

## **NCRI Consumer Liaison Group**

### **Introduction**

The year 2007 to 2008 has been a period of significant change for the Consumer Liaison Group (CLG). Roger Wilson completed his term as Chair in the summer of 2007 and was replaced by the incoming Chair Nina Ennis. Unfortunately due to unforeseen personal circumstances Nina was forced to step down from her role at the end of January 2008. However prior to her departure she was able to set in place a process for review of consumer involvement across the NCRI and NCRN with a view to setting priorities and making recommendations to improve the quality of cancer research through consumer involvement. This review was undertaken by a short term Working Group subsequently commissioned by Professor David Cameron. Their summary report and recommendations are shown in appendix 1.

Derek Stewart, the founding Chair of the CLG took on the role of interim Chair at the request of Professor David Cameron in February 2008 to ensure that the review of consumer involvement did not lose momentum. Following a national recruitment process David Ardron was appointed as the new CLG Chair on 1<sup>st</sup> June 2008 for a three year term with Derek Stewart continuing to provide advice and support to ensure a smooth period of transition into the role over the next few months.

It is to the credit of those already named along with the wider membership of the CLG that the work of the consumer involvement work stream continues to be driven forward with enthusiasm during this period of change.

### **Remit, structure, governance and membership**

The CLG operates to improve the quality and value of cancer research for patient benefit through consumer involvement and to raise public awareness of clinical research and cancer research in particular.

The Working Group also reviewed the CLG's terms of reference to the following:

- To advise the NCRI/N on appropriate ways of involving consumers effectively in the cancer research process.
- To work with other NCRI/N groups to develop policy and guidance for consumer involvement.
- To advise on and support the recruitment of consumers to other committees/groups.
- To capture, understand and demonstrate the impact of this involvement
- To monitor consumer involvement and contribute to evaluation of its impact towards patient benefit

The CLG brings together individuals with personal experiences of cancer including patients, carers and relatives as well as representatives of cancer support organisations, researchers and other professionals with an interest in consumer involvement in cancer research as part of their roles.

The CLG currently has one Chair, David Ardron and a Vice Chair, Alfred Oliver. In June 2008 the Working Group made recommendations as part of its final report regarding future work areas and priorities which may require a review of current structures and governance towards the end of 2008. Any proposed changes will be reviewed as part of the remit of the NCRI/NCRN Consumer Involvement Steering Group due to reconvene with a broader membership from September 2008 (see appendix 3 for their terms of reference). Any resulting action plans developed

through the steering group will be discussed at future NCRI Board, Board Sub Group and NCRN Co-ordinating Centre management meetings.

As part of its remit, the CLG provides up to 3 members for each of the NCRI Clinical Studies Groups (CSGs). In addition to the CLG, consumers are also involved in a broad range of strategic projects and committees managed by the NCRI and the NCRN. Many CLG members are also active in their local areas as representatives and advocates across a range of cancer research and service delivery networks covering the UK.

The current membership across all the CSGs now stands at 60. Some progress has been made in recruiting members from more diverse backgrounds and communities. This follows the introduction of a consumer recruitment process in April 2007 and subsequent national recruitment campaign in the early summer of 2007. The consumer recruitment process, which incorporates diversity monitoring, has subsequently been adopted by several national and regional organisations as an example of good practice.

### **Meetings**

The CLG meets 3 times a year and from April 2008 has introduced a calendar of additional meeting points/events to enable members to discuss and exchange information in further detail throughout the year. Details of these are available at: [www.ncrn.org.uk](http://www.ncrn.org.uk). Teleconference meetings were introduced in April 2008 with agreed themes; these have evaluated well and will continue in addition to the more formal meetings. Meetings held annually in June have been further developed in 2008 to encourage greater input and attendance from a broader range of stakeholder organisations with a remit and/ or interest in consumer involvement in cancer research as well as greater representation from local consumer research panels. The group plans to explore joint meetings and events with some of these stakeholders later in 2008/9. These include but are not limited to: Experimental Cancer Medicine Centres, Clinical Trials Units and local Consumer Research Panels.

