



# Impact of Patient, Carer and Public Involvement in Cancer Research

October 2012



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# Foreword

This report highlights the impact of patient, carer and public involvement (PPI) in cancer research. For researchers and clinicians it provides information about how patient and public involvement can contribute

to studies and to clinical trials. For patients and carers considering involvement, it shows the diversity and value of the opportunities open to them at national, regional and local levels.

'PPI in action' focuses on the impact in different research settings. 'How Patient and Public Involvement is organised and works in practice' provides insight into the way that the National Cancer Research Institute and the NIHR Cancer

Research Network involve consumers in the development and delivery of research. Consumers, in this context, are defined as 'patients, carers and members of the public whose lives have been affected by cancer'.



The National Cancer Research Institute provides bursaries for patients and carers to attend the annual NCRI Cancer Conference

# Patient and Public Involvement in cancer research - vision, principles and values

The National Cancer Research Institute ([www.ncri.org.uk](http://www.ncri.org.uk)) is a partnership organisation which brings government and major charitable funders from all parts of the UK together to ensure best value from their collective investment in cancer research. This is achieved by working together in areas of common interest, especially those which are considered to be priorities by and for patients and public. NCRI Partners support the full range of cancer research with application to the prevention, diagnosis and treatment of cancer, and the well-being of cancer patients. As well as funding cancer research, the NCRI Partners are individually committed to disseminating and implementing research results, to keep professionals and the public well informed.

The cancer research networks within the NHS in England, Wales, Scotland and Northern Ireland together form the UK's National Cancer Research Network. Their vision is to bring benefit to patients, the public and the NHS by improving the co-ordination,

integrity, inclusiveness and speed of delivery of cancer research.

Development and delivery of the clinical studies which are conducted through the UK-wide National Cancer Research Network is co-ordinated through 15 Clinical Studies Groups, each supporting research for cancers at specific sites in the body; working with 6 cross-cutting groups which take responsibility for broader themes, for example biomarkers and imaging. Each of these groups has professional and consumer members.

Since the founding of the National Cancer Research Institute and the UK-wide National Cancer Research Network in 2001, the number of patients participating in clinical trials and other research studies has increased five-fold in the UK, and at time of publication is approximately one in four new patients. This has resulted from a number of factors including new financial investment through the the National Institute for Health Research Clinical Research Network and the development of a

stronger research culture within the NHS. It is also in part the product of the growing and evolving spirit of partnership between patients and professionals which has been facilitated by involving consumers in research in a variety of ways.

Key principles for patient and public involvement in cancer research include:

- working with consumers as partners in research
- involving consumers in developing

strategy as well as specific initiatives and studies

- listening to the consumer voice on research needs and the experience of participating in research
- learning from experience and examples of good practice to use patient and public involvement in the most effective way in research.

The aim is to maximise the benefits of research to patients and the NHS through active, inclusive and



