

# *Growing Research Partnerships*



*3rd Year Report of the Northern Ireland  
Cancer Research Consumer Forum*

*September 2013 – August 2014*



# Contents

	Page
Welcome to the Third Year Report	3
Achievements in 2013-2014	4
• NICRCF Membership	4
• Forum Meetings	4
• Training Opportunities	7
• Shaping Cancer Research	11
- Research Activity of NI Cancer Trials Centre & Network 2013/14	11
- PPI in Review of New Clinical Trials	12
- PPI highlight: Studies Developed by Local Researchers	13
- PPI highlight: Grant Submissions with PPI Support	16
- PPI highlight: Forum Members become Members of NCRI Clinical Study Groups	19
- Summary of Other Highlights by the Forum/Forum Members	19
- UK and International Focus	19
- Northern Ireland Focus	26
Supporting Cancer Research Awareness	30
• Cancer Research with the X-Factor	30
• A Celebration of World Cancer Day	31
• International Clinical Trials Day and 'OK to Ask' Campaign	33
• Clinical Trials Videos	35
Supporting Forum and PPI in Research Awareness	37
Some NICRCF Future Plans	38
Post Script - A Tribute to our Members	40
Perspectives from the NI Cancer Trials Centre	41
Financial Summary	43
Appendix 1 NICRCF Purpose and Objectives	45
Contact details	46

# Welcome to the Third Year Report

Welcome to this third year report of the Northern Ireland Cancer Research Consumer Forum (NICRCF). The report highlights the on-going partnerships that have developed between researchers and Forum members in the area of Personal and Public Involvement (PPI).



Margaret Grayson, Chair, NICRCF

A big thank you to all Forum members for the part they play in influencing cancer

research in Northern Ireland. Their willingness to use and share their time; their energy; their life skills and their cancer experiences to enhance research. Research that leads to service improvements, new treatments and improved quality of life for people diagnosed with cancer now and in the future. I would really like you to meet all of these inspiring Forum members, as that is not possible, I hope this report gives you a snapshot of some of the areas of involvement.

The NICRCF would not have achieved such growth over the last three years without the input of Ruth Boyd, PPI Professional Lead. From all of us in the Forum thank you for your professionalism, support, guidance and friendship.

Thank you to Professor Richard Wilson, Dr Melanie Morris, the Executive of the NICTC and all the research staff – without your support the Forum would not exist. Also to Sharon Dunwoody for the excellent administrative support.

Please enjoy reading this update.

Best wishes

**Margaret Grayson, Chair, NICRCF**

# Activity and Achievements

September 2013–August 2014



## Membership

*Over the course of the reporting period, one Forum member left us and we welcomed 3 new members. This brings the Forum to a total of 23 members at the end of August 2014. We continue to invite anyone with an interest in influencing cancer research to get in contact with us. We are always humbled by the skills, experience and vision that others bring to involvement in cancer research.*

## Forum Meetings

*The Forum has maintained a schedule of quarterly meetings throughout the year. These meetings are always very productive with invited speakers/researchers, consultations to respond to and updates of all the various activities of members and an outline of future opportunities. In between meetings, e-mail communications are essential to respond to the many PPI opportunities that arise.*

## Some Highlights:



September

2013

*Mr Ronan Gray (centre) gave a presentation of his planned research followed by Forum discussion and feedback about the collaborative study proposal looking at the impact of statins in colon cancer.*



November

2013

*Two speakers in December – Miss Angela O'Neill (3<sup>rd</sup> from left) presented a plan of her research followed by Forum discussion and feedback about the proposal. Professor Mark Lawler (6<sup>th</sup> from left) presented information about a proposal to launch a European Cancer Patient's Bill of Rights in 2014.*

## **March 2014**



Professor Richard Wilson presented information about a new protocol being developed which involved a drug first discovered in Queen's University Belfast, and developed in collaboration with Almac. This new study of ALM201 would begin in clinical trials as soon as development for patient use, and all study approvals were in place. The Forum commended the exciting development and expertise in Northern Ireland, translating drug discovery to a phase I clinical trial and potential new therapy in cancers including ovarian cancer.

## **June 2014**

In June the Forum didn't have a guest speaker and utilised the opportunity to hear the reports and input from members and respond to a national request from the Health Research Authority (see page 23 for more details).

### **Ad hoc Meetings for Involvement**

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

# Training Opportunities

Once again, the HSC R&D Division funded Macmillan Building Research Partnerships Workshops (also supported by the NICTC) have provided a foundation training in Personal and Public Involvement (PPI) in research.



The informal and interactive workshop style helps to promote shared learning and develop opportunities for working in partnership with researchers. The workshop is facilitated by Margaret Grayson, now a Macmillan quality assured facilitator, and other Forum members have started facilitator training to support this workshop.



(From right) Margaret Grayson, Kate Burns, Janine McCann and Sandra Irvine have a de-briefing session following workshop training in Belfast with Jack Nunn, Learning and Development Co-ordinator, Macmillan Cancer Support, London

Sandra Irvine, one of the Forum members training to be a facilitator for the Building Research Partnerships workshop shares her experience:

When I mentioned to Ruth and Margaret that I would be interested in becoming a facilitator with Macmillan Cancer Support I envisaged a gentle introduction of watching the course take place a few times and then gradually starting to make some minor contribution. We met with Ruth, Margaret and Jack (Macmillan Learning and Development Co-ordinator) the afternoon before the event to talk through what was involved. We were approaching the end when Margaret announced with a twinkle in her eye that each of us would be taking a part of it. Beware that twinkle! – Margaret makes it look so easy that she makes you believe that it's a breeze. Just like after watching Rory McIlroy play golf! It was only when we went home that night that the reality dawned of what was expected.