### **Training**

All new and established members are now encouraged to undertake a total of 3 days of induction training as part of a programme introduced in the late summer of 2007 to support them in their roles on the CSGs. Based on commonly identified learning needs and the previous evaluation of the early pilot consumer research panels set up in 3 local research networks in 2005/6; the induction programme comprises:

1. Getting Involved and Influencing Research-1 day workshop run in partnership with Macmillan/Cancer Voices trainers
2. Cancer Policy and Politics, offered as part of the UKCRN training portfolio -1 day programme
3. Introduction to the NCRI and NCRN -1 day programme

The induction programme has evaluated very positively with a good level of uptake. The CSG Secretariat and the Consumer Liaison Lead (CLL) have worked together to ensure that all consumers have the opportunity to work regularly with a scientific mentor within their CSG and they are also encouraged to make use of peer support from more established consumers across the 23 CSGs. The CLL also provides additional individual support and advice as appropriate working closely with the CSG Secretariat and CSG Chairs.

Following induction consumers work with the consumer lead to identify and address additional learning needs through their attendance on training courses and

conferences delivered through a range of national and regional training providers. Elements of the induction and ongoing training programme available to CLG members have been adopted by several of the local cancer research networks as well as colleagues working in the devolved nations. Increasingly in 2008 we are seeing research staff opting to attend training alongside consumers to increase their knowledge and understanding of the issues faced by consumers engaged in cancer research. We are also seeing an increase in consumers working at local level as part of cancer research and service networks attending training.

Consumers have worked with members of the NCRN Training and Education Strategy Group to influence the redesign of the Cancer, Policy and Politics Course as well as assisting in piloting new courses developed through this group. CLG members have also provided advice to the UKCRN Training and Education/Patient and Public Involvement Strategy Group on future training requirements for consumers and research staff.

### **Consumers with additional roles**

As the profile of the CLG has increased over 2007-08, the CLG has been increasingly invited to take up membership of several national groups and organisations relevant to the group's terms of reference to provide a consumer perspective. As a requirement of acceptance of these roles the CLL works in collaboration with the requesting organisation(s) to ensure that consideration is made for consumers taking on additional roles to receive adequate information, training, mentorship and ongoing support enabling them to engage meaningfully in their additional role. Further detail is shown in appendix 2

### **Involvement in consultations and research studies**

In addition to their role as members of the CSGs, CLG members have been involved in providing advice for several consultations and research studies over the past year. Examples include:

- Advising on the development of the NCRI Strategic Plan 2008-2013
- Advising the UKCRN Training and Education/Patient and Public Involvement Strategy Group on future training requirements for consumers and researchers working with them
- Involvement in a national study to capture the experiences of people who are invited to take part in a clinical trial as part of their care: [www.dipex.org](http://www.dipex.org). The resulting website will provide a valuable teaching and learning aid for health professionals and researchers designing trials
- Advising on a research study proposal developed by Professor Karen Cox, University of Nottingham to examine the Psycho-social aspects of clinical trial participation and management for consumers taking part

### **Consumer metrics and capturing impact**

CLG members have been instrumental, through their collaboration with research network managers and NCRN Co-ordinating staff, in advising on the development of metrics for use across all the NCRN cancer research networks to capture consumer involvement activity as part of the wider annual reporting process. It is expected that the outcome of this reporting activity will be known in the autumn of 2008.

In addition they have worked with the CLL to develop consumer impact templates for use by consumers and researchers alike to help capture examples of the impact that consumers have on various aspects of the cancer research process. These templates, available as part of the re-launched NCRN website patient and public involvement pages ([www.ncrn.org.uk](http://www.ncrn.org.uk)) are currently being piloted and further details should be available towards the end of 2008.

**Priorities for next year**

These include:

- Developing action plans and supporting delivery against each of the Working Group's recommendations for further review by the NCRN and NCRI Board in 2008/9
- Developing links with industry using forthcoming guidance to be issued towards the end of 2008 by the UKCRN Industry/PPI Working Group
- Maintaining a diverse, trained, supported and active consumer membership in support of all the NCRI CSGs
- Strengthening links with local research networks as well as established and developing local consumer research panels
- Developing further consumer involvement activities with Clinical Trials Units and the developing Experimental Cancer Medicine Centres network
- Building upon joint training and capacity building activities established over the summer of 2008 with colleagues in the devolved nations

**Mr David Ardron  
CLG Chair  
July 2008**

## Appendix 1

### Summary of the Working Group's Recommendations:

1. To promote effective consumer involvement in cancer research both locally and nationally, to develop and continue to work in partnership with a range of relevant organisations and groups such as INVOLVE and the UKCRN Co-ordinating Centre.