Consumers at a Liaison Group meeting

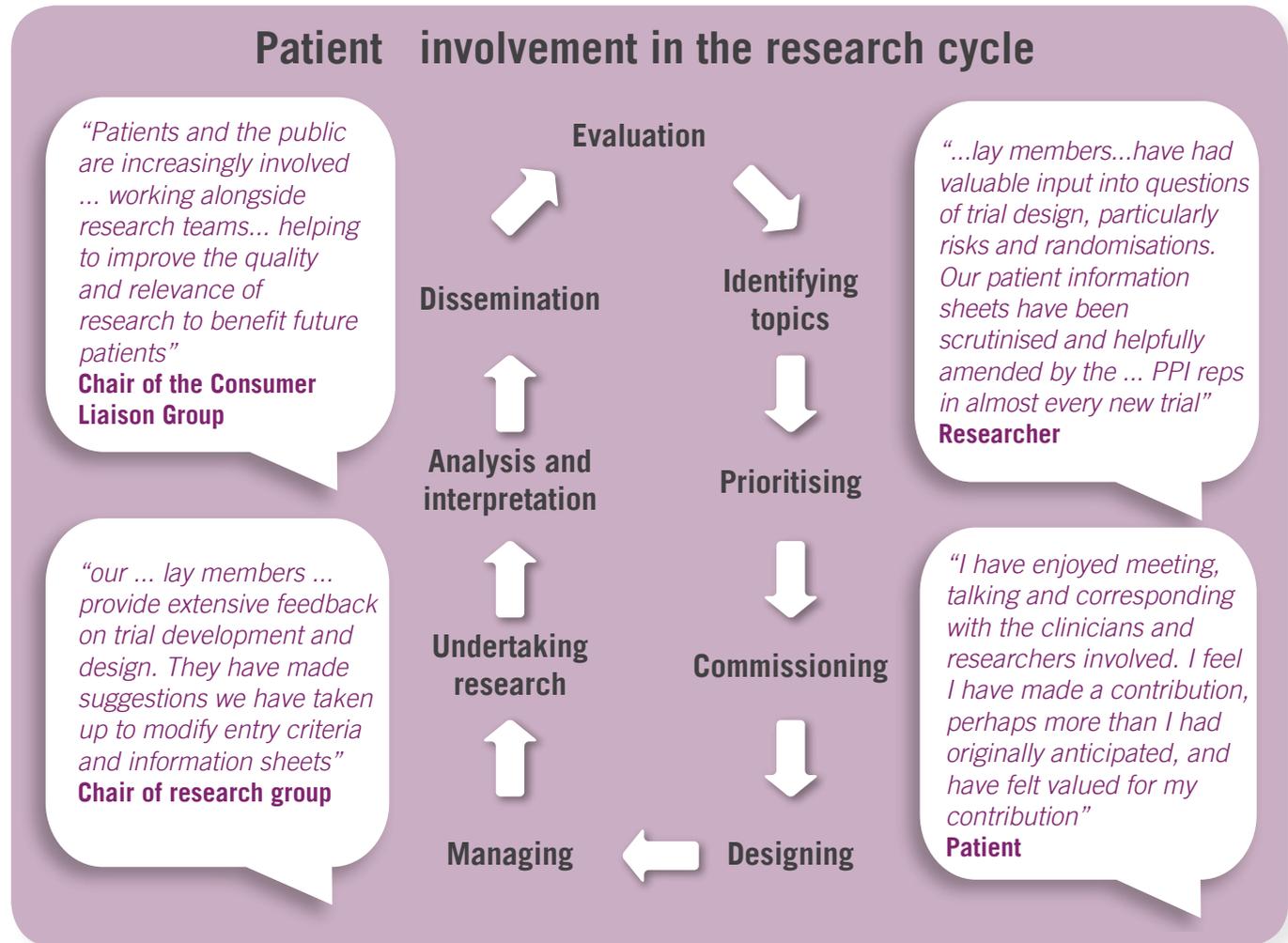
# Patient and Public Involvement in action

co-ordinated patient and public involvement.

Clinical studies rely on patients being willing to participate directly in research, when a new treatment needs to be tested or in circumstances where there is uncertainty as to the best treatment for a particular patient's condition / status. In these situations doctors rely on clinical studies (trials) to provide the evidence for best care. Each year in the UK, more than 30,000 cancer patients agree to participate in clinical trials that will lead to new medical knowledge.

Within this context, patient and public involvement focuses on bringing the consumer voice to research to influence priorities, progress and outcomes.

In the following section, five examples are given of patient and public involvement making a difference to cancer research – illustrating how this is enabling doctors to help patients better in the future.



# Patient and Public Involvement in action

## Example 1: Looking at design and recruitment from the patient's perspective – the POETIC trial

The breast cancer clinical trial 'Perioperative Endocrine Therapy – Individualising Care' (known as POETIC) required researchers, doctors, staff in cancer networks and consumers to work closely together to overcome substantial challenges in a highly complex study design. This trial is testing whether having hormone therapy for 2 weeks before, and 2 weeks after, surgery helps postmenopausal women with breast cancer. During the planning stage, the team considered all aspects of the study from a 'patient pathway' perspective: looking at the way in which standard care is delivered to that patient group, and then considering how that would change from a patient's viewpoint if she were to agree to participate in the trial.

