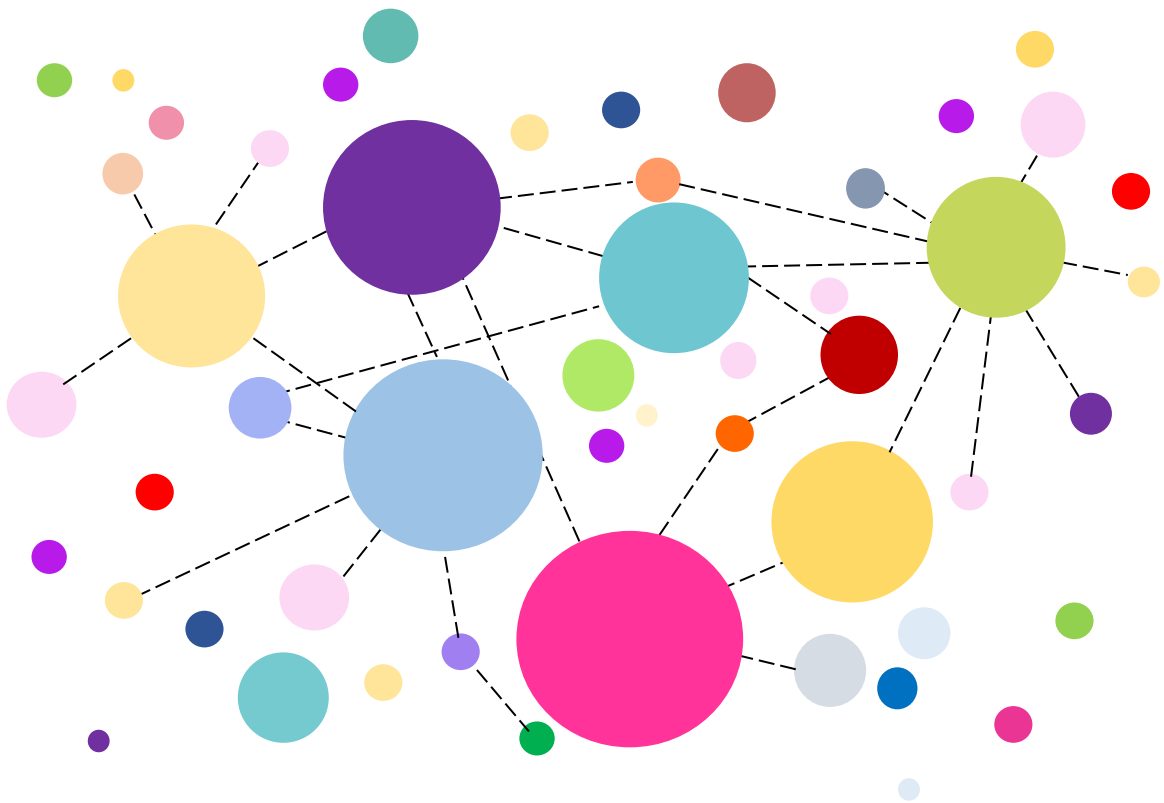




*5th Year Report of the Northern Ireland Cancer
Research Consumer Forum*

Extending the Reach of Partnership



September 2015 – August 2016

Final Version 1.0 23 January 2019

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>Training for Members and Others</i>	<i>9</i>
<i>Shaping Cancer Research</i>	<i>13</i>
• <i>NI Cancer Trials Network and Belfast ECMC</i>	<i>13</i>
• <i>Forum Involvement in the Review of New Clinical Research Studies</i>	<i>14</i>
• <i>Forum Involvement in the Management of Clinical Trials with Local Research Leadership</i>	<i>15</i>
• <i>Forum Involvement as PPI Partner in National Cancer Research Collaboratives</i>	<i>19</i>
• <i>Other Forum Involvement in Locally Led Cancer Research</i>	<i>20</i>
• <i>Forum Involvement in National Cancer Research PPI PPI</i>	<i>21</i>
• <i>Conference Involvement</i>	<i>23</i>
<i>Raising Awareness and Showcasing PPI and Cancer Research</i>	<i>27</i>
<i>Some Forum Future Plans</i>	<i>37</i>
<i>Perspectives from the NI Cancer Trials Network</i>	<i>38</i>
<i>Financial Summary</i>	<i>40</i>
<i>Appendix 1 NICRCF Purpose and Objectives</i>	<i>41</i>
<i>Contact Details</i>	<i>42</i>

Welcome to the Fifth Year Report

A warm welcome as you start to read this, the fifth report of the Northern Ireland Cancer Research Consumer Forum (NICRCF).