- Establish a post of an Associate Director for PPI to provide strategic leadership and drive across NCRI/N
- Invite NCRI to host a meeting of Board Partners to discuss 'what's next' for PPI with cancer research
- Develop and strengthen links with other key elements of NCRI e.g.: Clinical Trials Units and Experimental Cancer Medicine Centres and policy regulatory bodies

2. To map current consumer involvement activity in cancer research as a basis for future effective development of consumer involvement.

- Fund a review to document what is currently taking place by carrying out a simple mapping process of the wider aspects of consumer involvement in cancer research and set targets for 2012
- Support the development of more local consumer panels, promote local research 'champions' and hold satellite meetings for Scotland, Wales and Northern Ireland to assist in the early involvement and identification of issues

3. To develop research which provides a clearer understanding of how consumer involvement has or could enhance in future the quality of cancer research for the benefit of patients.

- Identify funding to provide an evidence base of effective consumer involvement assessing the impact of involvement in Clinical Studies Groups and other groups to be able target the most appropriate method/place for involvement
- Support the expansion of the Macmillan User Led Research competition currently held annually as part of the NCRI Conference

4. To encourage and promote a greater, more effective and diverse involvement of consumers involved in cancer research

- Develop a *menu* and register of patient & public involvement opportunities in research to encourage greater participation
- Encourage the reporting and collection of ethnicity data in cancer research
- Support NCRI partners in identifying some target areas for some preliminary research
- Raise awareness of the issues surrounding inequalities and hold some training events on diversity for the NCRI/N

5. To identify areas that require appropriate resources, the structures, clear roles, support mechanisms, and training for consumers and others, to enable meaningful involvement

- Implement the previous NCRN Coordinating Centre funding review for full time administrative support for the NCRN Consumer Liaison Lead

- Re-establish the Consumer Involvement Steering Group to oversee strategic direction and development of consumer involvement across NCRI/NCRN in line with agreed organisational goals
- Develop the post of consumer involvement project officer to work with the NCRN Consumer Liaison Lead to drive the development of distinct projects in support of consumer involvement across NCRI/NCRN. Projects identified by the Group were:
  - Project 1: Continuing support for current consumer research panels and the development and set up of further panels as a resource for the cancer research community across NCRI/NCRN
  - Project 2: Development of a communication/IT (COMMIT) structure to support the sharing of information/best practice relating to consumer involvement across the wider cancer research community
- Establish a calendar of meetings and events

## **Context and Setting**

### **Context of Consumer Involvement in National Cancer Research Institute**

The National Cancer Research Institute (NCRI) Strategic Plan 2008-2013 states that the NCRI and NCRN believe that by working with consumers the quality of research can be enhanced for the benefit of patients and the public. Their key principles for working with consumers include:

- Working with consumers as partners in the research effort
- 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 to further develop and increase the impact of the consumer role in cancer research

Consumer Involvement in the National Cancer Research Institute and Network has been led by the Consumer Liaison Group (CLG) whose members participate at a strategic board level, on committees and at the Clinical Studies Groups (CSGs). The CLG has also supported some local research panels. In addition to the CLG, consumers are involved in a broad range of strategic projects managed by the NCRI and NCRN. Many CLG members are also active in their local areas as representatives and advocates across a range of cancer research and service delivery networks covering the UK.

The CLG operates to improve the quality and value of cancer research through consumer involvement and to raise public awareness of clinical research and cancer research in particular.

Further information is available at: [www.ncrn.org.uk](http://www.ncrn.org.uk) , [www.ncri.org.uk](http://www.ncri.org.uk) and <http://www.ncrn.org.uk/csg/downloads/Consumer%20Liaison%20CSG%202005-6%20annual%20report.pdf>

### **The Terms of Reference\* for the NCRI Consumer Liaison Group are:**

(\*The Working Group reviewed these and the proposed changes are in italics)

- To advise the NCRI/N on appropriate ways of involving consumers effectively in the cancer research *process*.