The consumer members of a national breast cancer study group and others from one of NCRN's local Cancer Research Networks (Surrey, West Sussex and Hampshire) worked as integral members of the research team throughout the development and design of the study. This work included:

- ensuring that the initial approach made to each patient was well timed and was considered from a participant perspective
- helping to shape the study information sheets and consent forms and the way in which they are presented to patients
- providing advice to the Research Ethics Committee on whether patients were likely to be willing to consider taking part in further studies after having already participated in POETIC advising on patient priorities when balancing the need to allow time



Margaret Wilcox

to consider whether to agree to participate in the trial and the desire to undergo surgery as soon as possible

- liaising with national consumer groups to garner opinion on a 24 hour 'thinking period' for trial entry; the usual minimum recommendation to allow patients to make an informed decision about joining a research study. For POETIC this practice needed to be balanced against patients' wishes to go ahead with treatment without any delay. Taking opinions from consumers led to an agreement that the decision should be taken according to participant's wishes; so that patients could decide to join the study without the need for a return hospital visit
- providing ongoing reassurance to clinical staff (doctors and nurses) and research staff that patients were comfortable with the introduction of a research study at a sensitive stage in their cancer journey and that it was essential that competent adult patients were offered the chance to participate in clinical research.

One of the active advisors, Margaret Wilcox (pictured), continues to provide consumer advice and guidance as a member of the trial management group.

POETIC is currently recruiting around 100 patients per month in over 80 centres throughout the UK and is on track to complete recruitment by the end of 2012.

In the years ahead there are likely to be more trials which are complex in terms of combining different treatments (surgery, radiotherapy, chemotherapy) and a variety of laboratory tests for assessing the patient's suitability for a trial and progress once in a trial. This means that patients need to see a variety of professionals at different times. Coordinating this and ensuring that patients can navigate the pathway in as simple a way as possible is essential in these circumstances. Involvement of consumers is an important element in ensuring successful recruitment which, in turn, ensures that the research question can be answered and the results can make a difference to future patient care.

# Patient and Public Involvement in action

## Example 2 : Looking at research from the patient's perspective – the ProtecT study

The overall aim of the ProtecT study (Prostate testing for cancer and Treatment) is to evaluate the effectiveness, cost-effectiveness and acceptability of treatments for men with localised prostate cancer. Three treatments are being compared: surgery, radiotherapy and active monitoring.

The research team undertook in-depth focus group interviews with patients exploring interpretation of study information. This led to significant changes in the way that the study participants were approached:

- use of the word study, rather than trial. 'Trial' was felt to be a negative word and was associated with 'try and see' rather than determination of the best management of the condition
- the order of presenting treatments was changed to emphasise equivalence, i.e. that all arms of the study were accepted practice in clinical care; presenting active monitoring first, then the treatment arms
- the term 'active monitoring' was used in the approach to participants. Other options including 'conservative monitoring' and 'watchful waiting' were reported to create a negative interpretation, interpreted by patients as 'watch while I die'
- use of terminology was clarified, and equipoise (uncertainty over what is best for the patient) was presented more convincingly.

After this work with participants the acceptance rate for trial participation rose from 40% to 70% of the men approached. ProtecT closed to recruitment in 2009, at which time 1,435 men had agreed to enter, a total that exceeded the target by 16%. Follow-up assessments are in progress. This example indicates how changes in the way information about research is communicated can have a fundamental effect on the acceptability of a study to potential participants, and shows how the consumer voice in the research process can make sure studies are presented to patients in the way they find most helpful thus ensuring success.