Next day, Margaret was her usual calm, organised self while the three of us just kept saying to each other 'What have we let ourselves in for?' How did it go? I thought my two colleagues were great but I hardly remember my own contribution. Did I enjoy it? Yes, I did. It was the people. They were so committed and interactive. I learnt a huge amount and came out feeling truly humbled by all that I had seen and heard. I felt really privileged to have met such a great bunch of people. There is just so much to learn!

Sandra Irvine, Forum Member



Two workshops were held during the course of the reporting year, on 24 October 2013 and 30 April 2014. Feedback about the workshops has always been very positive and a formal evaluation of the training programme in Northern Ireland was reported (<http://www.qub.ac.uk/research-centres/media/Media.420311.en.pdf>) in September 2014, and published on the NICTC website.

In December 2013, the HSC R&D Division facilitated a joint workshop of PPI representatives from both the HSC R&D Division and the Forum. One of the themes addressed was service users and carers in mental health research. This was presented by Professor Gerry Leavey, Director of the Bamford Centre for Mental Health and Wellbeing. Mr Billy Dixon facilitated a session on personal development.



Billy Dixon (far right) with some of the PPI Representatives attending the Christmas Workshop held in Grosvenor House December 2013

*As a member of Independent Cancer Patients' Voice, Margaret Grayson attended a 5 day residential course 'Project Voice – Science for Patient Advocates', based at Barts Cancer Institute, London. This was the first time such a course had taken place in the UK. Margaret provided a report of her experience:*

I was quickly put at ease as I met the other course members and the staff. Monday to Thursday mornings comprised a series of lectures and the afternoons involved practical learning in the lab. The first series of lectures on basic cell biology was the foundation for the rest of the week – how normal cells behave, each part of the cell and its “job”; the structure of DNA and how that is copied every time a cell divides. This led on to what happens to normal cells to make them cancerous and the part oncogenes and tumour suppressor genes play in the hallmarks of cancer. Amazing facts about my body – over 200 types of cells; over 100 trillion cells; 1,000 million cells in 1 gram of tissue (about the size of a sugar cube). We looked at how cells grow, survive or die and how they talk to each other in cell signalling.

The course was a series of personal “firsts” for me in relation to the lab sessions. It was a tremendous experience which highlighted the patience and passion of the researchers in their work. From learning to pipette; extracting and processing DNA; using a microscope to observe the appearance of different cancer cells and testing the sensitivity of cells to cytotoxic drugs. The most memorable session was in the pathology lab as breast tissue was processed for diagnosis and tissue banking, following the process through the various stages. I was impressed at the way the pathologist and all the staff handled the tissue with such care and respect.

The knowledge gained from this amazing week will be used as a building foundation in my understanding of research as I partner, as a patient advocate, with researchers in the Clinical Research Division and Trial Adoption meetings.

Margaret Grayson

*The value of the opportunity has encouraged the Forum to explore further laboratory-linked learning experiences available locally.*

# Shaping Cancer Research through PPI

Shaping cancer research in NI through PPI is at the heart of the work of the Forum. The overall picture of research activity across NI has again been positive. The Forum congratulated Mr Stuart McIntosh on his appointment to Deputy Clinical Director of the NI Cancer Trials Network, and was delighted to hear the news, in January 2014, of the investment by Friends of the Cancer Centre of £900,000 funding over 3 years for clinical trials. In February 2014 there was further good news when the Movember Foundation awarded the Centre for Cancer Research and Cell Biology, Queen's University Belfast, in partnership with Manchester University, £5 million, over a 5 year period and the status of the first regional Centre of Excellence for prostate cancer. During the reporting period important core funding was sustained with the renewal of the Experimental Cancer Medicine Centre and NI Cancer Trials Network grants, both co-funded by the HSC R&D Division and Cancer Research UK, along with the Cancer Research UK Centre award.

## Research Activity of the NI Cancer Trials Centre and Network: April 2013 – March 14

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 2013 to March 2014, 1665 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 246.

Although recruitment was to a wide range of studies, recruitment to urology, breast and haematology cancer trials far exceeded other disease areas accounting for 55% of overall recruitment.

Activity in Belfast HSC Trust accounted for 63%, and the Cancer Units in Altnagelvin, Antrim, Craigavon and the Ulster hospitals made the significant contribution of 37% of overall recruitment.

### **PPI in Review of New Clinical Trials**

Forum members have automatic access to attend NI Cancer Clinical Trials Review and Adoption meetings co-ordinated by the NICTC. Members identify if they are interested in attending or reviewing patient documentation, and if so, they are sent the relevant study information and then give feedback during the review meeting or e-mail comments. The Forum has developed a template for reviewing Patient Information Sheets, so that key aspects of the review are always considered and this also facilitates comments from various members being collated in a systematic format. Last year 22 studies were reviewed, this year during the reporting period 34 studies were reviewed by at least one member of the Forum (see table over).

