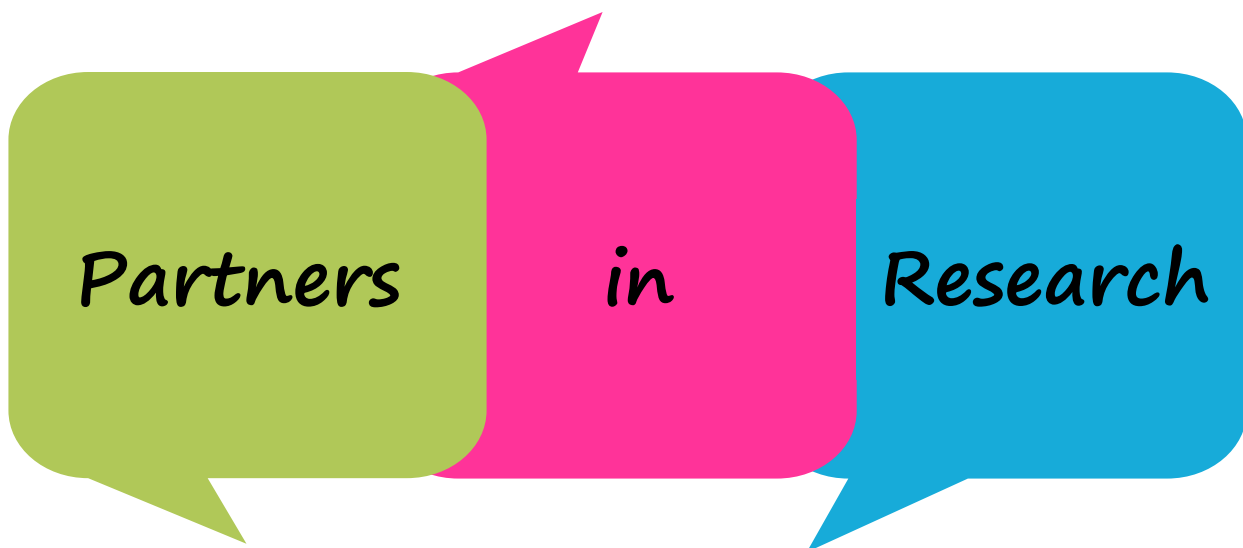




*4th Year Report of the Northern Ireland Cancer
Research Consumer Forum*



September 2014 – August 2015

Contents

	<i>Page</i>
<i>Welcome to the Fourth Year Report</i>	<i>3</i>
<i>Membership, Meetings and Training</i>	<i>4</i>
• <i>Membership</i>	<i>4</i>
• <i>Forum Meetings</i>	<i>4</i>
• <i>Research Progress Following Forum Meetings Last Year</i>	<i>5</i>
• <i>Training for Members and Others</i>	<i>7</i>
<i>Shaping Cancer Research</i>	<i>10</i>
• <i>NI Cancer Trials Network and Belfast ECMC</i>	<i>10</i>
• <i>Forum Involvement in the Review of New Clinical Research Studies</i>	<i>11</i>
• <i>Forum Involvement in the Management of Clinical Trials with Local Research Leadership</i>	<i>12</i>
• <i>Forum Involvement as PPI Partner in National Cancer Research Collaboratives</i>	<i>13</i>
• <i>Other Forum Involvement in Locally Led Cancer Research</i>	<i>14</i>
• <i>Forum Involvement in NI Cancer Research Management Structures</i>	<i>16</i>
• <i>Forum Involvement in National Cancer Research PPI</i>	<i>16</i>
<i>Raising Awareness and Showcasing PPI and Cancer Research</i>	<i>23</i>
<i>Some Forum Future Plans</i>	<i>29</i>
<i>Postscript - A Tribute to our Member</i>	<i>30</i>
<i>Perspectives from the NI Cancer Trials Network</i>	<i>31</i>
<i>Financial Summary</i>	<i>32</i>
<i>Appendix 1 NICRCF Purpose and Objectives</i>	<i>33</i>
<i>Contact Details</i>	<i>34</i>

Welcome to the Fourth Year Report

Welcome and please enjoy reading this 4th year report to give an update of the work of the Northern Ireland Cancer Research Consumer Forum (NICRCF). When the Forum was formed in 2011 no one could have envisaged the level of partnership working that has developed between the members and researchers. Only a small percentage of this partnership can be



Margaret Grayson, Chair, NICRCF

captured in the report. Welcome to the new members who have joined the Forum over the past year, thank you for your enthusiasm and valuable input.

It is a privilege to Chair the Forum and a big thank you to all the Forum members for your continuing passion and willingness to share your cancer experience, your life skills and your time in enhancing research. This research makes a difference to other cancer patients and the people of NI in the area of prevention, diagnosis, treatment and quality of life. Thank you to all the researchers we have partnered with over the past year, too numerous to mention by name, all the Forum members are impressed by your passion in your specific research area – thank you for your part in answering “the cancer questions”.

Thank you from all the Forum members to Ruth Boyd, our PPI professional lead for her friendship and guidance, and to Sharon Dunwoody for our administrative support. The Forum would not exist without the support, encouragement and professional guidance of NICTN so thank you to Dr Melanie Morris and Prof Richard Wilson.