Consumer members (research partners) presenting their poster at an NCRI Cancer Conference

# Patient and Public Involvement in action

## Example 3 : Building relationships with research teams - experiences from the COMPASS Collaborative

The COMPASS Collaborative shows active PPI from concept to completion of a research project. It was one of two collaborative groups set up in 2006 to boost research in supportive and palliative care, for cancer patients in particular. It was funded for 5 years by a consortium of government and charity research funders, on the understanding that collaborations would be developed across



COMPASS Patient and Public Involvement Board Meeting and Training Session, June 2008 - from left to right: David Ardron, Peter Rainey, Marilyn Kendall, Carolyn Morris, Scott Murray, Derek Stewart OBE

disciplines, and across institutions, to address some complex research questions.

Within this initiative two consumer members, Carolyn Morris and Peter Rainey, were appointed to provide advice, governance and advocacy as well as active participation as part of the research team.

Their work included:

- establishing a consumer research panel
- developing a User Involvement Award for best practice approaches to patient and public involvement
- developing web resources for researchers
- developing and delivering user involvement Masterclasses for researchers.

An independent evaluation of the Masterclasses, published in November 2011, concluded that they did make a difference to researchers' practice in the long term. In particular, it made them "think about involving service users much earlier and at every stage of their project, as well as making involvement an integral part of their day-to-day activity". The evaluation report also makes recommendations for the wider use of this type of training (<http://bit.ly/CompassMClass>)

## The COMPASS Collaborative...

One of two NCRI-funded research groups focusing on supportive and palliative care; COMPASS (2005-2011) aimed 'to research the development, evaluation and implementation of interventions to improve the supportive and palliative care of people living with cancer and other serious illnesses'

# Patient and Public Involvement in action

## Example 4: *Find Your Sense of Tumour* patient conference - working to raise awareness of research in young people with cancer

Young people with cancer, broadly those aged 13-24 years, often fall between cancer services traditionally designed for children or older adults. Young people with cancer have unique clinical, psychosocial and research needs. To address their specific research needs there is a Teenage and Young Adult (TYA) Clinical Studies Group which generates research to improve outcomes for young people. Their role is also to provide evidence to encourage the two distinct paediatric and adult clinical communities to adopt a patient-orientated approach to teenage and young adult cancer care. To achieve an active patient and public involvement focus, a Core Consumer Group with four young people was created. The Core Consumer Group was supported by the Group's research coordinator, Dr Lorna Fern - funded by Teenage Cancer Trust<sup>1</sup>.

At Teenage Cancer Trust's annual patient conference (*Find Your Sense of Tumour*<sup>2</sup>) in 2008 and 2010, the Core Consumer Group presented the work of the TYA Clinical Studies Group to over 300 young people diagnosed with cancer aged 13 to 24 years. In 2009/10 the Core Consumer Group also worked as co-researchers on 'The Essence of TYA Cancer Care' research project with Professor Jeremy Whelan (Chair of the TYA Clinical Studies Group), Professor Faith Gibson and other members. The one year feasibility project, also funded by Teenage Cancer Trust, asked the questions 'what is specialist care?' and 'what is the experience of young people treated with cancer?' Using participatory research

to describe young people's experience of cancer care, the Core Consumer Group facilitated a one day workshop and were involved in the analysis and writing up of results. Their contribution was invaluable for funding of the larger study BRIGHTLIGHT<sup>3</sup>. Participants in the workshop expressed the benefits of having other patients working as co-researchers:



The Core Consumer Group with Dr Lorna Fern at an NCRi Cancer Conference

*"... you could relate to them ... on a personal level ... it created a comfort zone which enabled you to talk easily about all aspects of your treatment and also the emotional side ... because you are safe in the knowledge they have experienced the same."*

In 2011, *Find Your Sense of Tumour* won an Excellence in Patient Education award from the European Oncology Nursing Society because 'the conference aims to empower young people by giving them the information that they need about their illness and its treatment, as well as life skills'. *Find Your Sense of Tumour* also provides an ideal way to raise awareness of the work of the National Cancer Research Institute and the NIHR Cancer Research Network to young people with cancer.

