

Northern Ireland Cancer Research Consumer Forum (NICRCF)



The First Year Report

September 2011 – August 2012

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Welcome to the First Year Report

We are delighted to reflect back over an amazing year that launched the Northern Ireland Cancer Research Consumer Forum (NICRCF) and set a benchmark for Personal and Public Involvement (PPI) in Cancer Research in the region.



Margaret Grayson and
Dori-Anne Finlay Blackstock

Members of the Forum bring a wealth of cancer experience (as someone who has been affected by cancer or a carer) and a variety of other skills, along with heaps of commitment to work alongside researchers and healthcare professionals to shape cancer research; to improve existing treatments and services and to help in the development of new treatments for all people diagnosed with cancer.

We want to take this opportunity to say well done to everyone involved in the Forum. We also wish to thank the researchers and professional support, in particular Ruth Boyd, the PPI Lead, for her expert guidance, skills and boundless energy; and Sharon Dunwoody, for facilitating the opportunities to get involved in the research in this way.

Mrs Margaret Grayson, Chair

Mrs Dori-Anne Finlay-Blackstock, Deputy Chair

Northern Ireland Cancer Research Consumer Forum, August 2012

Personal & Public Involvement in Research

'Increasingly patients, carers and members of the public are contributing their perspectives to the way clinical research is designed, commissioned, managed and supported. Active involvement in clinical research is very different from being a participant in a study. It means:

- research done with members of the public, not to, about or for them*
- getting involved in the research process or activity itself*
- making sure that clinical research is relevant, useful and to the benefit of the NHS and the people who use it.'*

From the National Institutes of Health website
http://www.crnc.nihr.ac.uk/ppi/get_actively_involved/index

NICRCF Purpose

The Northern Ireland Cancer Research Consumer Forum (NICRCF) brings together people affected by cancer to influence cancer research and contribute a consumer perspective to research being conducted in Northern Ireland. The work of the Forum also includes networking and planning. The Forum provides a visible focus of Personal and Public Involvement (PPI) in cancer research in Northern Ireland.



Forum Meeting September 2011

NICRCF Objectives

To promote, provide, monitor and evaluate:

- effective consumer involvement in cancer research both regionally and, as appropriate, nationally*
- effective consumer involvement in cancer research across various stages of the research process and, as appropriate, act as an advisory group for researchers*
- consumer membership of relevant research committees, steering groups or trial management groups*
- a forum for identification of consumer training needs and training delivery and evaluation*
- a forum to facilitate and maintain communication pathways and networks about news and developments in research and personal and public involvement*
- a forum for researchers to formally liaise with the cancer consumer community*
- the role of PPI in cancer research*
- awareness of cancer research in Northern Ireland*
- the contribution of consumer involvement in cancer research in Northern Ireland, and generate recommendations and plans*

The above objectives were agreed by Forum members in 2011.

Achievements in 2011-2012

NICRCF Membership

Throughout the year, membership has fluctuated between 15-17 members. This number of members has brought a diversity and wealth of experience and skills which enhances the Forum and the contribution of PPI to cancer research in NI. The Forum remains open to new members who also want to help shape cancer research.



Forum Meeting September 2011

Establishing Forum Meetings

In its inaugural year, the Forum was keen to establish working processes and make progress in the areas of training and involvement with cancer researchers. Forum office bearers were designated, terms of reference and values were agreed by the group and a schedule of meetings planned.

Quarterly meetings took place at the Cancer Centre at Belfast City Hospital, covering various aspects of Forum business.



Forum Meeting June 2012

A feature of the meetings was also the opportunity to hear about current research activities. The Forum wishes to thank the researchers and study participants who gave their expertise and time to speak at Forum meetings and provide stimulating discussion sessions.