- To work with other NCRI/N groups to develop policy and guidance for consumer involvement.
- To advise on and support the recruitment of consumers to other committees/groups.
- *To capture, understand and demonstrate the impact of this involvement*
- To monitor consumer involvement and contribute to evaluation of its impact towards patient benefit

### **Context of the Working Group**

The Working Group was set up to look at ways of extending consumer involvement to improve cancer research and the structures/ governance that may be required.

This was a short-lived task focussed working group commissioned by Prof David Cameron Director of the National Cancer Research Network (NCRN) and chaired by Derek C Stewart, founder chair of the Consumer Liaison Group. As a result of the unexpected resignation of the incumbent chairperson, Derek returned to the role in an interim capacity during this period.

The Working Group met 4 times between November 2007 and April 2008 including a visit to the local Consumer Research Panel in Sheffield. Information about membership, terms of reference and meetings are listed in the Appendix 2.

The Group defined its intention as being to enhance research through consumer involvement; leading to more effective partnership between people affected by cancer and professionals for improved benefits for patients and the public.

In providing this statement we recognised the continuing development of effective relationships between people affected by cancer and people working in research with mutual respect and understanding.

Consumers, who have become involved with the NCRI/NCRN, have welcomed the opportunities to participate and acknowledged the developments that have taken place to begin to address many of the issues that are important to people affected by cancer. We are keen to work together to improve research through the promotion of effective engagement.

Increasingly there is a greater sense of a set of common goals being addressed between the patient and research communities as demonstrated through the Database of Uncertainties about the Effects of Treatments (DUET) approach used by the James Lind Alliance ([www.duets.nhs.uk](http://www.duets.nhs.uk)). DUETs are being developed primarily to help those prioritising research in the UK to take account of the information needs of patients, carers and clinicians along with a better integration between research and service delivery illustrated throughout the Cancer Reform Strategy (CRS).

Many cancer patients are living longer and wanting to become involved with cancer research and it is likely that more will do so through the Survivorship Initiative launched earlier this year. ([www.macmillan.org.uk/Get\\_Involved/Campaigns/Survivorship.aspx](http://www.macmillan.org.uk/Get_Involved/Campaigns/Survivorship.aspx)). The CRS recommended that National Cancer Director, Prof Mike Richards, and Macmillan Cancer Support lead a new National Cancer Survivorship Initiative to develop new and better post treatment services. As cancer is increasingly being seen in the category of chronic disease, patients may look towards more research in co-morbidity. Additionally as more individualised treatments are being delivered so it will be of importance to better understand the patient experience.

The Working Group has sought to explore the ways in which we might extend and develop patient and public involvement in research whilst recognising the sterling work of the Consumer Liaison Group and the evolutionary manner in which change has already taken place over the past few years.

We sought to add to the issues raised in recent documents such as the Research for Patient Benefit Programme (RfPB), the nationally co-ordinated funding stream for regionally commissioned research to support projects in Health Services Research and Public Health of benefit to patients. ([www.nihr-ccf.org.uk/site/programmes/rfpb/default.cfm](http://www.nihr-ccf.org.uk/site/programmes/rfpb/default.cfm)). The group also took into account key messages from The Cooksey Report's 2006 review of publicly funded health research, the NCRN Strategic Plan (2008-2013) ([www.ncrni.org.uk/includes/Publications/reports/strategicplan\\_web.pdf](http://www.ncrni.org.uk/includes/Publications/reports/strategicplan_web.pdf)) and the recently published UKCRC Patient and Public Involvement Strategic Plan 2008-2011 (<http://www.ukcrc.org/pdf/UKCRC%20PPI%20Strategic%20Plan%20&%20Report%20April08.pdf>).

The development of consumer involvement in cancer research takes place in a broader context of change and development. Both in terms of the rapidly changing clinical research environment and the ever increasing amount of patient and public involvement activity going on in clinical research. This requires joined up thinking and working. To maximise full potential there needs to be excellent lines of communication and opportunities for partnership working with other groups and organisations UK-wide, internationally as well as working closely with organisations such as UKCRN and INVOLVE.