The NICRCF is a long name for a group of very special people. All of our members have been impacted by cancer as a patient, a carer or a friend and all are passionate about the importance of

research as part of excellence in health care. Research that will make a difference to the people in Northern Ireland, and globally, in the area of prevention, diagnosis and treatment. Thank you to each Forum member for their willingness to share time, experience, knowledge and life skills keeping the patient voice central and adding value to research that results in benefit to patients and to the NHS.

It might appear as though every year I repeat this next thank you but it is important to highlight the role of our Personal and Public Involvement (PPI) Professional Lead, Ruth Boyd. Ruth's dedication to research and patients as the CRUK Senior Research Nurse, her belief in PPI, her energy and genuine friendship and caring has been central to the success story of the Forum. Thank you Ruth!

We would not exist as a Forum without the support of the Northern Ireland Cancer Trials Network (NICTN) so thank you to Dr Melanie Morris and Professor Richard Wilson. Thank you Melanie! Thank you Richard!

Enjoy reading this snap shot of the Forum's Involvement in Cancer Research in NI.

Margaret Grayson, Chair, NICRCF

Members, Meetings and Training

Membership

At the end of August 2016 the NICRCF has a total of 22 members.

We continue to encourage anyone interested in influencing cancer research as a Personal and Public Involvement (PPI) Representative to get in contact with us. Four new members joined the Forum over the course of the year and we are indebted to them and existing members, for sharing their experience and skills for the benefit of others and contributing so much to the cancer research landscape in Northern Ireland.

Forum Meetings

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

Quarterly Forum meetings were held in the NI Cancer Centre. Each meeting agenda covered a range of topics including meeting researchers to discuss their proposals or research updates, as well as review of Forum activities and future planning.

Kicking off the 15 September 2015 Forum meeting, members were thrilled to welcome as a guest speaker, Colette Goldrick, Northern Ireland Director of the Association of the British Pharmaceutical Industry (ABPI).



*Colette Goldrick (ABPI) (Front right) with
Forum members September 2015*

Colette gave a dynamic presentation entitled 'Innovation in Cancer Care – possibilities and reality.' It was reported that it takes 10-12 years and \$100 million to bring a drug into use. Colette advised that the pharmaceutical industry was now focussed on combining targeted and immunotherapeutic agents. Access to drugs after licensing was another area of discussion within the group and there was a lively question and answer session on a range of issues. Members of the Forum were invited to take part in the Clinical Innovation Collaboration Conference due to take place October 2015 (see page 23).

An ad hoc meeting took place on 23 September 2015. This was to facilitate three researchers presenting their project proposals to the Forum. Members were delighted to welcome Dr Charlene Treanor (Centre for Public Health, Queen's University Belfast (QUB)) who presented the study proposal 'Interventions for cognitive impairment due to systemic cancer treatment'.



*Dr Charlene Treanor and Mrs Dori-Anne
Finlay Blackstock*

Mr Conor Doyle (Pharmacist, Antrim Hospital) described the rationale and design for the proposal 'Study of FKBPL and effects of ALM201 on Multiple Myeloma cells, and its potential to reverse angiogenesis in this patient group'.



Dr Conor Doyle and Mr Andy Anderson



Captain Robin Gray with Dr Joanne Reid

Dr Joanne Reid (School of Nursing, QUB) described 'Educational strategies to teach end-of-life care to undergraduate healthcare students: a scoping exercise.'

All three studies stimulated further discussion and follow-up with the researchers over coffee.

Forum member discussion over coffee



In addition to the regular quarterly meetings and ad hoc meeting, Forum action plans led to the establishment of two Forum working groups to focus on aspects of Forum activity where development was required. These were (i) Communication and Awareness (Researchers/Patients/Public) (ii) Training, Role Clarification and Evaluation (see page 10). The outcome of the communication and awareness discussions in 2016 was agreement to request development of:

- cards/hand-out members could use, explaining the PPI representative role in the Forum
- NICRCF stand-alone website
- Communication plan to maximise effectiveness
- Increased regional liaison
- More public events



Forum Members with the new NICRCF pop-up stand November 2015

The NICRCF welcomed Dr Lesley Anderson (Lecturer in Cancer Prevention, QUB) to the Forum 03 March 2016. Dr Anderson gave a presentation on her current research proposal, a feasibility study of a pedometer-based intervention for patients with myeloproliferative neoplasms (MPN). There was an extensive discussion following Dr Anderson's presentation, including many practical suggestions.