Some Meeting Highlights:

15 September 2011



Dr Jackie James, Director, NI Biobank
'An Update on the NI Biobank & and
the Consumer Role'

08 December 2011



Dr Olinda Santin, QUB Research
Findings: 'The health and wellbeing of
cancer survivors and their caregivers in
Northern Ireland'



Miss Myree McClure
Mr Brian Coburn
Research for cancer related fatigue -
'Experiences as participant on The
Back on Track Programme'

Meeting Highlights continued:

07 March 2012



Mr Conan Donnelly,
Biostatistician/Researcher, NI
Cancer Registry
'NI Cancer Registry- Who we are
and what we do'

07 June 2012



Dr Claire Millar, Research Nurse,
NI Biobank
'NI Biobank Update and Research
Nurse perspectives'

Developing Training Opportunities

The Forum has been very grateful for the contribution of researchers and healthcare professionals providing training and research tours tailored to the needs of NICRCF members. The year concluded with an exciting collaborative initiative enabling delivery of a nationally accredited Macmillan Cancer Support PPI workshop 'Building Research Partnerships' in Belfast. This also provided an opportunity for Forum members to work with professionals and PPI representatives from other disease areas. There was excellent feedback following the workshop which was facilitated by Mr Derek Stewart (below, left). The event was co-ordinated by Mr Jack Nunn (below, right).



'Building Research Partnerships' August 2012



The Training Programme 2011:

Date	Presenter	Topic
02.11.11	Margaret McManus, Information Manager, Macmillan Information and Support Centre	Getting to grips with research jargon
	Sally Campalani, Senior Cancer Nurse, Belfast HSC Trust	Hints for effective communication in research meetings
	Margaret McManus, Information Manager, Macmillan Information and Support Centre & Ruth Boyd PPI Lead, NI Cancer Trials Centre (NICTC)	What's involved in a review of clinical trial patient information sheets & principles of Plain English
14.11.11	Helen, Barnes, Cancer Research UK Local Engagement and Development Manager	Belfast Cancer Research UK Centre
	Professor Dennis McCance, Scientific Director, CCRCB	The Centre for Cancer Research and Cell Biology
	Dr Dean Fennell, Consultant and Cancer Research UK Clinician Scientist	Developments in Lung Cancer Research



Centre for Cancer
Research
and Cell Biology
with Dr Alex Chacko
(2nd from left)
November 2011



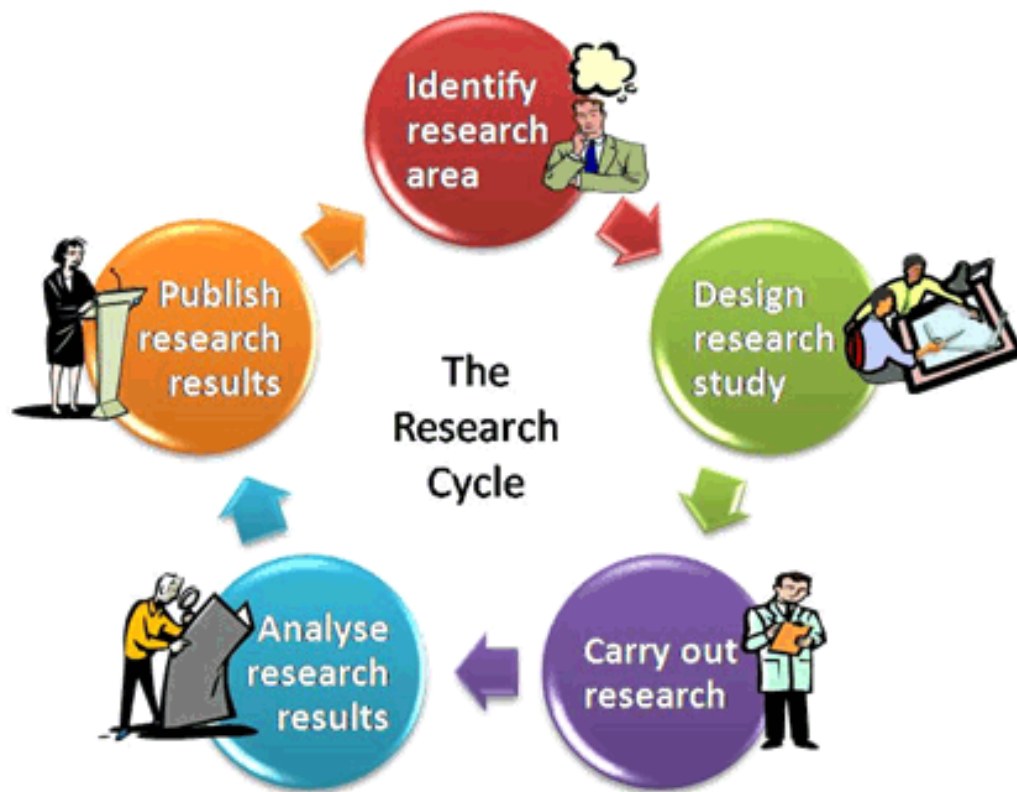
NI Cancer Registry
with Dr Anna Gavin
(4th from right)
May 2012