Margaret Grayson, Chair, NICRCF

Members, Meetings and Training

Membership

Over the course of the reporting period, we welcomed 6 new members. This brought the Forum to a total of 25 members at the end of August 2015. We encourage anyone interested in influencing cancer research as a Personal and Public Involvement (PPI) Representative to get in contact with us. We are, as usual, astounded by the skills, experience and passion that members are so willing to share.

Forum Meetings

The original purpose and objectives of the Forum remain unchanged (see appendix 1).

Quarterly Forum meetings were held in the Cancer Centre. The agenda of the meetings cover the array of PPI activity being undertaken, but on two occasions they also provided an opportunity for researchers to share their work and discuss it with the Forum members.



(LEFT) Forum members with Dr Michael Donnelly (6th from right) Lead in Health Services Research, Centre for Public Health, Queen's University Belfast (QUB), who gave a presentation on 'Developing a Programme to Improve Cognitive Problems among Cancer Patients'

September 2014

(RIGHT) Forum members with Dr Paul Mullan (5th from left), Senior Lecturer, Centre for Cancer Research and Cell Biology (CCRCB), QUB, who gave a presentation on a research proposal for 'Earlier Detection and Chemoprevention of Ovarian Cancer in BRCA families'



June 2015

There were ad hoc Forum meetings arranged during the year to facilitate discussion about research projects or plan events. These are covered in other sections of the report.

Research Progress Following Forum Meetings Last Year



In last year's annual report we highlighted research presented at Forum meetings during 2013/14. An important hallmark of successful PPI is on-going involvement, evidence of impact, and progress in research for patient benefit. We are delighted to report that all these hallmarks are demonstrated in these updates provided by the researchers

Research: CASPIR - Calcifications as an alternative to urgically implanted fiducial markers for Prostate Image guided Radiotherapy
Researcher: Angela O'Neill

Since presenting to the Forum in November 2013, Angela has been awarded a NI HSC Research and Development (R&D) Division doctoral fellowship. 'Presenting my research proposal to the Forum facilitated useful discussion with members which helped me to further refine the study protocol. Subsequently Forum members also provided invaluable input in the development of the patient information sheet (PIS) for the study which is now open. At time of writing, 2 patients have been recruited.' Angela O'Neill

Research: The impact of statins on colon cancer survival

Researcher: Mr Ronan Gray

'This research project is funded by a HSC R&D Division doctoral fellowship and its aim is to assess the association between incidental statin medication use and colon cancer survival. This study will contribute to the body of evidence currently available on the topic which is important in terms of determining whether progress to a clinical trial of statin therapy in colon cancer is warranted. This three year project commenced in August 2014 and after the first year tumour sample retrieval and clinical follow-up has been completed for the cohort of cases within the Belfast and South Eastern Health and Social Care Trusts. The study steering group met in July 2015 and two Forum members, Sandra Irvine and Maire Gribbon, provided valuable contributions regarding sample retrieval for cases outside of the Northern Ireland Biobank where additional ethical approval is required.'

Overall the contribution of the Forum members to our study steering committee has been informative and worthwhile. Incorporating their perspectives has undoubtedly enhanced the quality of our subsequent ethics submission and hopefully leads to a positive outcome.' **Ronan Gray**

Research: Phase I Study of ALM201 in Solid Tumours

Researcher: Professor Richard Wilson

'ALM201 is a drug discovered in QUB and developed by Almac. We are delighted this treatment is now available in a national clinical trial led from Belfast. Forum members have been involved in the progress of this study since June 2014. Currently Forum Member Janine McCann sits on the study Steering Committee. Janine's contribution to the oversight of the study is invaluable and the patient perspective is a key dimension of the management of this trial.' **Richard Wilson**

On-going Impact

We also reported on building relationships with the School of Nursing, QUB. Forum members had previously forwarded research priorities.

Forum Research Priorities 2014:

Communication, carer needs, information, CNS role, cancer patients in the Emergency Department, meeting complex needs, addressing treatment side-effects

In February 2015 Forum members were delighted to welcome back Dr Olinda Santin and Dr Gillian Prue. They provided members with an update on research being undertaken in the School of Nursing and how this links with the Forum's priority areas, and how these priorities were influencing research development.

Training for Members and Others



Once again, foundation training in Personal and Public Involvement (PPI) in research was provided by the HSC R&D Division funded **Building Research Partnerships Workshop** (also supported by the NICTN). The workshops continue to be facilitated by Macmillan quality assured facilitator Margaret Grayson, with support from HSC

R&D Division and Forum members. Workshops took place in October 2014 and April 2015 and they continue to receive very positive evaluation by participants.

An annual HSC R&D Division joint workshop for PPI representatives from both the HSC R&D Division and the Forum took place in December 2014. The event

was facilitated by Bec Hanley from Twocan Associates. Bec has worked in INVOLVE and was an adviser to the Medical Research Council Clinical Trials Unit on patient and public involvement. She has undertaken and published research on patient involvement in clinical trials, and provided helpful insight into the impact of PPI. Another feature of the workshop was the synergy created by members of each PPI group working together. Group work focused on action plans to deliver strategic goals. The workshop was enjoyed by all those attending.



