

NCRI Consumer Liaison Group

Introduction

During 2008-9 the Consumer Liaison Group (CLG) has built upon the good progress it has made in previous years under the leadership of Mr David Ardron who was appointed for a three year term as the new CLG Chair on 1st June 2008 as part of an open recruitment process. At the invitation of Professor David Cameron, NCRN Director, Mr Derek Stewart, the previous Interim Chair of the Group, provided advice and support to Mr Ardron for an initial 6 month period to ensure a smooth transition. Mr Ardron is supported in his role by the CLG Vice Chair, Mr Alfred Oliver.

Patient and public involvement across the NCRI and NCRN continues to be driven by the CLG whose members participate at a strategic board level for the NCRN and NCRI, on various committees and on each of the NCRI Clinical Studies Groups (CSGs). In addition to the CLG many consumers continue to be involved in a broad range of NCRN and NCRI managed strategic projects and are also active in their local areas as representatives and advocates across a range of cancer research and service delivery networks.

The activities of the CLG continue to be supported by the consumer involvement work stream delivered through the NCRN Coordinating Centre (NCRN CC) in Leeds. The consumer work stream is managed by a full time Consumer Liaison Lead (CLL) and a full time consumer administration support post.

Since their last annual report the Group has:

- Supported the development of a more *outward looking* collaborative approach to consumer involvement across NCRI and NCRN by supporting the establishment of the NCRI/NCRN Consumer Involvement Steering Group (CISG). The CISG was established as a result of recommendations from a previous (2007-8) review¹ of consumer involvement supported by the CLG. The CISG now oversees the strategic direction and development of consumer involvement in support of key objectives outlined as part of the NCRI Strategic Plan. The Group has membership of a broad range of stakeholders across the key cancer research and patient involvement groups and organizations as well as a strong consumer input (see Appendix 1).
- Supported the development of an open recruitment process to facilitate more diverse recruitment, training and ongoing peer and mentorship support for all consumers working in CSGs and more broadly across other NCRI/NCRN projects and committees.
- Contributed to the development of a more accessible *menu of choices* available as part of the NCRN website for consumers wanting to find out more with a view to getting involved in cancer research at different stages and levels. This has included consumers promotion of involvement both locally and nationally with the emphasis on one influencing the work of the other and vice-versa. This has been supported specifically through development of the *patient and public involvement* pages on the NCRN website, group email networks, teleconferencing, national

- and local meetings, conferences, road shows and use of different communications materials and formats.
- Provided input to the design and further development of consumer led sessions at the NCRI Conference in 2008. The NCRI Conference is widely considered as the premier cancer conference in the UK bringing together different sectors, professions, disciplines and career stages under one roof, together with cancer patients and carers. In addition in 2008 consumers worked closely with the NCRN CC to develop communications materials as part of their role in managing the NCRN's information stand at the Conference.
 - Worked with the NCRN CC to provide advice and support for local research networks, clinical trials units, and experimental cancer medicine centres to increase levels of consumer engagement in cancer research and sharing of best practice.
 - Contributed evidence illustrating the range of past, current and planned consumer involvement activity across NCRN/NCRI as part of the publication submitted to the Department of Health in support of the successful review of the NCRN CC in January 2009.
 - In April 2009 provided written and oral evidence to a Progress Review Panel with national/international membership as part of its successful 3 year progress review. A summary of the Review Panel's report outlining the CLG's key strengths and issues is shown in Appendix 2.
 - Contributed through the CISG to drive progress against recommendations outlined from the previous consumer involvement working group's report (2007/8) to:
 - establish the post of Associate Director for Patient and Public Involvement in Cancer Research in 2009
 - contribute to the development of plans to commission a 2 stage process to map and evaluate consumer involvement in cancer research in 2009/10

Membership and structure

As part of its remit, the CLG continues to provide up to 3 members for each of the NCRI CS(D)Gs thereby providing opportunities for consumers to be routinely involved in commenting upon clinical trials. The current consumer membership across all the CS(D)Gs stands at 58. In 2008/9 this membership additionally includes young people recruited by the Teenage and Young Adult CSG Research Coordinator, Dr Lorna Fern. Later in 2009 the CLG plans to work with the Children's Cancer and Leukemia Group to develop closer working relationships.

