has now been in full operation for six years and is made up of twenty five former and current cancer and palliative care patients and carers, from diverse demographic and socio-economic backgrounds. These patients and carers have a variety of cancer types including breast, lung, prostate, oesophageal, colorectal, gynaecological, myeloma and many have metastatic disease. Their ages range from 35 to 75 years. The main aim of the panel is to improve communication and information exchange between health care professionals and patients/carers by providing a lay perspective at all stages of cancer research, clinical trials and service development initiatives.

Guiding principles and scope of the Panel

The panel activities are guided by eight key principles of successful consumer involvement in research (Telford et al 2003). Training is one of the key elements in successful consumer involvement and from the CRP’s inception, all new members attend a one-day induction programme aimed to provide members with a general overview of cancer research and to empower these patients and carers to effectively engage, communicate and voice their views about developing or new cancer research studies being undertaken in the North Trent Region as well as nationally. This programme has since been adapted for use in other organisations across the UK. Both the CRP training and individually tailored handbooks (CRP introduction handbook and overview of cancer research handbook) have proven very popular and requests for advice and input on how to develop similar initiatives have been provided to many health care professionals working across the UK. The CRP works alongside cancer and palliative care research teams, health professionals and professional bodies to provide a patient perspective at any or all stages of research projects and clinical trials both locally and nationally. The panel has been involved as partners of research with health professionals and researchers in all stages of the research cycle (Stevens et al 2003a, 2003b; Collins & Ahmedzai, 2005; Collins, Stevens, Ahmedzai, 2006).

The CRP uses four main tools of communication to further its purpose –
1. Consumer-chaired meetings to discuss research and service development proposals and requests for review by cancer researchers. One or more academics and clinicians are also present, but the direction is in the hands of the consumer. The whole panel contributes to an annual report

2. A consumer-designed website and newsletter which are designed by panel members and supported by the North Trent Network. The newsletters are circulated to health professionals and patient groups across North Trent Region but are accessed internationally.

3. Many local, regional and national representations and invited talks given by panel members locally, regionally and nationally on the work of the panel, its structure, how members get involved with health professionals and projects and how the involvement of members influences cancer research and service development locally and nationally.

4. The panel forms an annual subcommittee to organise a unique annual professional-consumer national cancer conference

There has been considerable commitment and enthusiasm towards the CRP both from panel members and from the health professionals working both within North Trent network and the NCRI. The pursuit of effective communication and information exchange between health professionals, researchers and the panel members has been central to the work of the CRP. This effort by all parties 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 set up. However, the establishment of the consumer voice within the medical domain has not been easy and many challenges have emerged which initially inhibited effective communication between the two sides. For example, the principle of former and current patients and carers working alongside health professionals on research teams and committees was in the early days a new experience. It is probably fair to say that both parties were initially very wary of working together, neither sure of each other’s roles and responsibilities and neither being aware of the skills, expertise and understanding required to successfully establish patient and public involvement in service development and research as a concept. There was initial concern by members that they would not be able to contribute anything significant to the process and some felt unable to vocalise their views in the presence of
medical ‘experts’. Some members were also concerned that they were being involved in the process as a ‘token’ patient or carer. Not all health professionals welcomed consumer involvement in their work. Some appeared concerned that consumers were ‘unrepresentative’, were ‘consumers with their own agendas’ and did not reflect the ‘true’ voice of the patient. Since the inception of the CRP, mechanisms have been put in place to understand and tackle such difficulties (i.e. provision of support and training, mentoring of new members, job description for consumers) which have helped to address some of the challenges to health professionals/researches and patients/carers working side by side.

It has been essential to ensure members are carefully recruited onto the panel and 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. In turn the 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. Professor Ahmedzai and Dr Collins (the panel facilitator) have worked hard to ensure that the health professionals clarify at the outset the role of patients and carers on research and service development initiatives and also the role expected of health professionals in guiding the members through the process. This has helped to resolve the issue the concerns of some health professionals about the ‘representativeness’ of CRP members. As a result, many physicians have stated that they feel more comfortable in talking about research alongside patients and carers.

The CRP is now at the forefront in 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 the perceived role, expectations and activities of the consumer members against those of the health professionals/researchers. Furthermore, since the CRP evaluation and feedback forms were introduced, other organisations have requested permission to adapt the evaluation tool for their own use. 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 NT CRP becoming
recognised as promoting good practice in consumer involvement. Some commentators have been critical of patients’ or carers’ abilities to engage effectively with health professionals and provide a useful objective scientific critique of research and service development, arguing they can only provide a non-scientific subjective view based on their individual highly variable experiences, which is counter to the medico-scientific paradigm of knowledge development (Canter, 2001). The pioneering and nationally recognised CRP model of patient and public involvement argues that though individual consumers cannot be assumed to represent the views of all members of the relevant patient group (as neither can the views of individual health professionals), their incorporation from the earliest stages in the clinical research team can provide an added dimension to the conduct and outputs of research and service development initiatives within the NHS which would otherwise be lacking.

The CRP model of consumer involvement in health research has become a beacon for the development and implementation of other panels in other cancer networks across the UK. It has shown evidence of a real commitment to changing the culture of an organisation by increasing dialogue and communication between health professionals and patients and carers. The CRP has succeeded in providing a forum for cancer and palliative care users and carers who are wishing to become actively involved in research. Panel members with particular relevant experience are now being invited to speak at professional national events.

CRP has given a real ‘voice’ to users of the health service which are considered and fed into the research process. It has also provided a valuable 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 onto disease specific committees nationally. The CRP is now at the forefront of consumer involvement developments in cancer and palliative care research nationally.

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On behalf of the North Trent Cancer Network Consumer Research Panel