Cancer Type	Number of studies with Forum member PPI in NICTC process
All solid tumours (early phase)	2
Anal Cancer	1
Bowel cancer	3
Bladder Cancer	1
Breast cancer	8
Children's Cancer	1
Endometrial cancer	1
Leukaemia	4
Lung cancer	2
Melanoma	1
Miscellaneous cancer types	2
Pancreatic cancer	1
Oesophageal	1
Ovarian cancer	1
Myeloproliferative disorders	1
Prostate cancer	4
<b>Total</b>	<b>34 studies</b>

### *PPI Highlight: Studies Developed by Local Researchers*

This year there has continued to be a number of studies led by local researchers. The *MERCuRIC* study for advanced bowel cancer was mentioned in last year's report. This research has been developed from the lab-based research of Dr Sandra Van Schaeybroeck, at Queen's University Belfast (QUB), who is also the co-ordinator of this European collaborative research programme. This year, Forum links have continued, with responsibilities for aspects of the 'Patient and Public Initiative', part of the *MERCuRIC* FP7 grant programme\*.

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

In December 2013 the programme was launched at Riddell Hall, QUB, and was followed by the 'kick-off' meeting, with researchers attending from the UK and Europe. Margaret Grayson is a member of the Working Group and the named patient representative for the Phase I study. The study is designed to find the best dose of a novel drug combination, and Forum members reviewed Patient Information Sheets for the study.



MERCuRIC research programme Kick-off Meeting 12 December 2013

Another clinical trial reported last year was the **Vitamin D** in Colorectal Cancer study. This Cancer Research UK funded study is led by Professor Charles Campbell, QUB and Belfast Trust. Margaret Grayson became a member of the Data Monitoring and Ethics Committee for this study however, Margaret subsequently had to step down, due to indemnity issues, unresolved at the time of publication of this report.

As mentioned on page 6, **ALM201** is a study that represents further local research success. Initial drug discovery was in the School of Pharmacy, QUB, and drug development and production took place in Almac, a company based in Craigavon. A phase I clinical trial of ALM201, for advanced ovarian cancer and other solid tumours, is now in development. Members of the Forum reviewed the Patient Information Sheet for this study, which is led by Professor Richard

Wilson, QUB and Consultant Oncologist, Belfast Trust and NICTC and Network Clinical Director.

Mike Moran is the named Patient Public Involvement contact for the **BALLAD** Protocol, which is an international study in small bowel cancer led by Professor Richard Wilson. This study looks at the benefit of adjuvant chemotherapy in small bowel cancer and is part of the International Rare Cancers Initiative. Mike has had input to the **BALLAD** protocol from its initial draft stages.

Mike has done a great job for all of us in THE BALLAD trial team with his input into the protocol and the Patient Information Sheets. He has helped significantly in developing a trial in a rare cancer where there is no prior evidence base for treatment decisions.

Professor Richard Wilson  
Consultant Oncologist / Director NICTC and Network

The **SPORT** study is led by Dr Suneil Jain, Clinical Senior Lecturer in Radiation Oncology, QUB, and Consultant Oncologist, Belfast Trust. This study will evaluate stereotactic radiotherapy in high-risk, localised prostate cancer with or without Elective Nodal Irradiation. Forum members had the opportunity to review the Patient Information Sheet for the study.

Lauri McDermott is undertaking a PhD based on the **EXACT** study, research to evaluate a home-based walking and strengthening intervention in colorectal cancer. This study is led by Dr Jackie Gracey, University of Ulster. Margaret Grayson met with Lauri, during the

study development to discuss the protocol and Patient Information Sheet. Forum members then provided review of the Patient Information Sheet in advance of submission for ethics review.

Forum members Andy Anderson, Kate Burns and Janine McCann are Project Advisors in the Steering Group for a study being undertaken by James Millman for a PhD, supervised by Karen Galway, QUB. The study is designed to explore the experiences of people who have been affected by both mental illness and cancer.

Andy, Janine and Kate on the Steering Group has been invaluable. In particular, they ratified the participant information sheets and interview questions and made some interesting suggestions which were incorporated into the revised documents. I am very grateful for their contributions so far and look forward to meeting with them in the future.

James Millman

PhD Student, QUB

The Forum looks forward to the continuing growth of locally led and driven cancer research in Northern Ireland.

### **PPI Highlight: Grant submissions with PPI Support**

This is a new section to the report this year to acknowledge the increasing involvement of PPI during the early stages of the research grant process. The Forum is grateful for the foresight for early contact and collaboration in the genesis of cancer research projects where there is local leadership. Not every funding submission will be successful, however, the application process is building relationships and developing effective



partnerships with PPI representatives, which will not only benefit the research proposal, but also enhance any future research process.