In addition to the CLG/CS(D)Gs, consumers continue to be involved in a broad range of strategic projects and committees managed by the NCRI and the NCRN, for example the National Awareness and Early Diagnosis Initiative, National Cancer Survivorship Initiative and the National Cancer Informatics Initiative.

Consumers recruited independently to the NCRI Board, Board Subgroup or other committees also join the CLG. Increasingly many CLG members are also active in their local areas as representatives across a range of cancer research and cancer service delivery networks covering the UK. Consumers working with NCRN/NCRI are now present in 29 out of the 33 research networks in England with additional representation and links established through the CLG with consumers and researchers based in Wales and Scotland. Early discussions are underway with colleagues based in Northern Ireland.

A process for openly recruiting consumers to the CS(D)Gs was introduced in 2007. During 2009 the CLG will contribute to a review of this process through the CISG and NCRN CC prior to further recruitment being undertaken later in 2009.

The CLG currently reports on its activity via the NCRN Operational Steering Group, NCRI Board and NCRI Board Sub Group for clinical and translational research.

Meetings and communication

The CLG continues to meet three times a year typically in January, June and September. From mid 2008 the NCRN CC has worked with the CLG to introduce and develop a calendar of additional meeting points/events to enable consumers to keep in touch, provide a degree of peer support and to discuss and exchange information on specific areas in further detail throughout the year. Details of these are made available at: www.ncrn.org.uk following the link to *patient and public involvement*. Meetings in 2008/9 have continued to make greater use of workshop, market stall methods in addition to the more traditional presentation format.

Teleconference meetings were introduced from mid 2008 with themes agreed by consumers. These continue to be well received and will continue in addition to the more formal meetings. Such meetings have enabled more regular contact and discussion between consumers from across the country with each other and with the NCRN CC staff. The annual open meetings held in June have been further developed to encourage greater input and attendance from a broader range of researchers, clinicians, consumers from stakeholder groups and organisations with a remit and/ or interest in consumer involvement in cancer research as well as greater representation from local consumer research panels.

In January 2009 the Group held their meeting jointly with staff from one of the Experimental Cancer Medicine Centres at the Institute of Cancer, Bart's and the London School of Medicine and Dentistry in London. The Group plans to work with the NCRI and NCRN to further broaden the June meetings into *annual gatherings* for the exchange of best practice for all those engaged in promoting consumer involvement in cancer research. Meeting papers and workshop reports are routinely made available via the website at: www.ncrn.org.uk following the link to *patient and public involvement*.

CLG members have contributed to the design of the patient and public involvement pages (PPI) as part of the NCRN website that was re launched in October 2008. The PPI pages on the website contain a wide range of information aimed at a broad audience on recruitment, training, conferences and events, how and where to get involved, CLG meetings, raising awareness about clinical trials as well as signposting to further information and advice.

In addition there are plans later in 2009 to explore piloting a web based communications facility between consumers, researchers and the NCRN through the resources available as part of the National Institute for Health Research (NIHR) Portal.

Other activities

The Groups other activities include training, mentorship and ongoing support.

During 2008/9 all new and established consumer members have been encouraged to undertake a total of 3 days of induction training to support them in their roles on the CSDGs. Based on commonly identified learning needs through the recruitment process, consulting with consumers and the previous evaluation of the early pilot consumer research panels set up in 3 local research networks in 2005/6 the induction programme currently comprises 3 one day programmes/workshops:

- Getting Involved and Influencing Research - run in partnership with Macmillan Cancer Support/Cancer Voices trainers
- Cancer Policy and Politics, offered as part of the NIHR CRN training portfolio
- Introduction to the NCRN and NCRI

Consumer induction and ongoing training places an emphasis upon enabling consumers to work flexibly and across organisational boundaries with researchers and clinicians to the benefit of the quality of research and its impact on patients.

During 2008/9 consumers have evaluated the induction programme positively and there has been a good level of uptake. Increasingly in 2008/9 research staff have opted to attend training alongside consumers to increase their knowledge and understanding of the issues faced by consumers engaged in cancer research. There has also been an increase in those consumers working at local level as part of consumer research panels, cancer research and service networks attending training alongside those consumers working as part of the CSGs at national level.

Additionally during 2008/9 the CLG and the NCRN CLL and the CSG Secretariat have worked to ensure that all members have the opportunity to work regularly with a scientific mentor from within their CSG and have also been encouraged to make use of peer support from more established consumers across all the CSGs. The CLL has also provided additional individual ongoing support and advice to consumers as needed.