Bec Hanley

This summer we welcomed Richard Stephens, Chair of the National Cancer Research Institute (NCRI) Consumer Forum, and Michael Maguire, facilitators in a *Masterclass in Communicating Research in Plain English*. This workshop, funded by HSC R&D Division, was held 11 June 2015 in Riddel Hall, QUB. The workshop was designed to bring researchers and patients/carers/public together, to provide practice based tips and practical sessions and facilitate work on current documents researchers brought with them. The consensus of the participants was the workshop really highlighted the importance of plain English, challenged thinking and was very helpful.



Michael Maguire and Richard Stephens – Masterclass in Communicating Research in Plain English facilitators



Ignatius Maguire, Dr Gail Johnston, Margaret Grayson, Professor Carmel Hughes and conference delegates Ciara Kirke and Anne Friel at the pharmacy conference

Gail Johnston, Programme Manager in the HSC R&D Division, invited Margaret Grayson and Ruth Boyd to join her and R&D PPI Representative Ignatious Maguire in facilitation of a workshop at the Health Services Research & Pharmacy Practice Conference. This national conference was co-ordinated by Carmel Hughes, Professor of Primary Care Pharmacy, QUB. The workshop, held in Riddel Hall, QUB, was entitled 'Making Good Research Excellent – Improving pharmacy practice research through rigorous Patient and Public Involvement (PPI).' The focus of the workshop was on PPI and practical ways to support PPI in pharmacy research. The workshop was warmly received and conference attendees were very participative. 92% of those who provided feedback thought the quality of the workshop was good or very good.



Last year we reported on sharing our learning in PPI with the Experimental Cancer Medicine Centre (ECMC) at the Sir Bobby Robson Cancer Trials Research Centre in Newcastle, during a visit there in March 2014. What a delight for Margaret Grayson and Ruth Boyd to return to Newcastle in July 2015 (with the support of an *ECMC cross-centre placement*) to meet the members of their recently established PPI group. This group, facilitated by Cancer Research UK Senior Nurse Julie Burton, was already making an impact in the region and members were eager to hear from Margaret and Ruth about the value of their involvement and how a group develops over time and the PPI opportunities that can arise.



Margaret and Ruth meet members of the new PPI group at the Experimental Cancer Medicine Centre, Newcastle upon Tyne, July 2015

PPI Shaping Cancer Research

Seeing good cancer research happen is a shared objective across Forum members, clinical and research communities and the public. Forum members are enthused and encouraged by the dynamic landscape of cancer research in NI and the motivation of researchers and their teams, as they work with them.

NI Cancer Trials Network and Belfast ECMC

The Northern Ireland Cancer Trials Network (NICTN) Co-ordinating Centre based at Belfast HSC Trust, is the organisation that supports and facilitates the work of the Forum, and as such there is a strong working partnership relationship with the Forum and the Network/Belfast ECMC, its activity, staff and associated researchers. Forum members are routinely involved in the study adoption approval process and wider review of portfolio development. Here we provide a summary of Network/Belfast ECMC research activity for the financial year 2014/15.

The NICTN continues to facilitate the delivery of cancer clinical trials and other high quality clinical research throughout Northern Ireland. It 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 2014 to March 2015, 1409 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 218.

Although recruitment was to a wide range of studies, recruitment to urology, breast and haematology cancer research far exceeded other disease areas accounting for 65% of overall recruitment. Activity in Belfast HSC Trust

accounted for 66%, and the Cancer Units in Altnagelvin, Antrim, Craigavon and the Ulster Hospitals made the significant contribution of 34% of overall recruitment.

The NICTN acknowledges the support of its funders: HSC R&D Division, Cancer Research UK, Friends of the Cancer Centre, Bloodwise Trial Acceleration Programme (TAP), Movember and Prostate Cancer UK.

Forum Involvement in the Review of New Clinical Research Studies

During the reporting period of September 2014 – August 2015 Forum members attended a number of the 37 NI Cancer Clinical Trials Review and Adoption meetings co-ordinated by the NICTN. At least one Forum member was involved in the review of each of the 31 studies reported below. On occasions when studies were not reviewed by the Forum, this was usually due to short notice of the meeting or patient documents not being available.

Cancer Type	Number of studies with Forum member PPI within NICTN process
Lung cancer	6
Haematological cancers	5
Gynaecological cancers	5
Breast cancer	5
Prostate cancer	3
Bowel cancer	1
Bladder Cancer	1
Head and Neck Cancer	1
Miscellaneous cancer types	1
Pancreatic cancer	1
Stomach and gastro/oesophageal junction	1
Brain Cancer	1
Total	31 studies

Forum Involvement in the Management of Clinical Trials with Local Researcher Leadership

Many Forum members are involved in the on-going oversight of clinical trials being conducted in multiple sites in NI or in NI and other sites in the UK/Europe, as listed below:

<i>Study Title</i>	<i>Researcher</i>	<i>Role / Committee/ Group</i>	<i>Forum member</i>
<i>MERCuRIC* 1: MEK and MET Inhibition in Colorectal Cancer</i>	<i>Prof R Wilson, Principal Investigator</i>	<i>Study Patient Representative and Project Work Stream</i>	<i>Margaret Grayson</i>
<i>Vitamin D in Colorectal Cancer</i>	<i>Profs R Wilson and C Campbell, Co-Chief Investigators</i>	<i>Data Monitoring and Ethics Committee</i>	<i>Sandra Irvine</i>
<i>Phase I Study of ALM201 in Solid Tumours</i>	<i>Prof R Wilson, Chief Investigator</i>	<i>Steering Committee</i>	<i>Janine McCann</i>
<i>BALLAD UK: A trial to evaluate the potential benefit of adjuvant chemotherapy for small bowel adenocarcinoma</i>	<i>Prof R Wilson, International Chief Investigator</i>	<i>Study Patient Representative and Trial Management Group</i>	<i>Mike Moran</i>
<i>EASI-SWITCH Trial: Early switch to oral antibiotic therapy in patients with low risk neutropenic sepsis</i>	<i>Dr V Coyle, Chief Investigator</i>	<i>Trial Management Group</i>	<i>Margaret Grayson</i>
		<i>Steering Group</i>	<i>Robin Gray, Edward Goodall</i>
<i>Haematuria Biomarker Study (HaBio)</i>	<i>Dr K Williamson, Chief Investigator</i>	<i>Steering Committee</i>	<i>Edward Goodall</i>

*This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602901.

The *Easi-Switch Trial* is one of the grant submissions mentioned in our report last year – well done to the study team as *Easi-Switch* was awarded a National Institutes of Health Research grant and has progressed through study regulatory approvals.



On-going
Impact

The *MERCuRIC* research programme of clinical trials in advanced bowel is an international collaboration for which the Forum is a partner for the 'Patient and Public Initiative'. Margaret Grayson attended the *MERCuRIC* Annual Plenary Meeting, held in Vall d'Hebron University Hospital, Barcelona, Spain, 15/16 December 2014.



Margaret Grayson (2nd from right) attending the *MERCuRIC* Meeting in Barcelona, December 2014

Forum Involvement as PPI Partner in National Cancer Research Collaboratives

Last year we reported on the Forum's involvement in the grant submission for the proposal *S-CORT : Stratification in COloRectal cancer - from Biology to Treatment prediction*. In January 2015 it was announced this research collaboration, led by Oxford and including collaboration across Belfast, Birmingham, Leeds, Aberdeen, Wellcome Trust Sanger Institute and University College London, had been awarded £5 million from the Medical Research Council and Cancer Research UK. The Forum is a partner in the project's involvement and engagement strategy. Forum members



On-going
Impact

Sandra Irvine and Ed Goodall now rotate in attendance at the Belfast S-CORT Committee meetings, which have been established, alongside local researchers involved from CCRCB and Almac.

Other Forum Involvement in Locally Led Cancer Research

In April 2015 Forum members met with Dr Joanne Reid, School of Nursing, QUB, and a fruitful discussion took place about the research project, that Professor Hudson is leading on, which focuses on the development and evaluation of a web-based educational intervention for family carers of people approaching the end of life.

Sometimes the Forum members don't get to meet researchers face-to-face, but they can inform research in development through e-mail consultation and review. Studies where they were involved in this way during this reporting period were:

An Evaluation of a Therapy Radiographer undertaking Follow-Up for Prostate Cancer patients (TRUFU)

Stacey Hetherington, Investigator and Education and Professional Development Radiographer, requested Forum input for her patient documents and questionnaire for the study. Stacey's feedback was:

'I found the Forum extremely beneficial in finalising patient specific information and as a result of Forum feedback some amendments were made to reflect patient thoughts.

It highlighted to me that although I felt I had addressed all patient issues, that there are aspects of the service, and specifically in relation to trials, that were maybe more important from the patients perspective.' Stacey Hetherington

RISR: A single centre, assessor blind, randomised pilot study to evaluate the safety, tolerability and acceptability of Radiobase emulsion compared to standard of care for Radiation Induced Skin Reactions (RISR), in subjects undergoing palliative external beam Radiotherapy (RT).

The Chief Investigator for this study is Dr Gerry Hanna, Consultant Clinical Oncologist/Senior Lecturer, who forwarded draft patient documents for Forum review and input ahead of the ethics submission. This study is now being set-up for conduct in the NI Cancer Centre. Gerry commented:

'The NI Cancer Research Consumer Forum have been invaluable in their help and support to me as I endeavour to increase the trial opportunities for patients with breast and lung cancer. For example, during the design process of a Belfast led study of a novel skin treatment for patients receiving radiotherapy, the Forum reviewed the study design, patient information sheets and consent form. With the Forum's input, they helped me redesign the study to make it easier for patients to participate in and helped amend the patient information to make easier to understand. These important inputs will help make this study more acceptable and more likely to be successful with the aim of reducing skin reactions from radiotherapy. Without the key work of the Forum, there are a number of new radiotherapy treatments and trials that would not have been available in Belfast were it not for the hard work and support of the Forum. The unique skills and insight that the Forum have are so very much appreciated. Thank-you!' Gerry Hanna

My Follow Up

For the first time Forum members were invited to review patient materials for a study related to the bowel cancer screening service. Ethna McFerran, Investigator and HSC R&D/National Cancer Institute Health Economics Fellow,

forwarded the content of a patient survey designed for people diagnosed with adenomas. Ethna commented:

'In our work this year in developing a research protocol the Forum members provided really useful, timely feedback on our content and wording of our research. They helped to keep our focus on what a patient and service user experiences, being involved in research. This really helped figure out how to get our ideas to connect and to understand practical ways to make changes, that will I believe keep the patient at the centre of our work.' Ethna McFerran

Forum members Andy Anderson, Kate Burns and Janine McCann continue to be involved as Project Advisors in the Steering Group for the **Cancer and Mental Health** study being undertaken by James Millman, at the School of Nursing, QUB.

