



A Brighter Future Together

*2nd Year Report of the Northern Ireland
Cancer Research Consumer Forum*

September 2012 – August 2013



Contents

	Page
Welcome to the Second Year Report	3
NICRCF Purpose and Objectives	4
Achievements in 2012-2013	5
• NICRCF Membership	5
• Forum Meetings	6
• Training Opportunities	8
• Shaping Cancer Research	12
- Research Activity of NI Cancer Trials Centre & Network 2012/13	12
- Review of New Clinical Trials	13
- PPI highlights: Studies Developed by Local Researchers	14
- Forum Member Involvement in Other Research Committees and Meetings	15
- In Northern Ireland	15
- Nationally and Internationally	17
- Industry Links	21
- Feedback from Researchers about PPI in Cancer Research	21
• Communications and Research Awareness	25
- A Brighter Future Together	25
- Other opportunities to raise awareness about cancer research and PPI	28
Some NICRCF Future Plans	31
Perspectives from the NI Cancer Trials Centre	32
Financial Summary	33
Contact details	34

Welcome to the Second Year Report

The Northern Ireland Cancer Research Consumer Forum (NICRCF) has been in existence for two years. It is good to be able to report that Year Two built on the foundation blocks laid in Year One in terms of increased Personal and Public Involvement (PPI) within Cancer Research in NI.



Margaret Grayson, Chair, NICRCF

It is my privilege to Chair the NICRCF and I would like to say thank you and well done to all the Forum members. They are a truly inspiring group of people, their enthusiasm and willingness to share their life skills and cancer experiences through partnering with researchers to enhance their research.

Members have been involved in many different areas of cancer research – research that is of benefit to both Health and Social Care (HSC) and the people who use it. This report only reflects part of the PPI involvement in helping to shape cancer research that leads to improved services, treatments and quality of life for all people diagnosed with cancer.

Thank you to the Directors and all the staff at NI Cancer Trials Centre/Network (NICTC/NICTN) for their support and encouragement. Special thanks to Ruth Boyd, the PPI Lead, for her endless energy, professional skill and expert guidance; also to Sharon Dunwoody for her excellent administrative facilitation.

Mrs Margaret Grayson

Chair, NICRCF, August 2013

NICRCF Purpose and Objectives

Our purpose and objectives are unchanged from Year 1.

Our purpose is to bring 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.

Our objectives are:

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*

Achievements in 2012-2013

Membership

Over the course of the year we have said goodbye to some members and have also welcomed new ones. At the end of August 2013 the Forum (NICRCF) has 21 members, an increase from last year. Once again, Forum membership represents a range and wealth of experience that creates a very dynamic group of people, all very committed to PPI in cancer research.



Some members celebrating the Forum's
1st Birthday in September 2012



Supporting 'Action on Access' to clinical trials
November 2012

Forum Meetings

The Forum has maintained a schedule of quarterly meetings throughout the year. These meetings have provided both the opportunity to hear from guest speakers and also the means for members to get together to share their PPI activities.

The Forum members wish to thank all the speakers who so willingly shared their time and expertise to give such insightful presentations and generate lively discussion.

Some Highlights:

September 2012



Katie Scott (left) Cancer Research UK Research Engagement Manager:

'Engaging the Public with Research'

Dr Sandra Van Schaeybroeck (right) Consultant in Medical Oncology/Clinical Senior Lecturer:

A new trial in bowel cancer 'Mercuric'

March 2013



Sally Campalani Senior Nurse,
Cancer Services, BHSCT

*'Drug Funding and drug access
- Clinical trials and beyond'*

May 2013

Dr Siobhan McGrath (centre)
Head of the Office for
Research Ethics Committees
Northern Ireland

*'Understanding Ethics and
Performing Ethical
Research'*



Training Opportunities

This year Forum members have once again demonstrated a desire to avail of every opportunity to learn more about cancer research in NI and the role of PPI representative in research.



Masterclass: Dave Ardron in action

Judith and Dave Ardron receive a token of appreciation from Margaret Grayson and Ruth Boyd on behalf of the NICTC

The year started with a unique 'Masterclass' opportunity in September 2012. The Forum and the NI Cancer Trials Centre welcomed facilitators Mr Dave Ardron, Chair of the North Trent Consumer Research Panel, and Mrs Judith Ardron, a member of the research panel. Mr Ardron, a past Chair of the National Cancer Research Network Consumer Liaison Group, shared his wealth of experience from the podium, during the afternoon workshop 'Personal and Public Involvement (PPI) in Research – a Masterclass', exploring the impact of lay advocacy in research and recruitment of lay researchers. He also highlighted the support structures that are necessary to facilitate PPI in research. The event, supported by the NI Cancer Trials Centre (NICTC) was held in the Centre for Cancer Research and Cell Biology (CCRCB), Queen's University Belfast (QUB). It was attended by 40 PPI representatives, researchers and

research professionals from Northern Ireland and the Republic of Ireland, evidence of the growing interest in PPI.