Later in 2009 the CLG plan to work with the CLL, CSGs Secretariat and CSG Chairs to develop guidance on mentorship as well as processes to capture a review of progress for consumer members of CSGs.

Consumer involvement in industry trials

During 2008/9, consumers have worked with the NCRN CC and other clinical research topic patient and public involvement leads to provide initial advice to the National Institute for Health Research Clinical Research Network (NIHR CRN) Industry Working Group to support the development of national guidance on consumer involvement in industry led trials currently in development by NIHR CRN.

It is envisaged that by late 2009 the NIHR CRN Coordinating Centre will have in place letters of agreement addressing some of the legal implications in this area along with guidance on involvement for all the clinical research topics. The initial focus will be on lay involvement in industry adoption panels. The CLG and CLL will contribute to future

working groups to be convened by NIHR CRN CC to look at putting developed guidelines into operation and making provisions for consumer recruitment and training to enable meaningful engagement.

Raising awareness of cancer research and the benefits of consumer involvement

During 2008/9 members of the CLG have continued to support this aspect through the following activities:

- Provision of consumer biographies and contacts database available via a dedicated consumer mailbox (consumers@ncrn.org.uk) managed by the NCRN Coordinating Centre. This has led to raised awareness of how consumer involvement in cancer research can be of benefit to a range of research organizations and an increase in consumers contacted by researchers as a result
- Newsletter articles- from consumers, researchers in NCRN, NCRI, NIHR, and INVOLVE newsletters
- NCRN website -Through information provided on the patient and public involvement pages of the NCRN website which CLG members helped to design
- Regular attendance and presentations at workshops/conferences, for example:
 - NCRI Conference 2008/9
 - INVOLVE Conference 2008
 - NCRN Road Shows 2008
 - CTU Annual Trials Conference 2008/9
 - NCRN Research Network Managers meetings in 2008/9
 - National Development Programme (NDP) June 2009 Conference/research workshop
- Contributing to the development of communications materials, leaflets, banners, posters for use at conferences and meetings
- Providing guidance to other organisations (UKCRC, INVOLVE, NIHR CRN, CR-UK, Macmillan Cancer Support) whose core activities include raising awareness of clinical research including cancer research

Consumer driven research

The CLG has through the NCRN CC worked closely with Macmillan Cancer Support over the past 2 years to raise awareness of and encourage consumer involvement in their user led research grant competition which is currently run on an annual basis as part of the NCRI Conference. People affected by cancer must be involved in the design and conduct of proposed studies with only research proposals that are reviewed and approved by consumers being submitted for short listing to the awarding panel. The competition provides opportunities for consumers to influence research priorities and to become actively involved themselves in driving the research itself. Examples of some of the research studies awarded funding via this route from the 2006 and 2007 competitions are shown at:

http://www.macmillan.org.uk/About_Us/Force_for_change/Cancer_care_research/Macmillan_research_grant_competition.aspx

In addition consumers are involved in driving research with support from local researchers and members of consumer research panels. An example of this is the DOCTER project; further details from the CLG Chair.

Priorities for next year:

- *Contribute through the CISG to drive progress against recommendations outlined from the previous consumer involvement working group's report (2007/8) by:*
- Establishing the post of Associate Director for Patient and Public Involvement in Cancer Research in 2009
- Contributing to the development of plans to commission a 2 stage process to map and evaluate consumer involvement in cancer research in 2009/10

- *Build capacity to enable consumers working at local level to inform the national research agenda and vice-versa*
- Working through the CISG and the NCRN CC the CLG will support the delivery of training at local and national levels to develop skills and expertise of consumers to engage in cancer research activities. These activities will include membership of NCRI CS(D)Gs, trial management, steering groups and consumer research panels.
- Working through the CISG and the NCRN CC the CLG will support development of the current programme of training events, workshops, meetings, conferences, website resources to increase opportunities for collaborative working, communication and sharing of best practice in consumer involvement across local and national networks and organisations.