Forum Involvement in NI Cancer Research Management Structures

As mentioned in previous reports, the Forum has a role embedded into the structure of the management and oversight of cancer clinical research in NI. During the reporting period Margaret Grayson and Dori-Anne Finlay Blackstock have been part of the NICTN Executive Committee and NICTN Steering Group. Margaret Grayson and Andy Anderson have been members of the Cancer Research UK Centre Governance Board.

Forum Involvement in National PPI

NCRI Consumer Forum Steering Group and NCRI Consumer Forum

Margaret Grayson is the National Cancer Research Institute (NCRI) Consumer Forum Steering Group NI Representative and she is also a member of the NCRI Consumer Forum. These new groups form part of new structures in cancer research nationally. Not only does Margaret contribute to these groups, but

she also shares locally her insight of issues of national significance relating to cancer research PPI.

Experimental Cancer Medicine Centre (ECMC) Network

The national ECMC Network established a new PPI Working Group in 2015. Forum member Geoff Hill is the Belfast ECMC representative and here he gives an update on this initiative:

'Through being a member of our Forum, I represented the Forum as the PPI Rep on the local ECMC Committee. ECMC stands for the Experimental Cancer Medicine Centres Network of which there are 18 centres in the UK and Belfast (NI Cancer Trials Network at the NI Cancer Centre and the Centre for Cancer Research and Cell Biology, QUB) is one of those.

The ECMC initiative supports the infrastructure needed to both deliver world-leading early phase clinical trials and to enable a network of experts to translate scientific discoveries into new cancer treatments for patients.

It was decided by ECMC that a national ECMC Patient and Public Involvement Working Group should be set up so that all local ECMC PPI representatives from the 18 centres could meet to help shape ECMC PPI strategy, provide advice about what specific PPI issues there are within early phase cancer research and identify PPI activities at ECMCs and share best practice.

It was decided that there should be a Professional and a PPI Rep from each centre and so Ruth Boyd and I attended the first meeting in April 2015 in London. This meeting was about getting to know each other and what PPI activity is going on in each centre. Ruth was asked to give a presentation on what was happening here in Belfast and it became clear that we are certainly setting a great example through our Forum structure. The meeting went on to discuss a PPI Strategy for ECMCs and clarifying the remit of our group. It was also agreed to look at what training needs the PPI reps might need as we move forward.

I am honoured to be our ECMC rep both locally and now nationally and hope that the national group will allow Ruth and I not only to promote our Belfast PPI Model but also help shape a dynamic PPI strategy across all 18 ECMCs.' Geoff Hill

NCRI Clinical Study Groups (CSGs)

The CSGs play an important role in shaping the national portfolio of cancer trials available to patients in the UK. The Forum is delighted that Debbie Keatley continues her role as a lay member of the brain cancer CSG. In July 2015 Sandra Irvine was successful in her application to become a lay member of the colorectal cancer CSG. We look forward to the increasing presence of Forum members playing significant roles in the national clinical research landscape.

National Conference Involvement

The annual National Cancer Research Institute (NCRI) Conference was held in November 2014 in Liverpool and once again Margaret Grayson, as a member of the NCRI Consumer Liaison Group, was fully involved in the conference and requests for PPI.

Forum members were active participants in the All Ireland Cancer Consortium (AICC) Conference in May 2015. There was participation throughout the programme and during the 'Patient and Charities' session 'Reclaiming Life After Cancer' which involved speakers and workshop style discussions.



Forum members (Left-Right) Dori-Anne Finlay Blackstock, Margaret Grayson and Kate Burns with speaker Dr Julia Rowland, Director of the Office of Survivorship, National Cancer Institute, Bethesda, Maryland, USA, attending the AICC Conference

Margaret Grayson and Ruth Boyd gave an oral poster presentation during the Clinical Trials session of the CCRCB Symposium.

During the year Margaret Grayson was involved in planning the National Cancer Intelligence Network (NCIN) Conference as a member of the conference Scientific Committee, led by Dr Anna Gavin, Director of the NI Cancer Registry. The result of the committee's preparations and diligence was a highly successful



Margaret Grayson delivers an opening address to the NCIN conference

national conference held in Belfast in June 2015. Margaret was one of the opening speakers. Sharing her patient perspective she introduced what was to become a recurring theme of the meeting around access to patient data and the importance of its use in

research. Later in the conference programme Margaret was a panel member along with the Chief Medical Officers/Deputies from each UK nation.

There was also excellent representation of Forum members attending the conference and networking with researchers.