A very progressive development this year was the establishment of a series of 'Building Research Partnership' workshops in NI.



The NI Cancer Trials Centre, NI Clinical Research Network and HSC R&D Division, Public Health Agency in collaboration with Macmillan Cancer Support invite you to a workshop on Personal and Public Involvement in Research:

Building research partnerships

This **free** workshop will outline the different types of research methods and terminology used in research and how **the public** can get involved as well as exploring the issues related to becoming and being a member of the public involved in research.

Who is it for?
People interested in getting involved in research and researchers interested in involving service users, carers or the public in their research.

How long is it?
1-day workshop from 10am until 4:30pm

What will I get out of it?
An understanding of what it means to be involved in research and how service users, carers and the **public** can be involved at each stage. This day could also be a first step towards [becoming a facilitator](#) on this course in the future.

When and where?
This workshop will take place on the 25 October 2012 in **Belfast**.

How do I find out more?
For more information, please contact cara.mcclure@hscni.net Tel: 028 90 55 3617

Registration
If you are interested in registering your interest for this workshop you can:
• Call Cara on 02890553617 or email cara.mcclure@hscni.net

www.macmillan.org.uk/learnzone Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).



Through the support of Macmillan Cancer Support and the HSC Research and Development (R&D) Division of the Public Health Agency, and in collaboration with the NICTC, this nationally recognised workshop has provided a valuable platform for health researchers and patient/carer representatives to not only learn about PPI in research – but put it into action! The workshop consistently receives very positive evaluation by participants. During the year, many Forum members have attended workshops and Margaret Grayson has undertaken facilitator training.

She is the first regional facilitator to complete this training in the UK. Other Forum members are also hoping to develop their role in this way.



Forum members and facilitators Derek Stewart (centre) and Jack Nunn (far right) 'Building Research Partnerships' workshop September 2012

Forum members and Gail Johnston (far left) HSC R&D Programme Manager, and Derek Stewart (far right) Facilitator/Trainer 'Building Research Partnerships' workshop May 2013



Forum members enjoyed another opportunity to witness the stimulating environment of CCRCB, QUB. Researchers enthusiastically explained their projects and the methods used to develop greater understanding of cancer, define new treatment targets and develop new therapies.



Forum members joined with BHSCT staff
and volunteers on a tour of CCRCB
March 2013

As a member of the Independent Cancer Patient Voices Group, Margaret Grayson attended a Radiotherapy Study Day with the National Cancer Action Team in London, in October 2012. Margaret described it as ‘an excellent day of a sharing and learning partnership between clinicians, academics and patients.’

In January 2013 Forum members attended a further excellent training event supported by the HSC R&D Division - ‘Personal and Public Involvement (PPI) in Biomedical Research: A workshop for researchers and PPI Representatives’. The workshop was facilitated by Mr Derek Stewart, Associate Director for PPI, National Institute for Health Research.

In February 2013 the Forum held a training event for members, looking at the role of the PPI Representative, and this was also used as an opportunity to identify future training needs. This informed subsequent plans for meetings and training.

Shaping Cancer Research through PPI

Shaping cancer research in NI through PPI is one of the Forum's core objectives. The overall picture of research activity across NI has been very positive this year.

Research Activity of the NI Cancer Trials Centre and Network: April 2012 – March 13

The NICTC/N facilitates the delivery of cancer clinical trials and other high quality clinical research throughout Northern Ireland. The NICTC/N co-ordinates a variety of trials from the National Cancer Research Network portfolio, Cancer Research UK, pharmaceutical and biotechnology industries, universities and local research groups. Between April 2012 to March 2013, 1936 people in Northern Ireland were recruited to cancer clinical trials and other cancer research studies. This exceeded the overall recruitment target of 850 participants (10% of incident cancers excluding non-melanoma skin cancers). Recruitment to interventional trials was 433.

Although recruitment was to a wide range of studies, recruitment to urology, gastrointestinal, breast and haematology cancer trials far exceeded other disease areas accounting for 89.5% of overall recruitment.

Activity in Belfast HSC Trust accounted for 40.4%, and the Cancer Units in Altnagelvin, Antrim, Craigavon and the Ulster hospitals made the significant contribution of 59.6% of overall recruitment.