The Core Consumer Group was disbanded in June 2012, however, the Teenage and Young Adult Clinical Studies Group remains committed to involving young people in research<sup>3</sup>.

<sup>1</sup><http://www.teenagecancertrust.org>

<sup>2</sup><http://www.teenagecancertrust.org/get-clued-up/talk-to-other-young-people/find-your-sense-of-tumour/>

<sup>3</sup><http://www.brightlightstudy.com>

# Patient and Public Involvement in action

## Example 5: Tissue donation and research - experience from the Wales Cancer Bank

In January 2003 a meeting was called to discuss the formation of a Wales Cancer Bank. This meeting was attended by a group of consumers and professionals and this mix was the template for the way in which all further decisions would be made.



The Wales Cancer Research Network stand at the NCR1 Cancer Conference

From the very start the voice of the patient was recognised as the defining and leading one to follow and all of the actions of the Bank have been undertaken with complete involvement of all consumer members working with the professional staff.

When Welsh Government funding was granted in April 2004 the Lay & Ethics Group was formed and led on the drawing up of the:

- Patient Information Leaflet
- Partner Information Leaflet
- Patient Consent Form
- Partner Consent Form

as well as having an equal input into the National Research Ethics submission (which was accepted on first application with very minor amendments). All of the above was completed in less than 2 months from the inaugural meeting of that committee.

These documents were judged by the Human Tissue Authority to be an exemplar for other tissue banks and have since been adopted by numerous other organisations.

The direct involvement of the lay members, working closely with the dedicated staff, has been one of the reasons that the Bank has been internationally recognised as a leader in its field. The level of confidence established for both donors and professionals is shown by the very high level of donation of tissue to the Bank. The result of this success is that the Bank is a major contributor to research not just in Wales but to UK, European and global studies.

The main lesson is that co-operative working does have major benefits to all areas of research and that involving the general public in these projects builds the trust and confidence needed for success.

# How Public and Patient Involvement is organised and works in practice

## A brief history of patient and public involvement in cancer research

The idea of involving consumers in cancer research in a systematic way at national level can be traced back to a multi-disciplinary working group that first met in 1999. They proposed the establishment of a 'Consumer Liaison Group' (CLG) which would develop a lay/professional partnership throughout the field of cancer research, nationally, regionally and locally. The initial remit of the CLG was to:

- advise on appropriate ways of involving consumers in cancer research
- work with other groups to develop policy and guidance for consumer involvement
- advise on recruitment of consumers to other committees/groups
- monitor consumer involvement and contribute to evaluation of its impact.

When the National Cancer Research Institute and the UK-wide National Cancer Research Network were founded in 2001 the CLG became part of their structure, working in partnership with both organisations.

Derek Stewart was the founder Chair of the CLG (2000-2004) and describes a time in which key relationships were forged, and a journey undertaken 'from establishing a presence, through achieving a mutual understanding, to sharing an effective dialogue'. Roger Wilson (Chair 2004-2007) led a period of considerable expansion of consumer involvement, including the appointment of Vice-Chairs with specific remits. One of them, Alfred Oliver, is still a member and maintains an interest across a wide range of research issues.



Derek Stewart OBE   Roger Wilson CBE   Alfred Oliver   David Ardron   Richard Stephens

Roger led a formal review of what the Group was doing and what it should be doing, strengthening links with research funders as well as forging relationships with overseas groups who showed interest in the pioneering work of the CLG. David Ardron (Chair 2008-2012) continued these themes during a period of consolidation. Under his leadership, PPI continued to expand whilst financial constraints made it essential to consider how to target involvement in the most effective way. Richard Stephens took up the post of CLG Chair in June 2012.