Forum members Kate Burns, Sandra Irvine and Hazel Fisher attending a presentation at the NCIN conference

Cancer Research UK Grand Challenge

One of the exciting announcements during the year was the Cancer Research UK Grand Challenge Award which would enable an international research collaboration to bid for £20million to address a major issue in cancer research. During the reporting period Forum members Margaret Grayson, Kate Burns and Janine McCann got involved as PPI representatives during preparatory workshops in London and Edinburgh. Here Kate reports about her experience:

On Thursday 19th and Friday 20th March 2015 I was fortunate to be involved with CRUK's Edinburgh Grand Challenge.

The workshops have been organised to enable researchers /scientists / clinicians and people affected by cancer to come together and tease out some big questions that will help identify and tackle innovative research challenges.

The event began on Day 1 with a patient representative briefing and evening reception with guest speakers. Day 2 was an intense day of interactive debate. The Grand Challenge ideas were collated at the end of the sessions and fed back to the groups for further consideration. The questions tackled areas including early diagnosis, prevention and treatment, how to get the optimum benefit from treatments, controlling cancer, overcoming resistance and targeting remission (and so much more!)

It was a privilege to be a part of the Grand Challenge and to feel I could contribute even in a small way. Everyone made me feel welcome and a genuine part of the process. It was invigorating and uplifting to sit among some of the greatest and dynamic thinkers in the country and to hear their passion and commitment to tackling this terrible disease first hand.

I am very grateful to CRUK for giving me the opportunity to attend their Grand Challenge in Edinburgh. Kate Burns

In May 2015 Margaret Grayson was informed she had a place on the Grand Challenge Patient Panel, which started meeting in August 2015. We look forward to hearing more about the ambitious research awards in the future.

Cancer Research UK Involvement Coach

In the summer of 2014, as part of Cancer Research UK's wider initiative to expand and develop ways of involving people in their work, the Patient Involvement and Communications Team launched an Involvement Coach pilot project. Margaret Grayson was recruited into this first group of 8 Involvement Coaches – people affected by cancer who already have significant experience of patient and public involvement. The role involves working closely with the charity's Patient Involvement and Communications Team to identify, develop and test new ways to involve people in their work.

Margaret reports on her involvement experience:

'Being part of the Involvement Coach (IC) pilot programme has given me the opportunity to work alongside the Cancer Research UK staff and as a team with the other ICs. It is a great experience. Over the months I have been involved in a wide range of activities and I share two examples:

- *Involvement Cafe – I sat at a table with 8 seats and I was joined by CRUK staff in London on a timed rotation. They had the opportunity to ask questions about why I was involved in research and what that involvement entailed. The aim was to help create a culture change within the organisation around the area of involvement.*
- *Staff Training and Development – I had the opportunity to help develop and co-facilitate an interactive workshop. The aim was to help increase staff confidence around setting clear expectations and support for people affected by cancer that get involved in their work.*

I have enjoyed being part of the ICs Pilot Project!' Margaret Grayson

Independent Cancer Patients' Voice (ICPV)

Margaret Grayson continues to be an active member of ICPV. ICPV is a group of patient advocates who aim to 'improve existing treatments for every cancer patient and develop new treatments by bringing the patients' voice into clinical research'. Margaret presented at the INVOLVE Conference in November 2014. She co-facilitated a workshop on the 'VOICE - Science for Advocates' course run by ICPV and Barts Cancer Institute. The workshop highlighted 'quality advocacy needs quality education'.

In July 2015 Margaret Grayson undertook a training course 'Qualitative Research & Research Methods', facilitated by ICPV and provided by Professor Janet Dunn at the Clinical Trials Unit, University of Warwick. Margaret commented on the course:

'This was an interactive and informative 2 day course covering qualitative research methods, ethics, qualitative research interview techniques and practical interview sessions. An important learning point for myself was the feedback on my practice interviews.' Margaret Grayson

Raising Awareness and Showcasing PPI and Cancer Research

Inspired, as ever, by the research undertaken by local clinicians and scientists, the Forum determined to continue to promote cancer research to patients/carers and the public this year. A Public Information Evening with a focus on Bowel Cancer, hosted by the Forum, was an event that highlighted not just research and innovation in the field, but the contribution and partnership of the scientific, clinical, research, charity and patient/carer communities, working together to benefit patients. The event was held in the NI Cancer Centre in December 2014. Feedback from those who attended was very positive.



Forum members along with clinical, scientific and Cancer Research UK and Bowel Cancer UK staff, join forces to provide information about Bowel Cancer and Bowel Cancer Research. Mr Norman Surplus (far right), a guest speaker, described his personal experience of the disease and recovery, including his adventures undertaking a round the world flight in a gyroplane

In February 2015, Forum members enjoyed a 'PPI Open Evening' hosted by the NI Biobank (NIB) based at the Centre for Cancer Research and Cell Biology, QUB. This event marked the launch of the NIB PPI Focus Group. Presentations were given by Dr Jackie James, NIB Director, and Professor Manuel Salto-Tellez, Chair of Molecular Pathology at QUB and Clinical Consultant Pathologist at Belfast HSC Trust. Forum members were then able to tour the NIB laboratory facilities and ask staff questions. Forum members gave very positive and enthusiastic feedback about the event, and they look forward to developing on-going links with the work of the NIB.