Forum members hear from the NI Cancer Registry about a grant proposal

During the reporting period the Forum have supported the following grant submissions:

<i>Grant</i>	<i>Local Leadership</i>	<i>Project Theme</i>
<i>Medical Research Council Stratified Medicine</i>	<i>Profs Lawler, Johnston, Kennedy, Wilson – Centre for Cancer Research and Cell Biology (CCRCB), QUB</i>	<i>Stratification in COloRectal cancer: from biology to Treatment prediction: S-CORT</i>
<i>Prostate Cancer UK</i>	<i>Dr Anna Gavin – NI Cancer Registry</i>	<i>Patient Reported Outcome Measurement Surveys (PROMs)</i>
<i>HSC R&amp;D Knowledge Exchange Scheme</i>	<i>Dr Anna Gavin – NI Cancer Registry</i>	<i>Improving public &amp; patient understanding of cancer epidemiology</i>
<i>National Institute of Health Research (NIHR), Health Technology Assessment (HTA)</i>	<i>Dr Vicky Coyle, Dr P Coyle, Margaret Grayson (co-applicant)</i>	<i>Neutropenic Sepsis</i>

*Of particular note is the fact Margaret Grayson is a co-applicant on the submission to the NIHR.*

*The input of the NI Cancer Research Consumer Forum was invaluable in the development of our research proposal for a NIHR commissioned call for a clinical trial to assess the effectiveness of early switch to oral antibiotics in patients with low-risk neutropenic sepsis, a common complication of systemic anticancer therapy. Starting with the support of the Forum for this topic of research as one of importance to patients to avoid over-treatment and the associated detrimental effects on quality of life we worked closely with Margaret as we prepared our application. As a key member of the team, and a co-applicant, Margaret had a critical role at all stages of the design and development of the application including helping to define the primary outcome measure and determining the most appropriate method for obtaining outcome data at the primary endpoint, balancing both data quality and patient priorities. I believe the input from Margaret and the Forum has resulted in submission of a robust application that will answer the primary research question in a patient-focused way, and look forward to working with the Forum again in this way on future applications.*

*Dr Vicky Coyle*

*Clinical Senior Lecturer, Consultant Oncologist*

*In next year's report we will provide an update of research progress following the outcome of these funding proposals.*

## *PPI Highlight: Forum Members become Members of National Cancer Research Institute (NCRI) Clinical Study Groups*

*This year 2 members of the Forum were successful applicants for membership of NCRI Clinical Study Groups (CSG). These Groups are composed of clinicians, scientists, statisticians and lay representatives and have responsibility for the strategic coordination and development of a portfolio of trials within a given cancer field. These groups are instrumental in shaping the national portfolio of cancer trials available to patients. Hence it is a significant landmark to have lay membership from Northern Ireland in clinical study groups for the first time. Debbie Keatley is a member of the Brain Cancer CSG and Allister Murphy, who left the Forum during the year, is a member of the Prostate Cancer CSG.*

## *Summary of Other Involvement Highlights by the Forum/Forum Members*

### *UK and International Focus*

#### *Committee and Group Membership*

*Margaret Grayson continues to represent Northern Ireland on the National Cancer Research Institute (NCRI) / National Cancer Research Network (NCRN) PPI Steering Group. This is an excellent forum for both sharing cancer research PPI activity in Northern Ireland and also learning about national developments and practice and resources in PPI.*

Margaret is also an associate member of the NCRI/NCRN Consumer Liaison Group, a member of the NCRN reference panel for the European Organisation for Research and Treatment of Cancer (EORTC) and this year was part of the European Patients' Academy on Therapeutic Innovation (EUPATI) National Liaison Team, which organised the first EUPATI UK Network Meeting which took place in Leeds in March 2014.

Being part of the Independent Cancer Patients' Voice, as a patient advocate, Margaret provides an informed and unfiltered patient perspective to cancer research on a nation-wide basis.

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

### **Sharing Learning in PPI**

One of the objectives of the Experimental Cancer Medicine Centres (ECMC) Network, funded by Cancer Research UK and the Departments of Health including the HSC R&D Division, is to promote cross-centre working and collaboration. In October 2013 Professor Ruth Plummer from the Sir Bobby Robson Cancer Trials Research Centre in Newcastle upon Tyne, shared her expertise in early phase trials and malignant melanoma. During that visit she met Margaret Grayson and Ruth Boyd and plans were laid regarding a visit to Newcastle. Subsequently Professor Plummer gained an ECMC cross-centre training grant and Margaret and Ruth visited Newcastle to share the experience of establishing the Forum in Northern Ireland and provided some PPI training for the enthusiastic early cancer trials team staff in Newcastle.



Margaret Grayson (back row, far right) with Professor Ruth Plummer (3<sup>rd</sup> from left) and members of the Newcastle team with Hannah Brown (front row, 2<sup>nd</sup> from right) from the ECMC Secretariat, London

*Following this, Professor Plummer and Margaret and Ruth were asked to speak at the ECMC Network Annual Meeting, held in London in May 2014 to talk about PPI and the cross-centre placement. There was also the confirmation that Newcastle planned to establish a PPI group for cancer research.*



Ruth Boyd and Margaret Grayson, speakers at the ECMC Network Annual Meeting in London, and Dr Clive Wolsley, HSC R&D Division, who chaired the morning session

## *Engagement and Consultation*

*In September 2013 many members of the Forum took part in Cancer Research UK's first patient engagement event which synchronised several workshops across the UK to share the work of the charity and gain patient and carer perspectives on how people wanted to be involved in the work of the charity, including the new strategy it was developing. The 'Your Say, Your Day' event included a presentation from Professor David Waugh, Scientific Director, CCRCB and Belfast Cancer Research UK Centre Director.*



Forum members and Professor David Waugh (3<sup>rd</sup> from right) and Leanne McCourt, Cancer Clinical Research Nurse, Craigavon Hospital, at the Cancer Research UK engagement event, September 2013

*In a follow-up to this event Forum member Allister Murphy attended a Cancer Research UK focus group held in Belfast in December 2013, which gave patients and carers an opportunity to give their perspectives on what should be future research strategy priorities for the charity. In May 2014, Forum member Mike Moran attended the Belfast launch meeting of the Cancer Research UK new strategy, marked by*

presentations from the Cancer Research UK Chief Executive, Harpal Kumar, Chief Clinician Professor Peter Johnston, and Belfast Cancer Research UK Centre Director, Professor David Waugh.