The Training Programme 2012:

Date	Presenter	Topic
16.02.12	Ruth Boyd, PPI Lead, NICTC	More about communicating in meetings and groups
	Mrs Anne McNulty	A personal experience of participating in a clinical trial
02.05.12	Ruth Boyd, PPI Lead, NICTC	Where clinical trials come from and Patient Information Sheet review update
	Sally Campalani, Senior Cancer Nurse, Belfast HSC Trust	More about communicating in Groups - team roles and preferences
	Sally Campalani, Senior Cancer Nurse, Belfast HSC Trust	Political Influencing for PPI Representatives
17.05.12	Dr Anna Gavin, Director NI Cancer Registry	Tour and information NI Cancer Registry
	Various researchers based in NI Cancer Registry and Centre for Public Health	<ul style="list-style-type: none"> -Why do Cancer Patients Die and proposed research -NAEDI -Prostate research Nutrition and Cancer Survival -Pharmaco Epidemiology Research and Cancer

Shaping Cancer Research

The key purpose embedded in the activities of the Forum is facilitating effective involvement of members across the various stages of the research cycle.



Research Cycle

from the Diabetes Research Network website
<http://www.ukdrn.org/lrn/nec/public.aspx>

Some Forum members had already been involved in research committees, but now there was an opportunity to expand on this, introduce a more systematic approach to involvement, and one that recognised best practice of at least two PPI representatives per committee. Members

have given an enormous number of hours of their time and experience to this work, to ensure the consumer perspective is represented. Involvement has different forms, dependent on the stage of research or research oversight, or whether the research has a local Chief Investigator, or is part of a national trial led from another centre.

The PPI vision

'Maximise the benefits of research to patients and the NHS through active, inclusive and co-ordinated Patient, Carer and Public Involvement'

Patient and Public Involvement Strategy to 2015
National cancer Research Network

<http://ncrndev.org.uk/downloads/MiscDocs/NCRN%20PPI%20Strategy%20to%202015%20final.pdf>

Background to the activity of the NI Cancer Trials Centre and Network 2011/12

The mechanism for Forum members' involvement with researchers is not simply through the Forum itself, but to a large extent, through involvement in the Northern Ireland Cancer Trials Centre (NICTC). The NICTC co-ordinates cancer clinical trials activity across the region, through the Northern Ireland Cancer Trials Network. The NICTC liaises with Trusts, universities, research institutions and the pharmaceutical industry to promote the conduct of cancer research and equity of patient access to new treatments through clinical trials. Between April 2011 to March 2012, 1020 people were recruited to cancer clinical trials and other high quality research studies in Northern Ireland. The type of trials delivered range from phase I (to gather safety information and find best dose) to phase III (to compare the new treatment with the existing gold standard treatment) and include studies on drugs, radiotherapy, surgery, imaging, screening, prevention and early diagnosis. Other studies also include genetic epidemiology, questionnaire, quality of life, palliative and supportive care and translational research (taking ideas from the laboratory into the clinic).

Although recruitment was to a wide range of studies covering most disease areas, recruitment to urology, gastrointestinal, breast and haematology cancer clinical trials far exceeded other disease areas accounting for 79% of the overall annual recruitment. 65% of activity is in the Cancer Centre in Belfast, however, a growing level of research activity is in the Cancer Units, throughout Northern Ireland, with a number of high recruiting studies open at several sites.