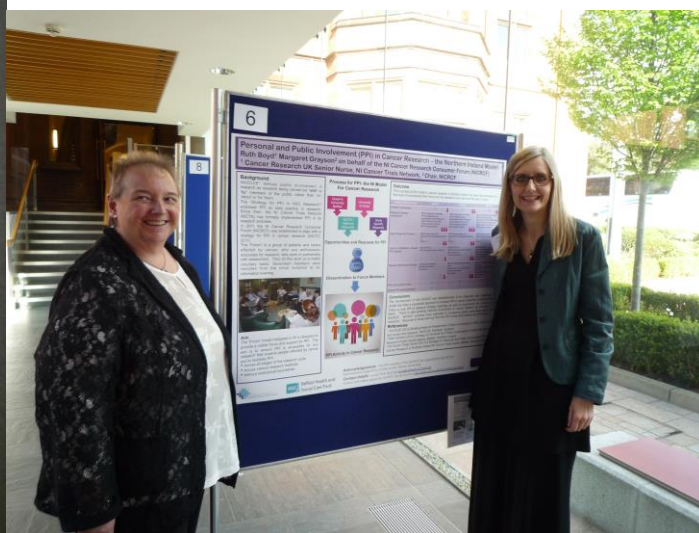


Forum members and staff hear of the fascinating work of the NIB in February 2015

Also in February 2015, Forum member Margaret Grayson and Dr Vicky Coyle, Consultant Oncologist and Clinical Senior Lecturer, co-presented a session on PPI at a workshop held in University of Ulster, Coleraine. The event was organised by the HSC R&D Division and the National Institutes of Health Research (NIHR) Evaluation, Trials and Studies Co-ordinating Centre and it was designed to help researchers secure grant funding from the NIHR. Drawing on their practical experience of submitting a grant for the Easi-Switch Study (see also page 13) Vicky, Chief Investigator, and Margaret, Co-applicant, described the role of PPI and the impact this had on the study.

Spurred on by increasing enquiries about its model for PPI, the Forum utilised conference posters to share information with professional and patient/carer audiences.

(Left) Margaret Grayson presents a poster about Building Research Partnerships at the NCRI conference Nov 2014. (Below) Margaret Grayson and Ruth Boyd at the AICC Conference with the Forum's poster about the NI model for PPI in cancer research, May 2015



Margaret Grayson collected an award for 1st prize in the Patient Choice category during Day 2 of the NCIN conference in June 2015.



Margaret Grayson collects the award for the Day 2 Poster Patient Choice category, presented by NCIN Director Chris Carrington



Conan Donnelly, Margaret Grayson, Dr Anna Gavin and Ruth Boyd with the prize winning poster 'Personal and Public Involvement (PPI) in Cancer Registry Research - the Northern Ireland Model' at the NCIN Conference

On 20th May 2015 Forum Members partnered with researchers and research staff in the NI Cancer Centre on International Clinical Trials Day. They raised awareness about the opportunity for patients and carers to get involved in influencing research, and they also promoted the availability and value of clinical trials, supporting the HSC R&D Division's 'OK to Ask... about Clinical Research' campaign, which entered its second year.



International Clinical Trials Day 2015 (above) Forum members Ed Goodall and Margaret Grayson with Cancer Clinical Research Nurses Janine Gill and Kairen McCloy, and Professor Joe O'Sullivan supporting the 'OK to Ask' campaign and (below) Ed and Margaret are joined by Dori-Anne Finlay Blackstock with researcher Angela O'Neill in the Cancer Centre





Kate Burns

Also linked to International Clinical Trials Day, we were thrilled to hear the news in May that Forum Member Kate Burns had won second prize in the Irish Times / Health Research Board – Trials Methodology Research Network clinical trials essay competition. Kate's essay ['Clinical Trials – The value and importance of 'new medicine' for patients and their families'](#) is a heartfelt must-read about the personal significance clinical research can have.

In June 2015 CCRCB held its first public Open Day. In a highly successful event the research centre welcomed over 350 people. There were a range of activities including tours of laboratories, conversations with researchers, and information stands and activities. Forum members welcomed the opportunity to talk about their involvement in research, including how local laboratory discoveries have led to drug development in clinical trials, such as ALM201 (see page 7) and informed clinical trials such as the MERCuRIC 1 study (see page 13). Margaret Grayson and Professor Richard Wilson co-presented a session on the partnership relationship of researchers and PPI representatives in cancer research in NI.



Margaret Grayson tells the public about the Forum

Other Forum members lent their support during the day to raise awareness about the Forum and opportunities to get involved, providing information at a stand in the Centre.



Cancer Clinical Research Nurse Leanne McCourt, Southern HSC Trust and Forum Member Robin Gray display information they provided to explain the Network of clinical research in NI and the way patients and carers can get involved

The Forum continues to use the [NICTN website](#) to provide information and news about PPI in cancer research, including how anyone interested in becoming part of the Forum can get in contact. This year the Forum issued 2 'Consumer Impact' Newsletters.

In June 2015 an article by Forum Member Mike Moran and his son Michael, working in cancer research and Head and Neck Surgery, was published in *Surgeons' News*, the quarterly magazine of the Royal College of Surgeons of Edinburgh. Mike described the Forum and highlighted what's involved in being a Forum member.