## The Consumer Liaison Group today

The CLG supports consumers in their work in cancer research through three

formal meetings per year, backed up by an active communication and discussion forum, hosted by the NIHR Cancer Research Network Coordinating Centre. The meetings provide a framework for learning and development, for sharing best practice, and for peer-support and networking. The National Cancer Research Institute further supports patient and public involvement by providing bursaries to attend the annual NCRI Cancer Conference in November where, in addition to the full scientific programme, there are parallel sessions relating to issues of mutual interest to consumers and clinical researchers. An important milestone occurred in 2010 when CLG Founder Chair, Derek Stewart, delivered a plenary lecture focussing on the continued development of patient and public involvement, not only in cancer research but in the wider world of medical research.

The Consumer Liaison Group comprises core and associate members. Core members are those who have been appointed, by an open

# How Public and Patient Involvement is organised and works in practice

competitive process, to membership of one of the NCRI's 22 Clinical Studies Groups. An online survey of core CLG members in 2010 (<http://bit.ly/CLGsurvey>) illustrated the diversity of what they bring to cancer research:

- consumers come from many walks of life, and bring a wide range of skills and expertise to the Clinical Studies Groups in addition to their perspectives as patients and carers
- consumers who are members of Clinical Studies Groups are also actively involved across a wider range of research organisations and groups, nationally, internationally, regionally and locally, creating a powerful network of influence
- many consumers are directly involved in leading or developing research, not just acting as advisors
- consumers are actively involved in all aspects of research from design to completion

- consumers contribute to service development and commissioning across a range of areas relating to quality in cancer care
- consumers lead specific initiatives such as the foundation of cancer charities, or establishing links to industry, bringing a wider dimension to patient and public involvement.

Associate members of the CLG include people who have completed their term of office as a core member (3 years with a possible 2 year extension) and also others who have a national, regional or local role in patient and public involvement which falls outside the work of the NCRI Clinical Studies Groups. The associate category also includes consumers who are members

of the NCRI Board and involved in other NCRI initiatives, including the National Awareness and Early Diagnosis Initiative (NAEDI), National Cancer Intelligence Network (NCIN), the Clinical Translational Radiotherapy Research Working Group (CTRad), the Confederation of Cancer Biobanks (CCB) and activities in survivorship and end of life care. In this way, the CLG maintains a strong network for learning and development, sharing best practice and maintaining peer-support. All who wish to be part of active patient and public involvement in cancer research can have access to the CLG, and the CLG can benefit from wider links and the experience of Associate members who come from a variety of backgrounds and research initiatives.

Core and Associate CLG members (of whom there are around 75 at any one time) may also be called on to advise or comment on strategic developments and public consultations; recent examples have included:

- advice on the NIHR Cancer Research Network's strategy for



Raising awareness of PPI in cancer research – CLG members at a Lung Cancer Conference

# How Public and Patient Involvement is organised and works in practice

patient and public involvement to 2015

- contribution to the work of the NIHR Cancer Research Network's four strategic working groups: Impact, Portfolio Balance & Delivery, Industry and Network Performance. A key specific outcome is the adoption of a question about research in the 2011/12 Cancer Patient Experience Survey
- submission of a report in response to 'Improving Outcomes: a Strategy for Cancer', Department of Health, 2011
- contribution to the Academy of Medical Sciences' Review of research governance
- contribution to workshops hosted by GlaxoSmithKline which focused on a clearer understanding of service user perspectives and experiences of clinical studies. This report was presented to Lord Howe, Parliamentary Under Secretary of State for Quality, and

further work continues to inform development of the UK Clinical Trials Gateway. (<http://bit.ly/UKTrials>)

- sharing the experience of consumer involvement at local, regional, national and international level.