Forum Membership in Research Committees

All the NICRCF members are automatically members of the NI Cancer Trials Co-ordinating Committee which has oversight of the adoption of research studies to the NI Cancer Trials Centre and Network portfolio. NICRCF members review the proposed information to be provided to patients as potential research participants, as part of the study informed consent process.

Studies with NICRCF input through NI Cancer Trials Co-ordinating Committee 2011-2012:

<i>Haematological</i>	<i>9</i>
<i>Breast</i>	<i>3</i>
<i>Lung</i>	<i>3</i>
<i>Prostate</i>	<i>2</i>
<i>Pancreatic</i>	<i>1</i>
<i>Renal</i>	<i>1</i>
<i>Bladder</i>	<i>1</i>
<i>Testicular</i>	<i>1</i>
<i>Ovarian</i>	<i>1</i>
<i>upper Gastro-intestinal</i>	<i>1</i>
<i>all solid tumours (early phase study)</i>	<i>1</i>
<i>supportive care</i>	<i>1</i>
<i>Total</i>	<i>25 studies</i>

Other studies reviewed:

International Cancer Bench-marking Partnership – Module 4

There is also PPI representation in committees that have various functions such as providing a strategic direction, co-ordination, and supervision of quality standards in the conduct of cancer research.

NICRCF members are in the following Research Committees:

- NI Cancer Trials Co-ordinating Committee
- NICTC Executive Committee
- NICTN Steering Group
- Experimental Cancer Medicine Centre Steering Group
- Belfast Cancer Research UK Centre Governance Board
- Study Specific Steering Groups

'In spite of my initial apprehension going to the first meeting, I've been made to feel very welcome by the NICTC Executive Committee and Network Steering Group. My experience has been valued and it's been a privilege to contribute to the group.'

Mrs Dori-Anne Finlay-Blackstock, NICRCF Deputy Chair

Working with local Investigators

The majority of studies being presented to the NI Cancer Trials Centre & Network this year have been national or international, multi-centre studies. However, the opportunity has arisen to work more closely with some local researchers from the design stage of their study. For example, Conan Donnelly, a Researcher in the NI Cancer Registry, invited Forum members to give feedback on study documents being sent to the public.

'In our population based cancer research, the input of consumers to study design is critical. In this respect the Northern Ireland Cancer Consumer Forum have proved to be a most valuable partner providing an accessible, highly informed and research literate voice which has really enhanced the quality of our work.'

Mr Conan Donnelly, Researcher

Researcher Cathy Payne invited members of the Forum to contact her if they were interested in PPI representative roles within the APRIL study, looking at 'active palliative rehabilitation in lung cancer'.

Dr Sandra Irvine, a local Chief Investigator in the Centre for Cancer Research and Cell Biology, Queen's University Belfast (QUB), received feedback from Forum members about a study Patient Information Sheet.

'I enjoyed talking to members of the Forum and found it very encouraging and educational. They definitely picked up on things in the Patient Information Sheet that I would never have thought of. I think they are making an extremely valuable contribution to the research process.'

Dr Sandra Irvine, Researcher

Closer working with researchers has also developed through membership of a study steering group. Mary Murphy is currently conducting a qualitative research study involving cancer patients.

'After completing my first patient interview, I met with the public member of the steering group (who had personal experience of cancer) on a one-to-one basis. This enabled me to discuss my interview technique including the suitability of some questions. The feedback was invaluable. I realised that for the most part that I was on the right track, however I received some very useful tips for future interviews.'

Mrs Mary Murphy, Researcher

Wider Networking & Involvement

During the year, members of the Forum contributed to a number of regional conferences and meetings. Some members were invited speakers or engaged with the media to promote the dissemination of research findings, or shared personal experiences of involvement in research.



Mr Brian Coburn, 2nd from right, shared his experience of the value of the 'Back on Track Programme' at a conference 'Cancer Survivorship: Expanding the Vision' held in Lisburn 10 October 2011. Brian is pictured with Mr Ciarán Devane, Chief Executive Macmillan Cancer Support, Dr Olinda Santin, Research Fellow, QUB and Dr Jackie Gracey, Lecturer, University of Ulster.



At the same event, Mrs Janine McCann gave radio and TV interviews to highlight new research about the health of cancer survivors and carers, and raise awareness of the needs of cancer survivors after treatment.