During the final Forum meeting of the year, once again there were three guest researchers. Forum members welcomed back Dr Charlene Treanor (Research Fellow at the Centre for Public Health, QUB) who presented a research proposal entitled 'Building resilience to face the challenges of cancer treatment'. This study would look at the opportunity for 'Prehabilitation' in cancer treatment, a concept and study design that generated much discussion. The second guest researcher was Dr Ciaran Moore (Academic Clinical Fellow, QUB and Specialist Registrar, School of Dentistry) who described a proposal around oral side-effects of radiotherapy in Head and Neck Cancer. This presentation provided a rare insight to the dental impact of treatment and the potential need to tailor care to take account of innovation in radiotherapy. The final presentation was Dr Finian Bannon (Statistician in Medical Statistics, Centre for Public Health, QUB) who described a research proposal looking at 'treatment effectiveness in elderly lung cancer patients'. This project planned to look at population based electronic data, to facilitate development of clinical guidance. This stimulated discussion on the use of data, and the endorsement of appropriate use of data for research and the benefit of patients.

Training for Members and Others

Core training on PPI remains the Building Research Partnerships Workshop which is funded and co-ordinated by HSC R & D Division and is supported by NICTN and facilitated by Margaret Grayson. A workshop was held 11 Nov 2015. These events consistently receive positive feedback from researchers, healthcare professionals and lay representatives alike.

An in-house questionnaire was disseminated to Forum members in September 2015 to help identify Forum PPI experience and training needs. There was a wealth of experience in various types of PPI in cancer research across the group. There was also a range of training relevant to PPI from a number of sources. What was apparent was that a more systematic approach to Forum member induction was required, as well as refresher opportunities and clarification of the PPI representative role and expectations. The survey results were discussed at the Forum meeting held in November 2015 and it was decided that a training-themed Forum Action Group (alongside a Communication and Awareness Action Group) would be set up to focus on training, the PPI role and evaluation.

Working Group in action February 2016



It was agreed to facilitate access to training. Where appropriate training would be incorporated into Forum meetings. A training workshop on Patient Information Sheets was facilitated by Ruth Boyd following the Forum meeting held in March 2016.

The annual HSC R&D Division joint workshop for PPI representatives from both the HSC R&D Division and the Forum was led by the team who conducted an evaluation of PPI in HSC. Dr Joe Duffy, QUB, and Dr Patricia Gillen, University of Ulster (UU), gave an insightful session on the background and methods utilised

for the evaluation process. Some Forum members had previously contributed to evaluation focus groups. At the time of the workshop the report was being drafted for review. Following an enjoyable workshop participants enjoyed a networking lunch.



Forum and PIER Group training with (front first and second left) Dr Joe Duffy and Dr Patricia Gillen, December 2015.

The training opportunities for the year concluded 02 June 2016 with a further joint Forum / PIER workshop facilitated by training consultant Sally Crowe of Crowe Associates. The objectives of the workshop were to develop critical thinking and analysis skills for use with research materials, proposals and protocols to increase confidence in communicating about research in the HSC context and beyond. The workshop involved group work and following a productive morning participants were much more familiar with the use of critical thinking in research within the PPI representative role. Sally provided a critical thinking checklist tool for use going forward.

In January 2016 Margaret Grayson provided an education session on PPI to second year medical students.

Sally Crowe workshop June 2016



Sally Crowe, Facilitator



Forum and PIER members together in group work



PPI Shaping Cancer Research

Effective partnership working between researchers and Forum members is core to personal and public involvement success in cancer research. This is demonstrated at various stages of the research process in the partnership of the Forum with the NI Cancer Trials Network and Belfast Experimental Cancer Medicine Centre.

NI Cancer Trials Network (NICTN) and Belfast Experimental Cancer Medicine Centre (ECMC)

The Northern Ireland Cancer Trials Network (NICTN), working regionally and co-ordinated at Belfast HSC Trust, supports and facilitates the work of the Forum. Belfast ECMC is a collaboration across NICTN and the Centre for Cancer Research and Cell Biology (CCRCB) in translational and early phase trials. Here we provide a summary of Network/Belfast ECMC research activity for the financial year 2015/16.

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 Institutes of Health Research Clinical Research Network (Cancer) portfolio, Cancer Research UK, the pharmaceutical and biotechnology industries and those developed by local research groups.

Between April 2015 to March 2016, 904 people in Northern Ireland were recruited to cancer clinical trials and other cancer research studies. This met the overall recruitment target of 850 participants (10% of incident cancers excluding non-melanoma skin cancers). Recruitment to interventional trials was 204.

Over the course of the year 108 studies were available for patient participation across a range of cancers.