- *Increasing the current level of research that is consumer driven*
- The CLG will work through the CISG and the NCRN CC to support the increase of consumer driven research activity by supporting expansion of the Macmillan Cancer Support User Led Research Competition
- The CLG will work through the CISG and NCRN CC to develop opportunities for consumers to access tailored training and support to enable them to take part in and drive appropriate aspects of research

- *Establishing processes that enable earlier and more consistent involvement of consumers across a broad range of research, including industry trials*
- In 2009/10 the CLG will work through the NCRI/NCRN CISG to map current and potential opportunities for early engagement of consumers in research. The CLG will support the NCRN CC to work with key partners to support consistent approaches to recruitment, training and ongoing support for consumers wishing to engage in identified research opportunities
- In 2009/10 the CLG will work through the CISG and the NCRN CC to contribute to the development of guidelines on consumer involvement in industry led trials being developed by the NIHR CRN CC through its Industry Working Group and will advise on their operational delivery. The initial step is likely to be consumer involvement in Industry study adoption panel

- *Address the key issues raised from the 2009 CLG Review (see Appendix 2)*
- The CLG will work through the CISG and NCRN CC to build upon the key strengths and begin to address the key issues identified from the Review Panels' Report

Mr David Ardron
Chair, Consumer Liaison Group
June 2009

Appendix 1

NCRI/NCRN Consumer Involvement Steering Group (CISG) Terms of Reference and Membership

Terms of Reference

Reports to:

- NCRN Board Sub Group
- NCRN Operational Steering Group
- NCRN Management Group

Membership:

- NCRN Assistant Director
- NCRN Consumer Liaison Lead
- NCRN Administrative Director
- NCRN CS(D)Gs Secretariat
- CS(D)G Chair
- CLG Chair
- CLG Vice-chair
- Consumers x4
- NCRN Principal Fellow Clinical Trials
- UKCRN PPI Lead
- Clinical Trials Units
- Experimental Cancer Medicine Centres, Consumer Lead
- INVOLVE
- Cancer Action Team
- Research Network Manager

Terms of Reference:

- To oversee the strategic direction and development of consumer involvement within NCRN and NCRI in line with agreed organizational goals and targets
- To oversee the effective operational delivery of consumer involvement within NCRN and NCRI
- To discuss, monitor and review issues related to the implementation, development and evaluation of consumer involvement
- To consider ways of improving, supporting and sustaining effective consumer involvement in NCRN and NCRI
- To oversee agreed budgets and resources allocated for consumer involvement to gain most effective involvement
- To review consumer involvement in other clinical areas so that latest developments and trends can be assessed and evaluated for NCRN and NCRI
- To provide a strategic forum through which to develop and steer best practice for organisations engaged in consumer involvement in cancer research
- To consider any other matters considered relevant

Frequency of Meetings:

Three times a year.

Appendix 2

Key strengths and issues from the Progress Review, April 2009

The key strengths of the Group identified at the review are:

- The Group's report to the Progress Review Panel
- The range of activities in which consumers are involved
- Training opportunities afforded to new members
- Greater visibility of involvement in NCRI activities
- Quantity and quality of work
- The energy and thought put into their work
- Increasing the numbers of consumers involved in research, increasing the number of projects and number of voices promoting consumer involvement
- Being in a strong position relative to other international groups

The Consumer Liaison Group needs to consider:

- Prioritising activities and focusing on a few priorities
- Alternative ways to achieving future goals which differ from those used in the past
- Getting the Associate Director role for PPI and its interrelationships right
- Establishing the correct structure for the CLG and terms of reference for the Associate Director PPI, Chair of the CLG, CLG and Consumer Liaison Lead and how they interact
- Continuing to develop international links
- Formally capturing some of the cultural changes which have taken place in CS(D)Gs as a result of having consumer members
- Ways to balance retaining experience in CS(D)Gs with new consumer members coming in
- Developing a clear communication strategy which includes how the CLG will interact better and more formally with local research panels and other groups and also internally within the CLG
- Capturing all the financial costs of consumer involvement from a variety of sources (NCRN, NCRI, NCIN) in a single place so that a fuller picture on the financing of consumer activities is achieved
- Identifying parameters by which the Group can be judged at the next review.

The NCRN/NCRI need to:

- Work with the CLG to help establish the correct structure for the CLG and the terms of reference for the Associate Director PPI, Chair of the CLG, CLG and Consumer Liaison Lead and how they interact
- Assist with bringing together information on consumer spend into a single place
- Provide training for the research community on consumer issues, the roles of CLG members and the new Associate Director in order to ensure that everyone has a clear understanding and can work together in productive ways