Miss Myree McClure spoke at the conference 'Improving Outcomes: The Role of Rehabilitation in Cancer Survivorship' held in Belfast 17 May 2012. She discussed issues with a leading researcher in the field of cancer rehabilitation, Dr Martin Chasen, Medical Director at Ottawa Hospital Cancer Centre, Canada.

The Forum Chair, Margaret Grayson, and PPI professional lead, Ruth Boyd, welcomed the invitation from the Manager of the NI Clinical Research Network to meet with Clinical Leads in June 2012. This was an opportunity to share ideas and information, with clinical researchers in other disease areas, about how to develop PPI within research networks.

Professor Bernie Hannigan, Director of the HSC Research & Development Division of the Public Health Agency invited Margaret Grayson to chair the morning session of a workshop 25 April 2012, to develop future work plans of the National Cancer Institute- All-Ireland Cancer Consortium.



Importantly, PPI representative activities have also strengthened links at national and international levels. Some of Margaret Grayson's feedback:

NCRI/NCRN PPI Steering Group (London)

'Representing NI at the National Cancer Research Institute/National Cancer Research Network PPI Steering Group facilitates sharing of knowledge on PPI best practice at a national level'

NCRI Conference (Liverpool)

'I would encourage all Forum members to apply for a bursary to attend the National Cancer Research Institute Cancer Conference in Liverpool . The conference is the major forum in the UK for sharing national and international cancer research and brings together leading experts from all disciplines and is a mixture of plenary lectures, parallel sessions and workshops – there is an opportunity to discuss and question researchers and network with other PPI reps – an experience not to be missed! Thank you to NCRI for providing patient bursaries for this 4 day conference!

EORTC Project Member *'Through my membership of the NCRI/ NCRN Consumer Liaison Group I was invited to be involved in the EORTC (European Organisation for the Research and Treatment of Cancer) on going project to improve the quality and relevance of the Patient Information Sheets and Informed Consent given to UK patients considering taking part in EORTC research activities. Attending their 50th Anniversary Conference in Brussels, highlighted to me the importance of international studies in relation to the number of patients taking part in a research project and also the financial implications.'*

Study Days, ICPV (Birmingham & London) *'ICPV (Independent Cancer Patient Voices) is a patient advocate group promoting the value of medical research to public health and national economy. Study days are a learning and sharing partnership between academics, clinicians and patients. They enable and empower patients to speak as patient advocates and research partners with the professionals.'*

NCIN Conference (Birmingham) *'National Cancer Intelligence Network (NCIN) "Cancer Outcomes Conference" highlighted the need for high quality data collection about cancer patients. Then using this information for analysis, publication and research to improve standards of cancer care and clinical outcomes. The large number of posters and research presentations by the researchers in the NI Cancer Registry showed the importance of their research locally, nationally and internationally. I was awarded a patient bursary to attend this conference and there was a significant input from patients at all sessions and through networking with other patient reps and professionals.'*

Communications and Research Awareness

Objectives of the Forum include promoting PPI as well as raising awareness of cancer research. A number of initiatives will be developed to support these aims. A key approach to enhance awareness among the general public is access to local cancer research information available on the internet. Members of the Forum have reviewed the content of 2 websites:

Northern Ireland Cancer Trials Centre (host to NICRCF information)

<http://www.qub.ac.uk/research-centres/nictc>

and clinical trials section of the Belfast HSC Trust Cancer Services website (due to go live in the near future).

Five issues of the Forum newsletter 'Consumer Impact' have been produced and disseminated to a wide professional and voluntary sector audience, and they posted on the 'getting involved' section of the NICTC website.



Some NICRCF Future Plans

Our future plans are to continue to raise awareness about cancer clinical research, promote PPI and maintain mentorship and training for members of the NICRCF.

The most ambitious project of the Forum has been planning a PPI Masterclass and Public Information Evening in September 2012, hosted by the Forum. The event will showcase the activity of NICTC/NICTN. We look forward to this opportunity to tell the public more about how they can get involved, and to hear from researchers, leading speakers in PPI, and cancer patient perspectives.