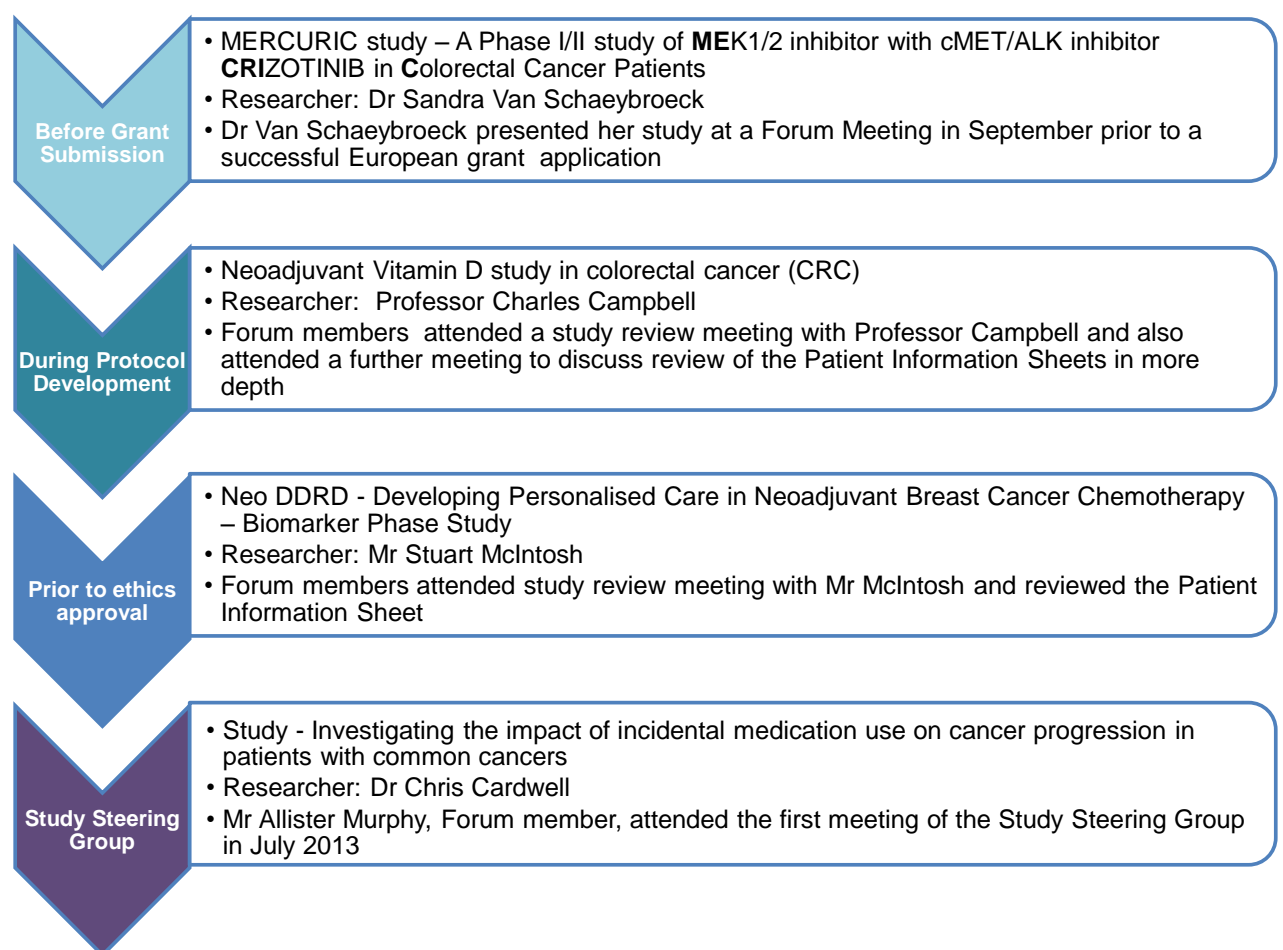
Review of New Clinical Trials

One of the changes in the study adoption process was the transition from a monthly Clinical Trials Co-ordinating Committee Meeting, to more frequent meetings with a focused agenda on study review and adoption decisions. This impacted on Forum members by reducing the period of notice about meetings, thus reducing the time to undertake a review of study information. However, in the majority of cases the Forum members have been able to continue to successfully contribute to the study review process.

Cancer Type	Number of studies with Forum member involvement in the NICTC review process
All solid tumours (early phase)	2
Bowel cancer	1
Breast cancer	5
Endometrial cancer	1
Liver cancer	1
Lung cancer	1
Miscellaneous cancer types	1
Multiple Myeloma	1
Oesophageal/Gastro-oesophageal /Gastric cancer	2
Ovarian cancer	1
Polycythaemia Vera	1
Prostate cancer	5
Total	22 studies

PPI Highlights: Studies Developed by Local Researchers

This year there has been an increasing number of research studies led by researchers in NI. Working as partners with local researchers, to maximise the patient benefit of research, is a fundamentally important dimension of the Forum's role. This work also highlights the different stages at which the Forum members have involvement with Researchers. The earlier in the research cycle Forum members are able to contribute, the greater the potential impact they can have.