Although recruitment was to a wide range of studies, recruitment to urology, breast and haematology cancer research continued to exceed other disease areas accounting for 84% of the overall recruitment. Activity in Belfast HSC Trust accounted for 75%, and the Cancer Units in Altnagelvin, Antrim, Craigavon and the Ulster Hospitals made the significant contribution of 25% 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 2015 – August 2016 Forum members attended a number of the 40 NI Cancer Clinical Trial Review and Adoption meetings co-ordinated by the NICTN. It was a bumper year for the review of new studies and at least one Forum member was involved in the review of each of the 35 studies referenced 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 at the time of the meeting.

Cancer type	Number of studies with Forum member PPI within NICTN process 15/16
Haematological	8
Miscellaneous	8
Breast	5
Bowel	3
Prostate	2
Gullet, Stomach & gastro/oesophageal junction	4
Gynaecological	2
Head and neck	2
Children's	1
TOTAL	35

Forum Involvement in NI Cancer Research Management Structures

Forum members continue to have roles embedded into the structure of the management and oversight of cancer clinical research in Northern Ireland. During the reporting period, Margaret Grayson has 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. Geoff Hill has been a member of the Belfast Experimental Cancer Medicine Centre Steering Group. From June 2016 Kate Burns joined the Steering Group for the two year 'Prostate Cancer UK Project Nurse' project.

Forum Involvement in the Management or PPI Advisory Role of Clinical Trials with Local Researcher Leadership

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

Study Title	Researcher	Role /Committee / Group	Forum member
MERCuRIC* 1: MEK and MET Inhibition in Colorectal Cancer (International)	Prof R Wilson, Principal Investigator	Study Patient Representative and Project Work Stream	Margaret Grayson
Vitamin D in Colorectal Cancer (Belfast)	Prof R Wilson and C Campbell, Co-Chief Investigators	Data Monitoring and Ethics Committee	Sandra Irvine
Phase I Study of ALM201 in Solid Tumours (UK multi-centre)	Prof R Wilson, Chief Investigator	Steering Committee	Janine McCann
BALLAD UK: A trial to evaluate the potential benefit of adjuvant chemotherapy for small bowel adenocarcinoma (International)	Prof R Wilson, International Chief Investigator	Study Patient Representative and Trial Management Group	Mike Moran
EASI-SWITCH Trial: Early switch	Dr V Coyle,	Trial Management Group	Margaret Grayson

to oral antibiotic therapy in patients with low risk neutropenic sepsis (UK multi-centre)	Chief Investigator	Steering Group	Robin Gray, Edward Goodall
HaBio: Haematuria Biomarker Study (NI multi-centre)	Dr K Williamson, Chief Investigator	Steering Committee	Edward Goodall
CIBRAC: Chemoprevention in BRCA1 Mutation Carriers – a Proof of Concept Study (Belfast)	Mr Stuart McIntosh Chief Investigator	Trial Management Group	Hazel Carson
CASPIR: Calcifications as an alternative to surgically implanted fiducial markers for prostate image guided radiotherapy (CASPIR): A prospective feasibility study (Belfast)	Prof Joe O'Sullivan Chief Investigator Angela O'Neill, Investigator	Prostate Cancer Research NICRCF PPI Advisory Group	Ffiona Crawford Dori-Anne Finlay Blackstock Hazel Fisher Ed Goodall Robin Gray Ken McBride Sonia Patton
ADDRAD: Neo-adjuvant Androgen Deprivation Therapy, Pelvic Radiotherapy and Radium-223 for new presentation T1-4 NO/1 M1B adenocarcinoma of prostate (Belfast)	Prof Joe O'Sullivan Chief Investigator		
SPORT High-Risk Trial: A Randomised Feasibility Study Evaluating Stereotactic Prostate Radio Therapy In High-Risk Localised Prostate Cancer With Or Without Elective Nodal Irradiation (Belfast)	Dr Suneil Jain Chief Investigator		

New this year

*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 June 2016 the Habio Study Team, including Ed Goodall (below, far right), got together to celebrate completion of recruitment to the study, with a total of 677 men and women participating in the study.



Habio Study Team June 2016

One of the studies which had Forum member PPI from the design phase and throughout was the APRIL (Active Palliative Rehabilitation in Lung cancer) study. Margaret Grayson and Dori-Anne Finlay Blackstock attended the results dissemination event in April 2016, held in UU. Dr Cathy Payne, All Ireland Institute of Hospice and Palliative Care and HSC R&D Division Doctoral Fellow, the researcher who had undertaken the research with UU, acknowledged the considerable positive impact the Forum and Lung Support Group members had had on the development and success of the study. The three key findings from the study were:

KEY FINDINGS

- 1) Many people diagnosed with advanced NSCLC (non-small cell lung cancer) are both willing and interested in engaging in palliative rehabilitation research.
- 2) Participation in APRIL led to perceived improvements in physical and psychosocial well-being.
- 3) Palliative rehabilitation to support people to live as they wish, for as long as they are able, should be a key consideration for all those diagnosed with a life-threatening or life-limiting condition.