In June 2014, the Forum was invited by Wendy Fisher, on behalf of the Health Research Authority, to comment on standard statements used in Patient Information Sheets in the UK regarding the risk of exposure to radiation in clinical trials. By law, patients must receive information about the risk of radiation and any additional radiation exposure they may receive as a result of participation in research. The Forum met and discussed each statement, from a patient/carer perspective, relevant to various settings, such as low or high dose radiation exposure as a result of scans or radiotherapy. The comments from the Forum were fed back via Wendy, to radiologists working on this issue nationally.

### **New PPI role**

In January 2014, Margaret Grayson was invited to attend a 'Thought Leaders' meeting about PPI in Cancer Research UK, London, as the charity developed plans around facilitating great PPI within its work. In May, Margaret then was successful in her application to become a Cancer Research UK Involvement Coach, as part of a pilot scheme for this role.

As a CRUK Involvement Coach I have had the opportunity to be involved in many areas and to act as an advisor at a national level in relation to engagement and involvement linked to CRUK's strategy.

Margaret Grayson

## *Conferences and Meetings*

*In November 2013 three members of the Forum, Margaret Grayson, Dori-Anne Finlay Blackstock and Allister Murphy attended the NCRI Annual Conference held in Liverpool.*



Margaret Grayson and Allister Murphy meet up with Jack Nunn, Macmillan Cancer Support, London, during the NCRI annual conference dinner

*Once again there was excellent involvement at the conference, including a lively Dragon's Den session with researchers and members of the NCRI Consumer Liaison Group, including Margaret and Allister.*



*In June 2014 Margaret Grayson and Dori-Anne Finlay Blackstock attended the National Cancer Intelligence Network (NCIN) Annual Conference in Birmingham. Dori-Anne gave this feedback about the conference:*

The theme for the NCIN Cancer Outcomes Conference in 2014 was certainly motivational: 'Harnessing the Power of Information to deliver: Quality and Innovation in Cancer Surveillance, Services and Outcomes. Improving survival rates and the quality of life of cancer sufferers.'

After the welcoming address by the Director of NCIN, first to be introduced was Kris Hallenga a young girl of 23 years of age and she certainly embraced the theme of the conference in her personal story, which really inspired all the delegates who heard her.

Kris, gave a truly enthusiastic account of how she believes everyone stands the best chance of 'Survival' through 'early knowledge' of cancer. Inspired by this belief, just two months into her diagnosis of breast cancer she began a crusade to help young people deal with the shock of being diagnosed with cancer, answering questions such as 'Why me?', 'I'm too young', 'I've just started my career,' and so on. She set up a charity Coppafeel and travels to schools and to doctors with an attitude of 'I can beat this....so can you' as she is fearlessly and actively trying to beat breast cancer herself.

The exhibition of Posters and the Sponsors showed an outstanding display of what is available in the pursuit of improving survival rates and quality of life for cancer sufferers as well as the nursing and carers' roles, and now there is this great opportunity of networking as a step closer in contacting and tapping into all the information and services to raise standards collectively.

We do have important issues to deal with regarding the proposed EU data collection details however we are confident that these can be resolved in the interest of raising global standards for all those patients who suffer the effects of cancer.

We were absolutely delighted to learn that we i.e. us in Northern Ireland will be hosting the NCIN in Belfast in June 2015. I personally felt this will bring a great awareness of the PPI Forum which is working along with cancer researchers in trying to get the highest standards of treatment and care for our cancer patients.

It is a privilege for me to be able to help others who have suffered this terrible disease and sadly many still do die, as did my own daughter at 26 years old of breast cancer, and it is a really 'feel good' factor for me to give some of my time to help others so that their quality of life and the percentage of survivors can rise day by day.

Dori-Anne Finlay Blackstock

## Northern Ireland Focus

### **Committee and Board Membership**

During the course of the year, Forum members maintained their committee and Board membership. 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. Andy Anderson and Margaret Grayson are members of the Belfast Cancer Research UK Governance Board.

### **Sharing a Patient Perspective, Influencing Research**

In October 2013, Margaret Grayson was an invited speaker at a research strategy consultation event at the request of the Director of HSC R&D Division. Researchers and Health and Social Care leaders met to discuss future HSC R&D strategy development in Northern Ireland.

In May 2014, Margaret spoke about the value of PPI in Clinical Research at an open day hosted by the Northern Ireland Clinical Trials Unit (NICTU), based on the Royal Victoria Hospital site.