We have appreciated the opportunity to work with these researchers throughout the year.

'I was made to feel very welcome and my input seemed to be greatly appreciated. There was a wide mix of people on the steering group ranging from administrators to researchers so it wasn't just a collection of medics with PhDs etc. I know quite a few men with my own disease who self-medicate, especially where statins and NSAIDs are concerned and this was of interest to the panel. In addition I cautioned about the ways and means of disseminating the final report – hint that prescription drug 'X' will fight cancer and many will be tempted to self-medicate with potentially lethal results 😞

Patient representation on steering groups like this can only lead to better research.'

Allister Murphy, Study Steering Group, Forum Member

Forum Member Involvement in Other Research Committees and Meetings

In Northern Ireland

Committee and Board Membership

During the course of the year, Forum Chair, Margaret Grayson, and Deputy, Dori-Anne Finlay-Blackstock, have been members of the NI Cancer Trial Centre Executive Committee and NI Cancer Trials Network Steering Group. Geoff Hill is a member of the ECMC Steering Group.

Andy Anderson is a member of the Cancer Research UK Governance Board.

Meetings

Clinical Research Division

A new development this year was the introduction of the Clinical Research Division Meetings of the Centre for Cancer Research and Cell Biology (CCRCB), chaired by Professor Joe O'Sullivan. These meetings are designed to increase the quality and quantity of clinical cancer research taking place locally and provide a discussion forum for all those involved. Forum members were welcome to attend, and they have contributed to many topics raised, including discussion of the clinical and research infrastructure necessary to deliver research plans.

The Launch of the NI Molecular Pathology Lab and NI Biobank

On 9th January 2013 the Forum welcomed an important research landmark in NI- the launch of the NI Molecular Pathology Laboratory and the NI Biobank, based in CCRCB. This new facility examines tumour samples at a molecular level. 'This new level of testing helps oncologists tailor individual treatments to individual patients, offering a new era of personalised medicine in Northern Ireland. It will also advance meaningful research in new cancer diagnostics and new cancer treatments' (MDBS News, QUB, September 2013).



At the launch of the NI Molecular Pathology Laboratory and NI Biobank: Margaret Grayson, Chair, NICRCF, Derek Stewart (centre) NCRI Confederation of Cancer Biobanks, Professor Manuel Salto-Tellez, Chair of Molecular Pathology, QUB

Nationally and Internationally

Committee Membership

Margaret Grayson is a member of the National Cancer Research Institute (NCRI) /National Cancer Research Network (NCRN) PPI Steering Group. Representing Northern Ireland, in this forum there is the opportunity to share PPI developments, knowledge and best practice at a national level. Margaret is an associate member of the NCRI/NCRN Consumer Liaison Group. She is a member of the NCRN reference panel for the European Organisation for Research and Treatment of Cancer (EORTC) and has also been involved in a consultation linked with the European Patients' Academy on Therapeutic Innovation (EUPATI).

'As an EORTC Project Member I was invited to Brussels to attend their first study day with patients. We discussed the EORTC's long term commitment to undertake clinical academic studies and to align EORTC Mission with patient expectations. There was discussion on EU legislation and patient role in influencing; appropriate study endpoints; value and validity of surrogate end points; the aim to make quality of life assessment mandatory part of clinical trials; for translational research programmes the challenges and pitfalls for collecting prospective and retrospective biological material across the EU due to lack of coordination. Over recent months I have reviewed four EORTC studies – 1 breast cancer, 1 melanoma and 2 colorectal cancer – highlighting the importance of high quality and relevant patient information in relation to EORTC studies offered to people in the UK.'

Margaret Grayson, EORTC Project Member, Forum Chair

Margaret is also a member of the patient advocacy group Independent Cancer Patient Voices, inputting to a wide range of important issues, research proposals, protocols and patient information sheets.

Debbie Keatley is a member of an advisory panel of the National Institutes of Health Research (NIHR) Health Technology Assessment (HTA) Programme.

'I was appointed as a public contributor to the Elective and Emergency Specialist Care Panel (EESCP) in March, one of the six UK-wide advisory panels that supports NIHR's Health Technology Assessment (HTA) Programme. The role of the advisory panels is to identify topics of health importance for which research is required, consider which research briefs on these topics should be developed and advertised; consider the importance of research proposals received and make recommendations on which research proposals should progress to the next stage. We also provide feedback to support the development of research proposals.