APRIL study results dissemination event April 2016

Forum Involvement as PPI Partner in National Cancer Research Collaborative

The Forum, and in particular the Bowel Cancer Interest Group of the Forum, continue its contribution to the UK Medical Research Council/Cancer Research UK funded project S-CORT : Stratification in COloRectal cancer - from Biology to Treatment prediction. Forum members Dr Sandra Irvine and Dr Ed Goodall are rotating members of the Belfast S-CORT Group Meeting and alongside Margaret Grayson are part of the UK-wide S-CORT Patient and Public Involvement and Engagement Subgroup, chaired by work-stream lead Professor Mark Lawler. One of the highlights of the Sub-group's activities this year was planning and supporting the S-CORT/bowel cancer event held in Belfast in June 2016 (see page 33).



*Prof Mark Lawler with Bowel Cancer Interest Group members
Edward Goodall and Sandra Irvine*

Forum Involvement in Other Locally Led Cancer Research

*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 representatives met with Dr Olinda Santin and Dr Gillian Prue, 19 January 2016, to discuss a Knowledge Exchange Carer's proposal. The meeting helped inform proposal direction and development and this meeting led to on-going project involvement by Forum members.



Forum members in discussion with Dr Santin and Dr Prue

Dori-Anne Finlay Blackstock continues as a member of the NI Palliative Care Research Forum Committee and Janine McCann is a member of the QUB School of Nursing PPI Curriculum and Research and Ethics Groups. Dr Edward Goodall and Janine McCann have been involved in the research lead by Terri Flood, Lecturer in Radiotherapy and Oncology at UU, undertaking research into the use of service users as educator for radiographers.

Forum Involvement in National PPI

As Forum member involvement in PPI in cancer research at a national level continues to grow, this section of the report is now tabulated!

Research Organisation/Group	Role	Forum members
National Cancer Research Institute (NCRI)	Brain Clinical Studies Group (CSG) and Palliative Care subgroup lay member	Debbie Keatley
	Bowel CSG lay member	Sandra Irvine
	CTRad Working Group Workstream 3	Sonia Patton
	NI representative NCRI Consumer Forum Steering Group member	Margaret Grayson
	NCRI Consumer Forum members	Margaret Grayson, Debbie Keatley, Sandra Irvine, Sonia Patton
Experimental Cancer Centres (ECMC) Network	Experimental Cancer Centres (ECMC) Network PPI Working Group member and Chair	Geoff Hill
Cancer Research UK	Grand Challenge Patient Advisory Panel member	Margaret Grayson
	Strategy and Research Funding Directorate Sounding Board member	
	Involvement Coach	
	Thank you Cards for research patients and other projects	Hazel Fisher, Dori-Anne Finlay-Blackstock
NCIN/CRUK	Use MY Data Working Group member	Margaret Grayson
Breast Cancer Now National Cell Bank	Cell Access Committee Member	Margaret Grayson

<i>Mammo-50 Trial (National multi- centre study)</i>	<i>Trial Steering Group Member</i>	<i>Margaret Grayson</i>
<i>All-Ireland Palliative Care Institute</i>	<i>Voices4Care member</i>	<i>Dori-Anne Finlay- Blackstock</i>
<i>Marie Curie</i>	<i>Research Expert Voices</i>	<i>Dori-Anne Finlay- Blackstock</i>
<i>Independent Cancer Patients' Voice</i>	<i>Member</i>	<i>Margaret Grayson</i>

It must be noted that the amazing contribution that Forum members give to these wider bodies is also a brilliant asset to the Forum and to cancer research in Northern Ireland. We benefit from their sharing of patient/carer perspectives representing Northern Ireland, but also they are building a wealth of PPI experience that comes back to Northern Ireland and benefits their peers and researchers alike.

Conference Involvement

Several Forum members attended the Clinical Innovation Conference 7/8 Oct 2015, held at Riddell Hall, QUB. Following an inspiring opening event with guest speaker Mark Pollock there was a busy programme of speakers the following day. Margaret Grayson was a panel member during a plenary session 'Real World Evidence and Outcomes' and a panel member for the conference's concluding debate. Margaret was, as ever, a very effective patient voice and advocate for PPI.