Margaret Grayson and Professor Danny McAuley, Director of the NI Clinical Trials Unit, at their open day in May 2014

*Professor Sean Duffy, National Clinical Director for Cancer for NHS England, was a guest speaker at CCRCB in February 2014, and Forum members were invited to meet him, taking this opportunity to emphasise the value of research embedded within the NHS.*



Professor Sean Duffy (centre) meets with members of the Forum and Professor Mark Lawler (2<sup>nd</sup> from right)

### ***Building PPI relationships – School of Nursing, QUB***

*During the year the Forum has appreciated the opportunity presented by Professor Sam Porter and other researchers in the School of Nursing, QUB, to establish links and influence research at an early stage of development within the School. Following an initial presentation and discussion with Professor Porter at the Forum meeting in September 2013, the Forum held a meeting in January 2014 to find out more about the cancer and palliative care research currently being undertaken in the School and also to explore how partnership working with the Forum could be further established.*



Forum members and researchers from the School of Nursing, QUB, meet to discuss PPI in cancer and palliative care nursing research

*Following this, the Forum generated research ideas and discussed their areas of priority at their next meeting, and forwarded these for review by the relevant researchers in the School and plans for working together are on-going.*

*Forum Member Janine McCann, links with the School of Nursing and Midwifery, QUB, through its Service Users and Carers Forum which was launched in July 2013. The members of this group are co-contributors to developing and implementing the teaching, education and research curriculum.*

### ***Meetings and Events***

*Attendance at Clinical Research Division meetings, joining with staff and researchers from CCRCB and Belfast Trust, continues to be informative and encouraging regarding current research activity and new developments. The meeting also gives insight to some of the issues that*

can arise in research implementation, and as research patient advocates, the Forum contribute to this discussion, highlighting the patient perspective.

In February 2014 members of the Forum attended a Cancer Research UK presentation about Early Diagnosis to the NI Assembly Health Committee in Stormont.



Forum members at Stormont in February 2014

In June 2014 Margaret Grayson attended a meeting of Health Committee members at CCRCB, including a tour of the NI Molecular Pathology Laboratory.

## Supporting Cancer Research Awareness

As research advocates the Forum members are committed to raising awareness about cancer research in Northern Ireland and the value of this research and the benefits of the PPI. This year there have been three key strands to Forum research awareness activity:

- Public events
- Support for the 'OK to Ask about Clinical Research' campaign
- Clinical trial videos

### Cancer Research with the X-Factor

One of the most memorable highlights in the Forum calendar was the public Information evening held in the NI Cancer Centre. On 16 October 2013 the Forum hosted 'Cancer Research with the X-Factor' showcasing new developments in radiotherapy research.



Forum members with speakers Dr Suneil Jain (left, seated) and (back row from 3<sup>rd</sup> left) Dr Aidan Cole, Dr Joe O'Sullivan and Dr Gerry Hanna, at the public information evening 'Cancer Research with the X-Factor' October 2013

The various speakers were enthusiastic researchers who left the audience in no doubt about the significant progress that was being made in Belfast. Advances in radiotherapy techniques were bringing benefits to patients through more targeted dose delivery to the tumour, while minimising the risk of side-effects. There was also a clear message about the value of research embedded within Health and Social Care Services in Northern Ireland, enhancing quality standards within the service.

## *A Celebration of World Cancer Day*

This year the Forum hosted an event to Celebrate World Cancer Day, which was 4 February 2014. The aim was to highlight the international context and impact of the cancer research being undertaken here in NI and inform public and health and social care leaders of the positive contribution of research. It was another inspiring event chaired by Margaret Grayson, who outlined the role of the Forum and PPI in cancer research. The Forum was delighted to welcome the Minister of Health, Mr Edwin Poots, to the celebration. The Minister remarked on the value of early cancer diagnosis and the important role of research in transforming practice.



Speakers (left – right) Professor Richard Kennedy, Margaret Grayson and Conan Donnelly

Mr Conan Donnelly spoke about NI cancer outcomes in relation to international benchmarking, and Professor Richard Kennedy highlighted a number of research areas where NI was leading in international developments.

This event also marked the NI launch of the European Cancer Patient's Bill of Rights, which is a call for European wide equality and commitment, for citizens to receive:

- the most accurate information and be proactively involved in his/her care
- optimal and timely access to appropriate specialised care, underpinned by research and innovation
- care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable healthcare

The event coincided with the European launch in Strasbourg which was attended by key drivers of the Bill from QUB- Professor Patrick Johnston and Professor Mark Lawler. Forum members met with Professor Lawler on a number of occasions in the lead-up and planning of the event.



Some Forum members attending the Celebration of World Cancer Day, including Forum speakers (front row from left) Paul Burns and Margaret Grayson



The event concluded with Forum member Paul Burns' heartfelt presentation, providing a personal perspective on the importance of the principles of the Bill of Rights.

The event was held in the McClay Library auditorium, QUB, and photographs were taken in the C.S. Lewis Reading Room. The Forum are very grateful to the Friends of the Cancer Centre for their support for catering at this event.

## International Clinical Trials Day and 'OK to Ask' Campaign

Once again, Forum members were delighted to lend their support for International Clinical Trials Day 20 May 2014. Along with staff from the NI Cancer Trials Centre and Margaret Carr, Cancer Research UK Research Engagement Manager, Forum members chatted to staff and patients and visitors at the NI Cancer Centre where there was an information table to raise awareness about cancer clinical trials.