Public contributors are full and equal partners on the panels, so there's a huge sense of responsibility and the remit is very wide, as we're considering proposals from right across the health specialisms. I'm new, so there's a lot still to learn but so far I'd say that on the upside I'd have to include meeting people who are experts in their field, passionate about their work and passionate about improving health research and health outcomes. The challenges are - lots and lots of reading, prioritising and decision making; there are always more research proposals than can be taken forward. It's a great opportunity, I'm delighted to be involved and it's really interesting work.

Debbie Keatley, HTA Advisory Panel, Forum Member

National Study PPI Contact

Mike Moran was invited to review the Ballad Protocol and become the study's PPI contact. This study is in adenocarcinoma of the small bowel and is part of a portfolio of studies being supported by the partners of the International Rare Cancers Initiative, and collaboration of the US National Cancer Institute (NCI), National Cancer Research Network (NCRN), European Organisation for Research and Treatment of Cancer (EORTC) and Cancer Research UK.

Meetings

National Cancer Research Institute Annual Conference

In November 2012 Margaret Grayson attended the NCRN annual conference in Liverpool. As always, PPI representatives from around the UK played a valuable role at this meeting. On this occasion, during one of the conference poster sessions, Margaret Grayson spoke to researchers about the 'Building Research Partnerships' initiative (see page 9) sharing information about the content of the course and discussing the impact of PPI in relation to their research.



Poster session: Karen Innes (far left) NCRN Consumer Involvement Lead, Margaret Grayson, Forum Chair Jack Nunn (Macmillan Learning and Development Co-ordinator, Jim Elliott (far right) Macmillan Facilitator

Margaret Grayson was also a member of the conference's 'Dragon's Den', a creative format for cancer research review. Researchers had the opportunity to pitch their projects to small panels of consumers involved in research. The process was a great success and a similar event will be held again during the 2013 conference.

'In my panel the research was around the problems women appear to have in adhering to taking Aromatase Inhibitors (AIs) for the recommended 5 years. (This held a personal interest as I have been taking AIs for 8 years).'

Margaret Grayson, Forum Chair

Margaret Grayson sharing Forum news with Jill Bartrop (left) NCRI Consumer Liaison Group and Richard Stephens, Consumer Liaison Group Chair



National Cancer Intelligence Network Conference

This year, 3 Forum members received bursaries to attend the National Cancer Intelligence Network (NCIN) conference held in Brighton in June 2013. Margaret Grayson, Dori-Anne Finlay-Blackstock and Allister Murphy found the conference presentations a fascinating insight into the value of data for patient benefit, and enjoyed networking with researchers.

'Attending the NCIN annual conference was a wonderful experience in learning and being part of the on-going progress in cancer research.'

Dori-Anne Finlay-Blackstock, Forum Deputy Chair

Industry Links

This year the Forum was approached by a Clinical Research Organisation, on behalf of a pharmaceutical company, to review a study Patient Information Sheet (PIS) for use in the UK. Five members of the Forum were involved in the review and their comments were forwarded to the company.

Roche Products Limited approached NICTC and invited members of the Forum to comment on a new PIS template. The feedback from the company stated the Forum's input had been 'a huge help' and many of the points raised had been incorporated into the new document.

Researchers Feedback about PPI in Cancer Research

Forum members have been busy working with researchers during the year. As testament to the contribution they have brought to research we report here some of the feedback received from researchers.

Members of the Forum began their involvement in the APRIL study (Active Palliative Rehabilitation in Lung Cancer) last year. This year, the researcher, Cathy Payne, gave a most comprehensive review of the impact of consumer involvement on her study at the time of its launch in March 2013. She thanked member of the Forum and members of the Lung Support Group.

APRIL

Active Palliative Rehabilitation in Lung Cancer

Thank you for attending this event which marks the launch of APRIL, part of a doctoral research study supported by the All Ireland Institute of Palliative Care and the Health & Social Care Research & Development Office of the Public Health Agency.

Consumer/user involvement is a key component of our research and will continue throughout the 3 years of funding:

1. Influencing development of the research proposal
2. Supporting application to funders for research fellowship
3. Reviewing patient educational materials for ease of use and acceptability
4. Commenting on practical aspects of the APRIL for the benefit of potential participants
5. Advising on the wording of patient information leaflets
6. Supporting research processes
7. Publically raising the profile of rehabilitation research and sharing research findings

For further information on APRIL please contact Cathy Payne c.payne@ulster.ac.uk or telephone 028 90366380



AIIPC
All Ireland Institute of
Palliative Care



HSC Public Health
Agency

Asked about the impact of the Forum, Mr Stuart McIntosh, Consultant Surgeon, Belfast HSC Trust, Chief Investigator for the Neo DDRD study stated:

'The Forum members provide a valuable contribution to the development of research locally. Their input into study design, and the provision of a consumer perspective on study documentation, is extremely helpful for researchers, who may not always appreciate the issues of greatest relevance to consumers and patients. I have found that working in partnership with the Forum has been very useful for me as a Chief Investigator, and provides a perspective which is not always apparent to researchers'.