Clinical Innovation Conference – Forum members and NICTN staff and researchers, October 2015



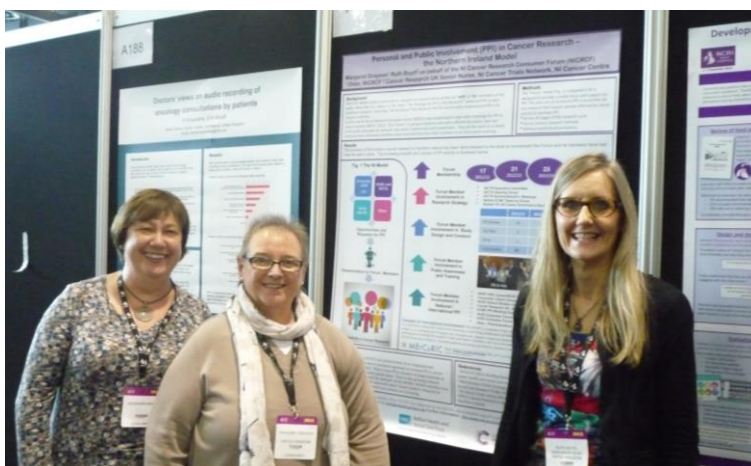
National Cancer Research Institute (NCRI) Annual Conference 2015

In November 2015 Debbie Keatley, Sandra Irvine and Margaret Grayson attended the NCRI conference. The NICRCF presented a poster at the conference, describing the Northern Ireland model of PPI in cancer research. One of the highlights was the 'Dragon's Den' event, where researchers and pharma 'pitched' their exciting ideas to various groups of NCRI consumer members. One of the other 'hot topics' of the conference for consumer members was the use of data and working to influence the planned EU legislation to ensure restrictions do not stop research conduct.

NCRI Conference November 2015

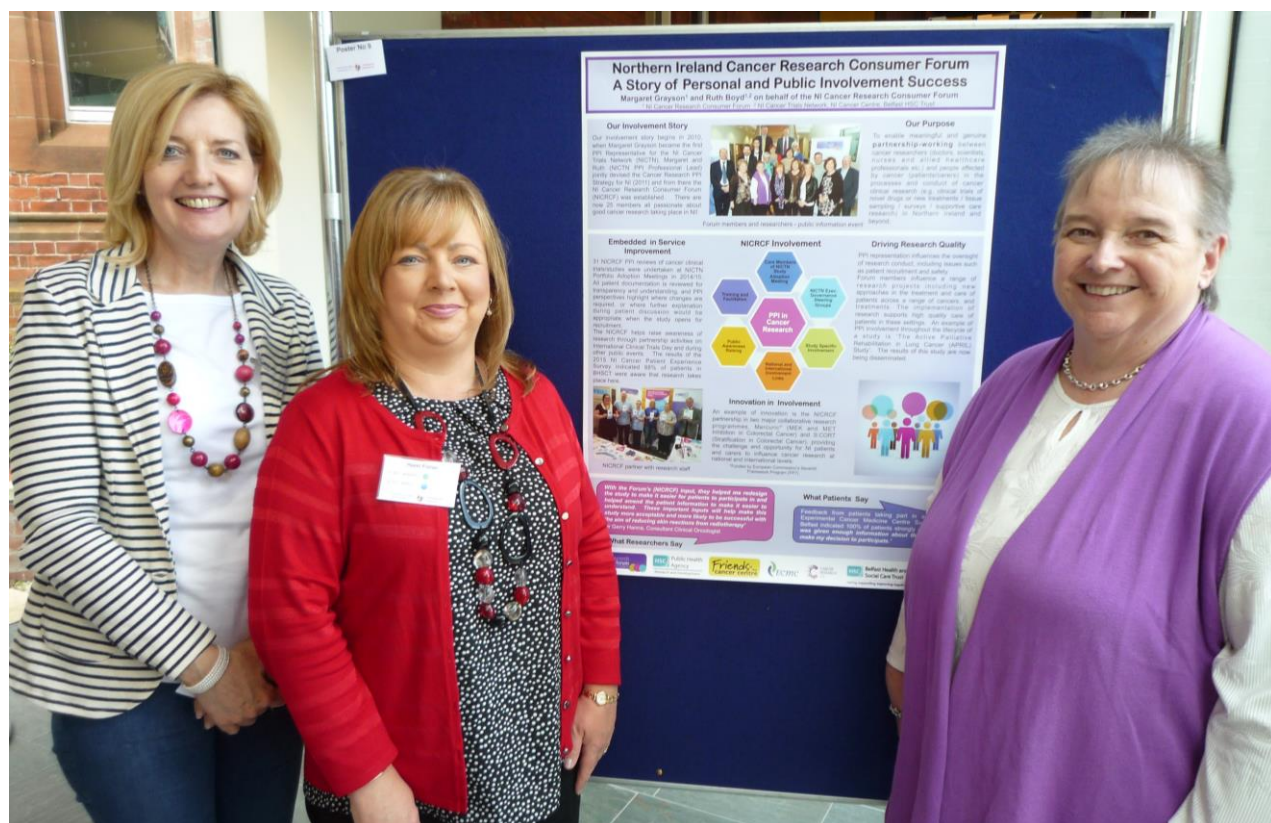


Professor Mark Lawler and Forum members with the NICRCF poster



Margaret Grayson was a speaker, and Forum members Kate Burns and Hazel Fisher also attended the HSC R&D/QUB conference 22 June 2016 'Involving You, Improving