The main activities, challenges and successes of the CLG are captured in their Annual Reports which are available on the NIHR Cancer Research Network's website. (<http://bit.ly/CLGreports>)

## Learning and development

It is essential that those who take on roles in patient and public involvement receive support and training to equip them for the task. This applies to both consumers and professionals. The NIHR Cancer Research Network Coordinating Centre in Leeds has worked with Macmillan Cancer Support to develop a number of modules for learning and development. These include:

- Getting Involved and Influencing Research - run in partnership with

Macmillan Cancer Support/Cancer Voices trainers

- Cancer, Policy and Politics
- Introduction to the UK-wide National Cancer Research Network and the National Cancer Research Institute
- Introduction to cancer, biology and treatments

Training days are consumer-led whenever possible, and achieve a consistently high score in evaluation. From 2012, the NIHR Cancer Research Network will be leading on Learning and Development across the whole of the NIHR Clinical Research Network in England, working across a number of diseases and conditions to meet the needs of consumers involved in research, again in partnership with



Lesley Turner explains the help that the CLG offers to researchers

# How Public and Patient Involvement is organised and works in practice

Macmillan Cancer Support ([www.macmillan.org.uk/learnzone](http://www.macmillan.org.uk/learnzone)). This will enable the good practice which has been developed in cancer research to be shared with consumers and professionals working in other areas of clinical research.

## PPI at local and regional levels

David Ardron, CLG Chair 2008-2012, describes his vision of PPI as a pyramid providing a network of involvement from local to national and vice versa. The NIHR Cancer Research Network has always encouraged its local cancer research networks to engage in PPI and each has two consumer members on their steering group. As patient and public involvement continues to evolve, organisations have developed and are continuing to develop ways to introduce PPI. Some, such as the Experimental Cancer Medicine Centres (ECMCs) and Clinical Trials Units (CTUs) have a cancer focus, whereas others, such as the NIHR Research Design Service are generic, looking at research across clinical disciplines.

The work of the National Institute for Health Research in England has brought together the various topic Clinical Research Networks

encouraging patient and public involvement across all clinical research disciplines.

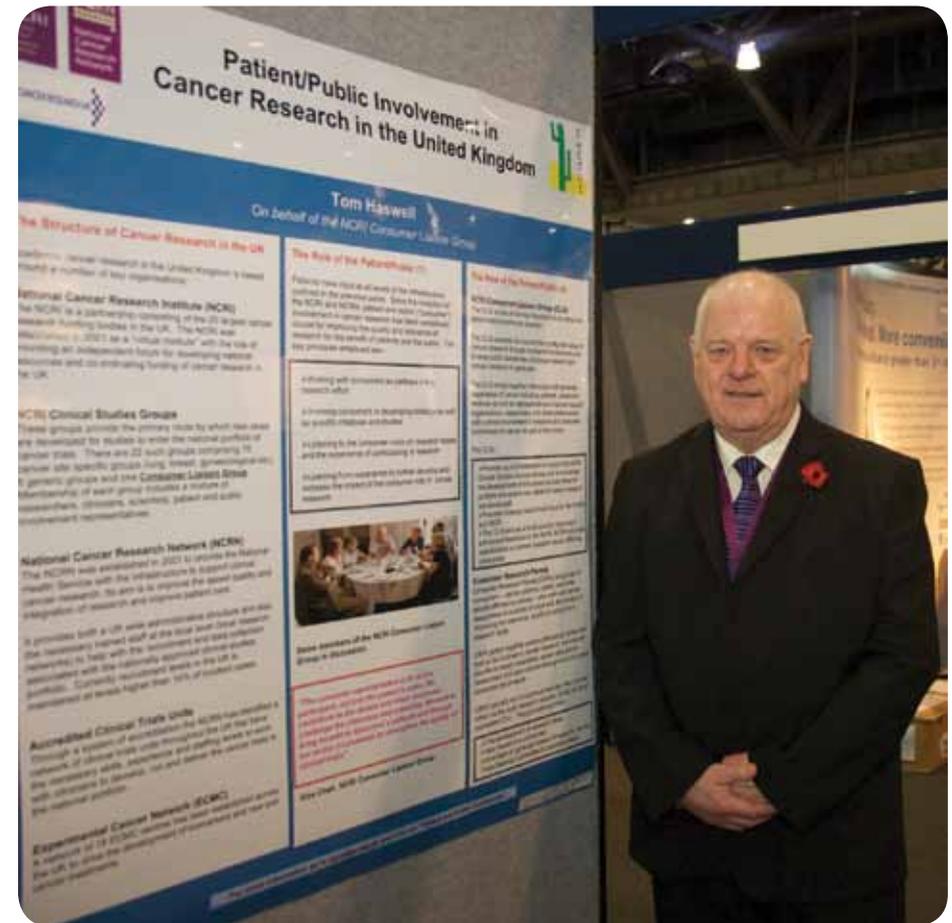
These developments are leading to a greater focus on regional patient and public involvement. The benefits include the ability to respond to local needs, to provide economies of scale and a forum for consumers and local researchers to meet, providing a platform for innovation in PPI. A number of regional groups are evolving and provide the opportunity to continue to enhance consumer leadership in cancer research but also to reach out to work with and share best practice with consumers working in other clinical conditions. An example of this work in progress can be found at the North West People in Research Forum which focuses on supporting patient and public involvement (PPI) and public engagement (PE) in health research in the North West, further details at