Mr Stuart McIntosh

Dr Paula Scullin, Consultant Oncologist, BHSCT, asked for review of a Lung Cancer Survey which was circulated to members via e-mail and responses were collated. Her feedback to Forum members was:

'This is extremely helpful. Please thank those who took the time to participate and we will keep you posted on the progress.'

Dr Paula Scullin

Dr Chris Cardwell, Statistician, Centre for Public Health, QUB, shared his perspective of Forum input and PPI representation on a study Steering Group:

'As part of our NIHR awarded and R&D funded project entitled "Investigating the impact of incidental medication use on cancer progression in patients with common cancers", we were supported by members of the NI Cancer Research Consumer Forum both by providing feedback on the original protocol and participating in the steering group. This support gave us a valuable insight into the perspective of cancer patients and has helped particularly to guide the strategy for dissemination of results.'

Dr Chris Cardwell

Gary Mitchell, PhD student in the School of Nursing, QUB, described the comments of Forum members about the Patient Information Sheet for the study 'An ethnography of communication processes involving the management of oral chemotherapeutic therapy by patients with a primary diagnosis of bowel cancer':

'They really were invaluable!'

Gary Mitchell

One of the studies presented at an NICTC study review meeting was not adopted, for various reasons, including the fact study eligibility constraints limited the potential to recruit to the study from patients in NI, a point raised by a Forum member. The Director of the NI Cancer Trials Centre, Dr Richard Wilson said:

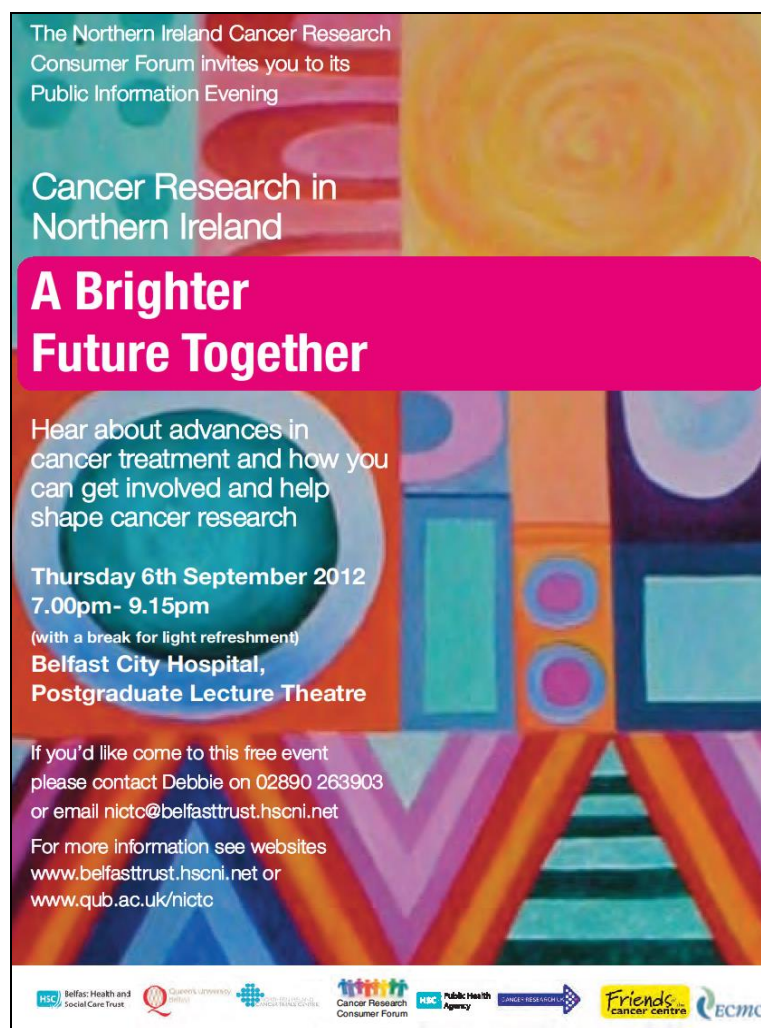
'I think that this was the right decision. We must applaud the important contribution of the PPI representatives.'