Sara McCusker, Cancer Clinical Research Nurse and Ian Sturgess, Pharmacist, International Clinical Trials Day, May 2014

*International Clinical Trials Day marked the launch of a new campaign co-ordinated by the HSC R&D Division 'It's OK to Ask.....about clinical research'. This campaign, which related to patient research across all health issues, encourages patients and carers to ask their healthcare professional about clinical research available.*



Mike Moran, Ruth Boyd and Margaret Grayson from the Forum show their support for the OK to Ask Campaign in the NI Cancer Centre

*Margaret Grayson was a speaker at the formal launch of the OK to Ask campaign, which was held in Stormont. Margaret gave the patient and carer perspective on the importance of research. Other speakers included Professor Joe O'Sullivan, CCRCB, Consultant Oncologist, Belfast Trust and Dr Michael McBride, Chief Medical Officer, DHSSPS. Other Forum members attended the event to demonstrate their support for this important campaign.*



Forum members join with some of the speakers, Margaret Grayson (front left), Professor Joe O'Sullivan (back, 2<sup>nd</sup> left) and Dr Michael McBride (back 2<sup>nd</sup> right) at the launch of 'It's Ok to Ask' campaign, Stormont, May 2014

## Clinical Trial Videos

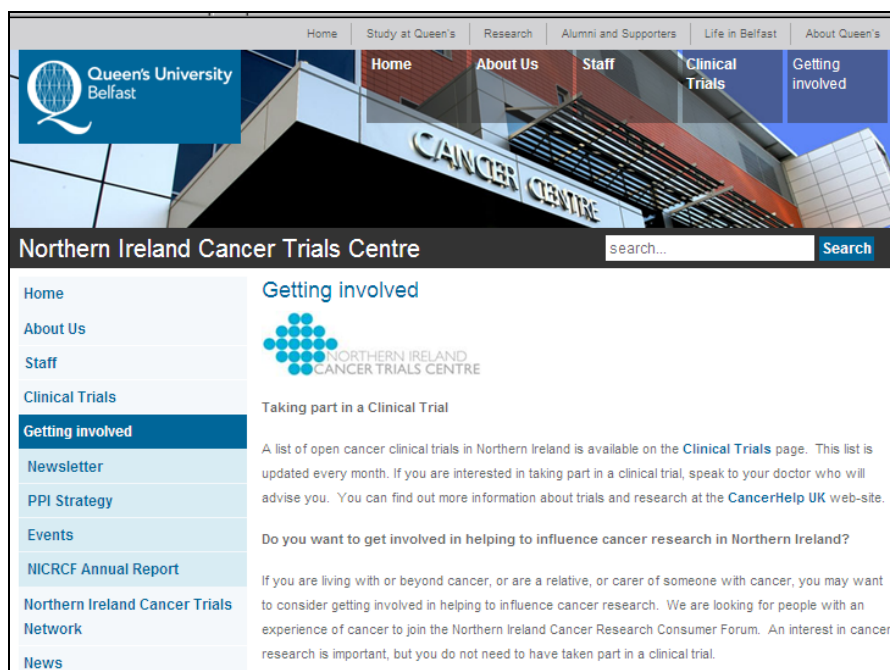
Forum members got involved in two video projects, which are helping raise awareness about clinical trials. Forum members Paul Burns and Dori-Anne Finlay Blackstock both volunteered to appear, acting in the role of participants, in a video about the Habio study. This study which is led by Dr Kate Williamson, QUB, and sponsored by Belfast Trust, aims to identify a panel of biomarkers for bladder cancer. The final video can be viewed on the internet on the [Habio study's home page](#).

Forum members gave their feedback and recommendations on a story board developed for a video to highlight the collaboration of CCRCB and the NI Cancer Centre in the development and conduct of cancer clinical trials, and the clinical trial activity taking place in cancer, based at the Belfast Trust. The video links to the 'It's OK to Ask' campaign theme encouraging patients and carers to find out more about clinical trials available. The video is funded by CCRCB and Friends of the Cancer Centre are funding a project which will facilitate access to the video in the NI Cancer Centre, on plasma screens. We are indebted to Derek McKnight, clinical trial participant, who took part in the making of the video.

# Supporting Forum and PPI in Research Awareness

The Forum continues to use the [NICTC website](#) to disseminate news and information and also provide details about how to become a member of the Forum. This year the Forum issued 2 'Consumer Impact' Newsletters.

The work of the Forum was one of the examples of PPI success presented by Ruth Boyd at a national conference 'Four Nations – Sharing Practice in Public Involvement'. The conference took place in Cardiff in May 2014.



## Some Forum Future Plans

The Forum aims to continue to strengthen the impact it can have for patient benefit, through the representation of the patient/carer voice shaping cancer research. Forum members will continue to welcome opportunities to network with the public, patients and researchers across Northern Ireland and beyond. The MERCuRIC Patient and Public Initiative will be on-going for the duration of the 5 year research Programme (see page 13/14). The key to the success of the Initiative will be raising awareness of the study and establishing patient/public communication pathways within the collaborating European countries, which is a new challenge.

Closer to home, the work of the Forum will continue to be integral to the NI Cancer Trials Network, and establishing early collaboration with the growing body of research originating from the talented researcher scientists and clinicians working in Northern Ireland, will be an on-going objective. This will include working more closely with NI Biobank and also growing the established links with the School of Nursing, QUB.