The Working Group has made some proposals which will need to be considered by the Consumer Liaison Group, the NCRN Operational Steering Group and the NCRN Board. We have suggested a timeline for these discussions.

More evidence needs to be gathered about consumer involvement in cancer research. There is a further need to understand and define what is meant by effective engagement and involvement and we were struck with the tangible evidence that was particularly apparent during our visit to a local Consumer Research Panel in Sheffield.

There is a need to take stock and assess the existing involvement that is taking place across a wider context than just the membership of the NCRN Clinical Studies Groups and take account of what might be required to support further development. We were also asked to consider what structures might be required and have still to do so.

We are keen to ensure that consumer involvement in cancer research is of the highest quality practice both locally and nationally, strategically at all aspects of NCRN/UKCRN, at all stages of the research cycle and with partners.

The Working Group is in the process of compiling an Action Plan where further practical suggestions will be listed.

The key principles which have developed throughout this work can be summarised as follows:

- Consumer involvement should become embedded as a vital component of cancer research working towards a position where involvement becomes the norm in all aspects of cancer research

- Consumers should be involved as partners in the research effort with the aim of enhancing the quality of research for the benefit of current and future patients
- The consumer role in research should be further developed based on learning from evidence gathered on the effectiveness of the impact of consumer involvement in cancer research
- People affected by cancer who wish to participate should be enabled to become meaningfully involved in cancer research through access to appropriate research opportunities, training, advice and support

**Working Group Participating Membership:**

Alf Oliver	CLG Vice Chair
Carmen Sobande	CLG member
Dave Ardron	CLG member
David Cameron	NCRN Director
David Rabjohns	CLG member
Derek C Stewart	Chair of Group and Interim CLG Chair
Eileen Loucaides	NCRI CSG Secretariat
Hilary Blackburn	NCRI Board Consumer Members
Jane Cope	NCRI
Joanne Eley	NCRI Board Consumer Members
John Belcher	CLG member
Julie Clifton	CLG member
Karen Inns	NCRN Consumer Liaison Lead
Karen Poole	Assistant Director NCRN
Lindsey Johnson	Clinical Trials Units
Louise Jones	Experimental Cancer Medicine Centres
Maryrose Tarpey	INVOLVE- PPI lead
Monica Jefford	CLG member
Nina Ennis	Former Chair of CLG
Philippa Yeeles	UKCRC
Tony Webber	CLG member

**Meetings held**

November 2007  
December 2007  
February 2008  
April 2008

## **Appendix 2**

### **Consumers with additional roles**

- NCRI Board: Hilary Blackburn and Joanna Eley
- NCRI Board Sub Group: Richard Stephens, Peter Rainey, Miriam Harris
- NCRI Supportive and Palliative Care Collaboratives: Peter Rainey (COMPASS), Roger Wilson (CECo)
- CR-UK CTAAC: Diana Robinson
- Experimental Cancer Medicine Centres Steering Committee: Alf Oliver, Derek Stewart
- NCRI Informatics Initiative Board: Julie Clifton
- OnCore UK: Derek Stewart
- NCRN Operational Steering Group: David Ardron, Alf Oliver
- National Collaborating Centre for Cancer: David Ardron, Daphne Havercroft

## **Appendix 3**

### **Consumer Involvement Steering Group**

#### **Draft Terms of Reference**

#### **Reports to:**

- NCRN Management Group
- NCRN Operational Steering Group

#### **Membership:**

- NCRN Assistant Director
- NCRN Consumer Liaison Lead
- NCRN Administrative Director
- NCRN CSGs Secretariat
- CSG 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

#### **Terms of Reference:**

1. To oversee the strategic direction and development of consumer involvement within NCRN and NCRN in line with agreed organisational goals and targets
2. To oversee the effective operational delivery of consumer involvement within NCRN and NCRN
3. To discuss, monitor and review issues related to the implementation, development and evaluation of consumer involvement
4. To consider ways of improving, supporting and sustaining effective consumer involvement in NCRN and NCRN
5. To oversee agreed budgets and resources allocated for consumer involvement to gain most effective involvement
6. To review consumer involvement in other clinical areas so that latest developments and trends can be assessed and evaluated for NCRN and NCRN
7. To consider any other matters considered relevant

**Frequency of Meetings:**

Three times a year or as required