[www.northwestpeopleinresearchforum.org](http://www.northwestpeopleinresearchforum.org)

At local level, CLG Core and Associate members are active in Clinical Trial Management groups and in Consumer Research Panels, often linked directly to active centres for clinical research.

This aspect of patient and public involvement forms a core part of the National Institute for Health Research's strategy for the next three years and

is essential in building active links between researchers and consumers to enable partnerships for best clinical research.



Tom Haswell presenting his poster on patient and public involvement in cancer research in the UK

# Looking to the future

The solid foundation which has been built for working with patients and carers was acknowledged by Dame Janet Husband, who became Chair of NCRI in 2011: 'Consumers have contributed so much to the successes of the National Cancer Research Institute. They are an integral part of all that we do. We congratulate and thank them for all their contributions in our first decade, and we look forward to even more successes in our second decade of working together in cancer research for patient benefit.'

The National Cancer Research Institute and the UK wide National Cancer Research Network are determined to maintain this strength, in spite of the economic difficulties of the time. This is evidenced in the outcome of a funding review conducted by the National Institute for Health Research in 2011,

which secured support for patient and public involvement in the clinical research networks in England up to 2015.

Consumer involvement is now integral to research, no longer regarded as optional or a luxury. The opportunity to transfer the learning from cancer to other diseases may lead to a focus on generic aspects of health and well-being from screening and prevention of diseases, through best therapy through to recovery from illness and living with late effects of treatment. Many of these areas which are so important for patients, carers and the public cross traditional boundaries, and the chance to work across disciplines in clinical research provides some challenges but also many new opportunities for patient and public involvement.



NCRI Chair, Dame Janet Husband, with members at a CLG meeting

<b>Consumers</b>	patients, carers and members of the public whose lives have been affected by cancer
<b>CLG</b>	Consumer Liaison Group
<b>CSG</b>	Clinical Studies Group
<b>NCIN</b>	National Cancer Intelligence Network
<b>NCRI</b>	National Cancer Research Institute
<b>NCRN</b>	NIHR Cancer Research Network / UK-wide National Cancer Research Network
<b>NIHR</b>	National Institute for Health Research
<b>NIHR CRN</b>	NIHR Clinical Research Network
<b>PE</b>	public engagement
<b>PPI</b>	Patient and Public Involvement
<b>TYA</b>	Teenage and Young Adult



## How to get involved:

The NIHR Cancer Research Network (NCRN) Coordinating Centre has worked with the Consumer Liaison Group to develop a menu of involvement aimed at encouraging a greater and more diverse involvement of patients, carers and the wider public in the work of the National Cancer Research Institute and NIHR Cancer Research Network.

Further details can be found at:  
<http://bit.ly/NCRI-NCRN-PPI>  
or by contacting Karen Inns, PPI Lead at the NIHR Cancer Research Network Coordinating Centre ([ppi@ncrn.org.uk](mailto:ppi@ncrn.org.uk)) or Angela Hagan at the NCRI ([info@ncri.org.uk](mailto:info@ncri.org.uk))