The Forum aims to continue involvement in cancer research projects throughout the various stages of the research cycle

*Building Research Partnerships will continue to be an important resource in PPI training. Forum members will also support training delivery, where their experience may be of value, and also ensure appropriate induction to PPI for its members and explore methods to further develop PPI skills. After 3 years of activity, with the help of the cancer research community willingness to embrace PPI and work in partnership, the Forum has exceeded expectations in the scale and breadth of their involvement, so it recognised it's an appropriate time for reflection, and strategic planning for the future.*

*The Forum recognises the financial constraints on health services, and will continue to advocate that clinical research is bringing benefits to the current services and patients, not only future patients, hence research remains a vital health investment.*

*Raising awareness of local cancer research will continue to be an informative and enjoyable objective. In the coming year, the Forum will host a further public information event. The Forum also aims to raise awareness of its work, through training and conference posters.*

## *Post Script - A Tribute to our Members*

*In January 2015, as this report goes public, Forum members are reflecting on a sad year when two of their members died, and members were bereaved. In December 2014, we were very sorry to hear of the death of Kathleen Casey's husband, Harry.*

*We also want to take this opportunity to acknowledge the wonderful work of our Forum members Brian Coburn and Paul Burns, who sadly died in recent months. Both men were very active and effective patient and research advocates within the Forum and beyond. Both men leave a lasting legacy through their dedicated, passionate and enthusiastic work, and they are dearly missed.*



*Brian Coburn was one of the founding members of the Forum, and he very quickly made his mark, getting involved in PPI activities and sharing his experience in cancer rehabilitation research, for which he was a passionate advocate. Brian was always articulate and direct, and effectively shared the patient perspective in every setting. He was undaunted by public speaking. Brian contributed so much to the Forum, working away enthusiastically, and ever a gentleman, always offering words of support for PPI and the work of the Forum.*



*Paul Burns was initially involved with the Forum as a guest speaker, at its first public information evening, before becoming a member the following year. Paul's warm, open and honest style of speaking touched everyone's heart, whether he was speaking about his personal experience of taking part in a clinical trial, or talking about wider research issues. Paul was up for anything if it would help to raise awareness of cancer research. Along with his wife Kate, also a Forum member, Paul worked tirelessly for PPI in Cancer Research.*



# *Perspectives from the NI Cancer Trials Centre*

*It's been another exciting year witnessing the growth of the Forum, not just expanding in size, but also in the breadth of their activity and the reach of their involvement and awareness-raising activities. The Forum's aims and objectives are outlined in Appendix 1.*

*Forum members are frequently inspired by the research taking place here in Northern Ireland, however, frequently it is also researchers who are inspired - encouraged by the involvement of Forum members in research projects. We continue to be indebted to Forum members' commitment to this work, to partnership with researchers, and to tirelessly asking researchers the key question - 'so what does this research mean for patients and the public?' We welcome this challenge, to ensure cancer research remains focused on patient benefit, and delivers research priorities based on patient and population need.*

*Much of the Forum's work isn't directly mentioned in this report, but the report alludes to the type of work the Forum undertakes. All Forum activity is voluntary, there are no time sheets (!), and much takes place through quiet reading, report preparation and e-mail, as well as the more visible aspect - attending meetings.*

*Once again, the leadership of Margaret Grayson, Forum Chair, has been vitally important. Aside from tireless PPI in Northern Ireland, Margaret's involvement in national PPI fora could fill a book, but this activity has not formed part of this report. However, this national work plays a crucial role in raising awareness of cancer research and PPI in*

Northern Ireland. Margaret is a potent and influential advocate of PPI. She is dedicated to patient and carer involvement in cancer research, both here and across the UK, and again we are grateful to her and all the Forum members for giving generously of their time, skills and experience. We look forward to continuing working alongside the Forum in the coming year.

**Ruth Boyd, NICTC PPI Lead**

**Cancer Research UK Senior Nurse**

*on behalf of the NICTC Executive Committee*

# Financial Summary

September 2013–August 2014

<i>NICRCF Expenses</i>	<i>Sept 2013 – Nov 2013 £</i>	<i>Dec 2013 – Feb 2014 £</i>	<i>Mar 2014 – May 2014 £</i>	<i>June 2014 – Aug 2014 £</i>	<i>Total for Year £</i>
<i>Catering</i>			46.58		46.58
<i>Travel Expenses</i>	41.52	84.96	149.07	122.98	398.53
<i>Public Information Evening*</i>	167.75				167.75
<i>Building Research Partnerships**</i>	150.00		100.00		250.00
<i>Celebration of World Cancer Day***</i>		275.50			275.50
<i>Quarterly Totals</i>	359.27	360.46	295.65	122.98	
<i>Total NICRCF expenses paid by NI Cancer Trials Centre</i>					1138.36

**\* 'Cancer Research with the X-Factor', 16 October 2013**

Photography	45.00
Catering	60.00
Hospitality	<u>62.75</u>
<b>TOTAL</b>	<b>£167.75</b>

**\*\*Building Research Partnerships, 24 October 2013 and 30 April 2014**

Hospitality 24.10.13	150.00
Hospitality 30.04.14	<u>100.00</u>
<b>TOTAL</b>	<b>£250.00</b>

**\*\*\* 'Celebration of World Cancer Day' 04 February 2014**

Catering	507.00
Hospitality	<u>100.00</u>
	£607.00
Donation from FoCC for catering	<u>-331.50</u>
<b>TOTAL</b>	<b>£275.50</b>

# 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, NICTC*

*East Podium, C-Floor*

*Belfast City Hospital*

*Lisburn Road*

*Belfast*

*BT9 7AB*

*Tel: 028 90 638468*

*E-mail Ruth Boyd at: [nictc@belfasttrust.hscni.net](mailto:nictc@belfasttrust.hscni.net)*