Dr Richard Wilson

Communications and Research Awareness

A Brighter Future Together

One of the outstanding and memorable highlights from Year 2 was the public information evening hosted by the Forum. The event entitled 'Cancer Research in Northern Ireland - A Brighter Future Together' was held on 6th September 2012, in the Post-graduate Lecture Theatre, Belfast City Hospital. In hosting the event, the Forum also worked in collaboration with the researchers, guest speakers, hospital staff, charities, HSC R&D and the public, all vital to the support and success of the event.



The Northern Ireland Cancer Research
Consumer Forum invites you to its
Public Information Evening









Cancer Research in
Northern Ireland

**A Brighter
Future Together**

Hear about advances in
cancer treatment and how you
can get involved and help
shape cancer research

Thursday 6th September 2012
7.00pm - 9.15pm
(with a break for light refreshment)
Belfast City Hospital,
Postgraduate Lecture Theatre

If you'd like come to this free event
please contact Debbie on 02890 263903
or email nictc@belfasttrust.hscni.net
For more information see websites
www.belfasttrust.hscni.net or
www.qub.ac.uk/nictc

 Belfast Health and Social Care Trust  Queen's University Belfast  Ulster University  Cancer Research Consumer Forum  HSC Public Health Agency  Cancer Research Agency  Friends Cancer Centre  ECMC

Event Programme:

Cancer Research in Northern Ireland – a brighter future together

Thursday, 6 September 2012

Postgraduate Lecture Theatre, Belfast City Hospital

7.00 pm – 9.15 pm

PROGRAMME

Welcome

Mrs Margaret Grayson & Mr Geoff Hill, Northern Ireland Cancer Research Consumer Forum

The What, Where, When and How of cancer clinical research in NI
Dr Richard Wilson, Director NI Cancer Trials Centre & Network, & Mrs Eileen Dillon, NI Cancer Trials Centre & Network Lead Nurse and Network Manager

Research advances in Breast Cancer Surgery
Mr Stuart McIntosh, Consultant Breast Surgeon, Belfast City Hospital

New discoveries in cancer, the journey from the laboratory to the clinic
Professor Richard Kennedy, Centre for Cancer Research and Cell Biology and Consultant Medical Oncologist, NI Cancer Centre

Question & Answer Session

Tea/coffee break and information stands

Innovations in prostate cancer treatment through cancer clinical trials
Professor Joe O'Sullivan, Centre for Cancer Research and Cell Biology and Consultant Clinical Oncologist, NI Cancer Centre

A patient perspective of participation in cancer clinical trials
Mr Paul Burns, formerly Director of Corporate Services at the Arts Council of N Ireland

The role of patient and public involvement in cancer research
Mr David Ardron, NCRI Consumer Liaison Group and North Trent Consumer Research Panel

What you can do

Mrs Margaret Grayson, Chair of Northern Ireland Cancer Research Consumer Forum

Question & Answer Session

Thanks and close





Some Forum members and Speakers – a successful collaboration



Paul Burns, guest speaker, gave a revealing account of taking part in a clinical trial



Questions from the audience.....
Mike Moran, Forum member

The speakers' passion for patient benefit through cancer research and PPI was tangible, and the feedback after the event described it as both informative and inspiring. Three members of the audience subsequently joined the Forum.

Other Opportunities to Raise Awareness about Cancer Research and PPI

Not only has the Forum taken the opportunity to learn more about PPI, it has also used available opportunities to promote the importance of cancer research for patients and PPI within the cancer research process. Often this happens informally, in the course of conversations, or through consultation or participation in national campaigns promoting research, but this year there have also been invitations to share, in more depth, the work of the Forum and the role of PPI in cancer research.

In October 2012 Margaret Grayson spoke at the 12th NI Society of Radiographers Conference about the work of the Forum and the importance for radiographers (and all health care professionals) to partner with patients/carers from the beginning of their research planning.

Margaret Grayson and Ruth Boyd both spoke about PPI at a NI Clinical Research Network staff training day in December 2012, and at a staff information session in April 2013 held for the NI Cancer Registry, Centre for Public Health, and School of Nursing, QUB.



PPI information session held at the NI Cancer Registry, QUB

Another collaborative highlight this year was joining forces with Cancer Research UK, CCRCB and the BHSCT on International Clinical Trials Day on 20th May 2013. Forum members and researchers raised awareness of the importance of clinical trials with staff and the public in the Cancer Centre.