Tackling cancer from all sides

Friday, 05 Jun 2015



The Northern Ireland Cancer Research Consumer Forum allows patients and doctors to work together to improve treatment. We speak to Michael Moran Sr and Michael Moran Jr about their involvement

What is the NI Cancer Research Consumer Forum (CRCF)?
Michael Moran Sr: The forum is a group of around 20 individuals who are or have been cancer patients or have cared for cancer patients. The group is supported by Cancer Research UK senior research nurse Ruth Boyd, who works at the Northern Ireland Cancer Centre, and is chaired by Mira Margaret Grayson. The group was set up in 2011 to represent the public and patient viewpoint in cancer research. Among members, there is a fairly wide range of cancer experiences, including prostate, breast, colorectal and skin cancers.

We organise public information sessions once or twice a year at which research clinicians present news on the latest advances and plans in cancer research and treatment. Furthermore, we attend meetings of the clinical research division of the Northern Ireland Cancer Centre, where we can discuss research plans with clinicians.

Some Forum Future Plans

As the Forum embarks on its 5th year it is taking stock and also developing future objectives. To inform its future direction of travel the Forum is undertaking an evaluation across members and the cancer research community. Lots of experience in PPI has been developed over the years, yet it is vitally important to remain representative, accessible and inviting to new members, as well as accessible and helpful to the cancer research community, maintaining the patient/carer voice in all its work. Training will also be reviewed next year.

It's also time to refresh our communication, and Forum members will work on a new website to enhance ease of access by the public.

As the report indicates, the last year has been very productive, not just at a NI level, but within the national context. It is envisaged the national involvement will continue to expand.

The Forum is delighted that PPI has become part of how cancer research is conducted in NI, and the collaboration of researchers and Forum members is constantly developing. What lies ahead in the research arena is not always predictable, but it's always exciting and hopeful, and we look forward to the next year of partnership working.

Postscript – A Tribute to our Member

At the time of preparing this report, we reflect with sadness at the loss of our esteemed member Maire Gribbon, who died in November 2015. Since joining the Forum in 2014 Maire worked steadfastly as a PPI Representative, making a significant contribution to the Forum and cancer research during this period. Maire was not keen on getting in front of a camera during Forum meetings, but that belied the level of involvement and commitment she had. Her proactive, straight talking approach and abundance of humour, humanity and wisdom was a very effective means of sharing the patient perspective in research. As a researcher in one of the projects Maire was involved in commented, ‘It was clearly evident that she was truly passionate about cancer research.’

Forum members miss her very much and we send our sympathies to her family.

Perspectives from the NI Cancer Trials Network

As ever, it has been a fascinating journey reflecting on the activity of the Forum. During 14/15 the Forum reached a milestone, getting their own logo. 'Partners in research,' their strapline, was universally endorsed by members, an indication of how it seems to capture the essence of the work of the Forum.

This year the report has aimed to highlight that the work of the Forum is not about one-off meetings. The 'snap-shot' an annual report is able to provide is only the surface of this kind of work. What may start as a single involvement activity can translate into wider impact on a number of levels – for example, through involvement in the life-cycle of a specific project, or sparking ideas for a future research proposal.

The NI Cancer Trials Network has embedded the work of the Forum within their research processes, and the Forum is a research resource for a much wider community of researchers. The Forum has been a means to developing relationships with cancer researchers and this has been extremely valuable within the research community.

As we observe in this report, involvement can be across a spectrum of activity and it should be noted that much of the Forum's work goes on quietly, un-photographed, as members respond to questions and review documents by e-mail. We are immensely grateful for Forum members continuing dedication to this work, for the benefit of patients. Members give freely of their time and willingly share their vital and unique perspectives. No summary would be complete without a specific mention of the work of the Forum's Chair, Margaret Grayson, whose modesty contradicts the massive contribution she makes in this field, and we are most grateful for her continued inspiration and cancer research PPI leadership. Ruth Boyd, NICTN PPI Lead, Cancer Research UK Senior Nurse, on behalf of the NICTN Executive Committee

Financial Summary

September 2014–August 2015

NICRCF Expenses	Sept 2014 – Nov 2014 £	Dec 2014 – Feb 2015 £	Mar 2015 – May 2015 £	June 2015 – Aug 2015 £	Total for Year £
Catering	28.22	32.22			60.44
Travel Expenses	6.24		144.48		150.72
Public Information Evening*		250.00			250.00
Quarterly Totals	34.46	282.22	144.48		
Total NICRCF expenses paid by NI Cancer Trials Network					461.16

* Bowel Cancer Public Information Evening – 2 December 2014

Photography	120.00
Catering	30.00
Hospitality	<u>100.00</u>
TOTAL	£250.00

Professor Richard Wilson, NICTN Clinical Director comments, 'This represents the best value for money of the entire NICTN budget.'

Appendix 1

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*

For More Information Please Contact:

Ruth Boyd, NICTN

East Podium, C-Floor

Belfast City Hospital

Lisburn Road

Belfast

BT9 7AB

Tel: 028 90 638468

E-mail Ruth Boyd at: nictn@belfasttrust.hscni.net