Planning Meeting July 2012

Over the coming year there will also be a drive to increase PPI within the trial management context, where studies are developed within Northern

Ireland, PPI Representatives will be invited to the study steering groups (e.g. Habio Study).

Activities that increase PPI opportunities and raise awareness of clinical research across the Cancer Centre and Cancer Units will continue to be explored in the context of patient information needs and also outreach to ethnic minorities.

Recruitment to support the activities of the NI Palliative Care Research Forum will be explored, offering the training and mentorship infrastructure of the NICRCF to anyone with palliative care experience wishing to influence research.

Have you something to say about hospice or palliative care?

Would you like to have your say about palliative care research?

We are looking for people like you:

- To promote personal and public involvement in palliative care research
- To help plan or comment on research studies, clinical trials and patient leaflets
- To become a member of a committee or group
- To help raise awareness of research studies and clinical trials in palliative care in Northern Ireland?

Training, support and the opportunity to meet with other PPI Representatives will be available



Do you want to find out more? Contact: Ruth Boyd at nictc@belfasttrust.hscni.net

Telephone: 028 9026 3903
or see 'getting involved' at www.qub.ac.uk/nictc

In Memory



In August 2012 we heard the sad news that an esteemed Forum member, Myree McClure, passed away. Myree was committed to the work of the Forum and its mission to shape cancer research to improve future cancer care and treatment. Throughout the year Myree contributed in many ways – at Forum meetings, training workshops, research tours, in the NI Cancer Clinical Trial Co-ordinating Committee, as a PPI representative for a cancer rehabilitation study and as a conference speaker. Many tributes have been expressed about Myree, from fellow Forum members and researchers, who all have great admiration for Myree. We will miss her very much. Her concern for others, cheerfulness, and tireless drive and enthusiasm are an inspiration to us all.



Perspectives from the Northern Ireland Cancer Trials Centre (NICTC)

Last summer, when the NICTC prepared for the first open information evening about opportunities to get involved in cancer research in Northern Ireland, we could not have predicted the level of interest, enthusiasm and commitment from PPI Representatives to working with professionals to help shape cancer research. Nor could we have anticipated how the first year would be packed with so many developments. In a short space of time the NICRCF has established a strong identity and its members have demonstrated their vital voice and role in the conduct of cancer research in Northern Ireland.

It has been a delight and privilege to work with members of the NICRCF who bring to cancer research a wealth of personal perspectives and skills. We are enriched by this and the way we manage, and undertake research has changed. As a consequence of this change the standard of research is being raised.

We want to thank the members of the NICRCF for their commitment and vision to support and influence cancer research in Northern Ireland, ensuring that the person affected by cancer is at the heart of this process.

We want to thank the cancer research community for recognising the value of PPI and being willing collaborators with NICRCF members.

Thanks also to the healthcare professionals and researchers who have provided training in various ways, and to Sharon Dunwoody, Administrative Facilitator for the NICRCF.

A special word of thanks must go to Margaret Grayson, Chair of the Forum, whose unwavering enthusiasm and commitment, and willingness to devote enormous amounts of time to PPI Representative and Forum activities, in NI or beyond, have been invaluable. The whole membership of the Forum has created a very dynamic and successful first year for the NICRCF.

We look forward to on-going collaboration with NICRCF members in the year ahead.

Ruth Boyd, PPI Lead,

on behalf of the NICTC Executive Committee

Financial Summary

September 2011- August 2012

<i>NICRCF Expenses</i>	<i>Sept 2011 - Nov 2011 £</i>	<i>Dec 2011 - Feb 2012 £</i>	<i>Mar 2012 - May 2012 £</i>	<i>June 2012 - Aug 2012 £</i>	<i>Total for Year £</i>
<i>Travel</i>	<i>154.02</i>	<i>114.00</i>	<i>61.20</i>	<i>176.54</i>	<i>505.76</i>
<i>Catering</i>	<i>35.00</i>	<i>30.00</i>	<i>40.00</i>	<i>00.00</i>	<i>105.00</i>
<i>Total NICRCF Expenses paid by NI Cancer Trials Centre</i>					<i>£610.76</i>

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