Forum members at the Cancer Centre on International Clinical Trials Day



Margaret Grayson and Brian Coburn



Robin Gray



Ruth Boyd and Allister Murphy

To share information about PPI in research, Margaret Grayson volunteered to take part in research with Healthtalkonline.org. Here Margaret gives an account of this experience:

I was invited to be a participant in a research study: Taking Part in an Interview – A Study of Experiences of Patient and Public Involvement (PPI) in Health Research. The researchers are based at the University of Oxford. The study is looking at people's experiences of getting involved in medical research, either as participants or lay advisors.

I was given a very clear Patient Information Sheet to explain the process of the research interview and also the opportunity to ask questions before agreeing to take part and signing the Consent Form.

The videoed interview was conducted in my own home. Once I was able to block out the camera and the microphone, it really felt like a chat with the researcher and I was amazed when I realised we had started at 12.00 and finished at 4.15. It was a very good experience due to the people / communication skills of the researcher. I simply talked (or rambled on for all those hours) about my experiences as a new PPI rep in NICTC 3 years ago through to the research opportunities I am involved with today. It was a great opportunity to talk about the NICRCF and the diversity and tremendous skills of all the members. Also the importance of the engagement with the PPI Professional Lead (in our situation – Ruth Boyd).

At the completion of the study the interview information may be used in several ways – on the healthtalkonline website, run by the DIPEx charity; to develop support, information and training resources for people and health and social care professionals; to support quality improvement in healthcare and encourage others to get involved in research.

Thank you to the researcher, Dr Anne-Marie Boylan for her patience, understanding and encouragement.

Margaret Grayson, Forum Chair

Some NICRCF Future Plans

The Forum aims to continue to grow in members and representation of the patient/carer voice, to help to shape cancer research for the benefit of patients. The Forum will continue to build on the existing positive links established across the NI Cancer Trials Centre/Network, and with cancer researchers across the academic institutions. An ambition is to further extend the reach of the patient/carer voice, and Forum members will continue to avail of opportunities to represent patients in various cancer research fora in NI, UK and Ireland and beyond.



Consistently encouraged by the insight into cancer research developments in NI, the Forum will continue to utilise opportunities to expand public and patient awareness about the value of cancer clinical trials, and their vital contribution to healthcare. To this end, one of next year's activities will include hosting another public information evening, this time focusing on developments in radiotherapy research.

Forum members will continue to contribute to the Building Research Partnerships workshop, working with researchers and also networking with counterparts from other health topics. Forum members are enthusiastic to engage and learn and will continue to utilise relevant resources and networks to continue to build on their growing experience.

Perspectives from the NI Cancer Trials Centre

Once again, we are indebted to the tireless involvement of members of the NICRCF, who have enriched the work, and workings, of cancer research in NI. After a busy first year, it transpired that Year 2 would be no less eventful and Forum members continued to rise to the challenge of requests, deadlines, meetings and training.

Without a doubt, this report is not a comprehensive account of the time, energy and commitment members have devoted to their role as a PPI representative. Even just glancing at the report you will also notice that Margaret Grayson, the Chair of the Forum, continues to be nothing short of a trailblazer in relation to PPI representation / leadership in cancer research in NI.

Clearly, in the course of the past year, the Forum has become an increasingly established part of the cancer research landscape, demonstrated by the level of PPI activity undertaken by members (in NI and beyond), the positive feedback received, and the sense of an ever growing momentum of researcher awareness and partnership. Add this to an increasingly dynamic local cancer research environment, and the future is looking very exciting indeed.

We are again privileged to work with this group of passionate research advocates, so enthusiastic to work alongside cancer researchers, and shape future research for the benefit of patients.

Ruth Boyd, PPI Lead

on behalf of the NICTC Executive Committee

Financial Summary

September 2012–August 2013

NICRCF Expenses	Sept 2012 – Nov 2012 £	Dec 2012 – Feb 2013 £	Mar 2013 – May 2013 £	June 2013 – Aug 2013 £	Total for Year £
Catering	67.50	0	0	0	67.50
Travel Expenses	54.24	31.56	128.79	161.62	376.21
PPI Masterclass*	772.90				772.90
Public Information Evening**	595.98				595.98
Quarterly Totals	1490.62	31.56	128.79	161.62	
Total NICRCF Expenses paid by NI Cancer Trials Centre					1812.59

***‘Personal and Public Involvement (PPI) in research – A Masterclass’ (6 Sept. 2012)**

Facilitators’ Expenses	556.15
Catering	61.10
Hospitality	<u>155.65</u>
TOTAL	£772.90

**** ‘Cancer Research in Northern Ireland – A Brighter Future Together’ (6 Sept. 2012)**

Photography	147.25
Video Recording & Editing	248.75
Catering	100.00
Hospitality	<u>99.98</u>
TOTAL	£595.98

For More Information Please Contact:

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