Care Conference, held in Riddell Hall, QUB. The Forum's poster about the success of the Forum model for PPI in cancer research received an award in the Safety and Quality category. The Forum were delighted and this was a welcome acknowledgement, not just of the value of PPI, but of the contribution of research in the Health and Social Care service.



Margaret Grayson, Kate Burns, Hazel Fisher and Ruth Boyd enjoy the PPI conference June 2016



Margaret Grayson (centre left) with other speakers and the conference organisers at Riddell Hall June 2016

Margaret Grayson and Hazel Fisher were successful in gaining bursaries and attended the National Cancer Research Intelligence Network Conference in Manchester, June 2016. In the last Forum annual report we reported that Margaret Grayson was one of the speakers giving an opening address at the National Cancer Intelligence Conference held in June 2015. We are delighted to report that a video of this speech was presented at a World Cancer Leaders Summit in Istanbul 18 November 2015. According to Michel Coleman (Professor of Epidemiology and Vital Statistics London School of Hygiene & Tropical Medicine) 'the reaction was extraordinary' generating 'spontaneous applause'. Well done Margaret!

Raising Awareness and Showcasing PPI and Cancer Research

NICRCF members and researchers are united in wanting to share the positive news about the cancer research happening here across both laboratory and clinical settings. To increase awareness of research, the Forum and the role of PPI, the Forum has been involved in public events and meetings with staff and researchers within Northern Ireland and beyond.

On World Day 04 February 2016 the Forum were delighted to be involved in a novel way of illustrating the collaboration between the Centre for Cancer Research and Cell Biology (CCRCB) and the NI Cancer Centre at Belfast Trust. A chain of clinical and laboratory staff alongside patient representatives held hands between the two buildings to demonstrate 'bench to bedside united!'.

World Cancer Day February 2016





Margaret Grayson speaks to NTV news

Margaret Grayson was interviewed by NTV for their feature on World Cancer Day. The event was a great success and a vivid display of the working relationship between the hospital and research centre.

One of the other highlights in the calendar was a public information event in the CCRCB 13 April 2016, hosted by the Forum. The event focused on developments in Breast and Ovarian Cancer Research. Not surprisingly, there was a lot to cover, and Margaret Grayson expertly chaired the evening's proceedings. Mr. Stuart McIntosh and Dr Stephen Dobbs spoke of changes in breast and ovarian cancer respectively, covering aspects of prevention, screening and therapy and Dr Laura Feeney described a new research project looking at ovarian cancer diagnosis. Dr Gerry Hanna provided an overview of clinical trials in breast

cancer radiotherapy and Professor Richard Kennedy provided a reflection on the impact of Northern Ireland research on innovation in breast and ovarian cancer. Dr Lisa Jeffers highlighted research and services relating to inherited breast and ovarian cancer and Hazel Carson, the founder of BRCA Link NI, described the support available through this group. We were also privileged to hear the story of Mrs Avril Law, an ovarian cancer clinical trial participant who described the physical, social and emotional journey of diagnosis and treatment. During refreshments the public were able to browse information stands provided by the NICRCF, NICTN, Macmillan Information and Support Centre, Cancer Research UK, Friends of the Cancer Centre, BRCA Link NI, Cancer Lifeline and Target Ovarian Cancer. Feedback about the event was very positive and the 'wealth of information' about research, trials and personal stories were all appreciated.



Speakers and Forum members all ready for the event to commence



Margaret Grayson kicks-off proceeding at the public information event



Mr Stuart McIntosh presents to a packed room



Forum member Brieghe Lyttle with BRCA Link NI volunteer Joanne Rock

As ever the Forum gave their support to International Clinical Trials Day. Forum members joined with the staff of the NI Cancer Trials Network and Cancer Research UK Research Engagement Manager in the foyer of the Cancer Centre. All worked together speaking to patients, visitors and staff, promoting clinical trials and the HSC R&D Division campaign 'It's OK to Ask about Clinical Research.' Researchers and staff showed their support for the event and the campaign. Dr Cathy Payne also shared information about the results of the April study (see page 18).



Dr Cathy Payne describes APRIL research findings to research staff at the Bridgewater Suite, Belfast City Hospital



Forum, researchers, NICTN staff, CRUK and HSC R&D Division join in their support for research on International Clinical Trials Day, Cancer Centre May 2016



The Forum Bowel Cancer Interest Group, as members of the S:CORT (Stratification in Colorectal Cancer) Patient and Public Involvement and Engagement (PPIE) work-stream were delighted to welcome to Belfast fellow PPIE representatives from Leeds and Cardiff on 29 June 2016.



S:CORT PPIE work-stream members including the Forum Bowel Cancer Interest Group members

The day started with an excellent experience visiting Almac Diagnostics. Patient representatives heard from Mr Michael Sloan, Vice President of Business Development at Almac Diagnostics, who described the work and ethos of Almac and future plans. Professor Mark Lawler, QUB, who chairs the S:CORT PPIE work-stream, emphasised the importance of industry and academia collaboration for healthcare in Northern Ireland. Mrs Jo-Anne Dobson, MLA, Chair of the All Party Group on Cancer, Northern Ireland Assembly, described the wider commitment to cancer care. The morning concluded with a lively Q&A session.

There was further insight into the role of Almac in S:CORT during the tour of the research laboratories. Everyone on the visit was very impressed with the scale, organisation and quality standards of the business.



Members of the S:CORT PPIE workstream visit Almac Diagnostic and heard from (centre left – right) Mark Lawler, Jo-anne Dobson and Michael Sloan

In the evening the Centre for Cancer Research and Cell Biology once again opened its doors to the public for an S:CORT event. The public information evening was entitled 'Delivering 21st Century Medicine for Bowel Cancer'. The event was opened by Mrs Paula Bradley, MLA, Chair of the Northern Ireland Assembly Health Committee. Dr Victoria Coyle set the scene with a presentation on 'what you need to know' about bowel cancer. Sara Bainbridge, Cancer Research UK policy manager for early diagnosis, addressed the topic of early diagnosis. Precision medicine, including S:CORT research was the theme of Professor Mark Lawler's presentation. We were privileged to hear about the personal experience of bowel cancer from Tom McGrath, Chief Commissioner of the Charity Commission for Northern Ireland. The evening concluded with questions and discussion. Feedback given indicated that the audience had valued the range of aspects of bowel cancer covered and they were excited by the research progress being made.

Before the event started, NVTV was there to record perspectives of the speakers and they produced an excellent platform to hear about the research developments and innovation in bowel cancer care and detection.



Dr Victoria Coyle, QUB and Belfast Trust – speaker at the information evening



Charities and organisations provided information stands at the evening event

Professor Mark Lawler with Paula Bradley, MLA, NI Assembly



Refreshment break, information and networking at the event



The NICTN website continues to provide Forum information acting as a resource about how the public can get involved and the work of existing members.

Some Forum Future Plans

As referenced earlier in the report, having reached Year 5 of Forum activity we have identified the need for a formal evaluation process, incorporating the current PPI strategy for Cancer Research in Northern Ireland and Forum activity. The Forum Working Groups have also highlighted several ideas to support developing robust PPI training and induction for new members and ways to enhance outreach and communication across both research and public communities. As always, we know we have the support of many in sustaining the role of the Forum and developing methods to enhance effective and meaningful PPI in cancer research in Northern Ireland and beyond.

Perspectives from the NI Cancer Trials Network

The publication of this annual report has been significantly delayed and I wish to apologise to members and supporters for the lapse in communication about the NICRCF. Our reduced administration capacity in no way reflects a change of pace in the activities of the NICRCF and cancer researchers. Everyone has been working away as hard as ever. We hope that in the future there will be more sustainable administrative capacity.

Once again, this report is merely a very brief overview of work and it can't reflect all that takes place relating to Forum members and PPI in cancer research in Northern Ireland and beyond. Forum members continue, voluntarily, to share their experience and they are accumulating wide PPI expertise. We thank them for their untiring commitment and support through partnership in cancer research. This report is entitled 'Extending the Reach of Partnership' and I hope it is evident from this report how open Forum members are to partnering, not just our local researchers and institutions, but wherever their input may bring patient benefit. Forum members see the big-picture and have welcomed opportunities to work in partnership within national and international projects and organisations.

After reaching the 5 year Forum milestone, there is an obvious sense of PPI now being part-and-parcel of our cancer research routine practice. This is great, but as time progresses it also highlights the need for formal evaluation of this work and related processes, to build in assurances that what is currently established is effective, and determine the best way forward for the future. The Forum members themselves are eager for further development and they have a wealth of great ideas, as evidenced by the lively Forum Working Groups and meetings. In fact, that is a real hallmark of the Forum - there is no complacency where PPI for patient benefit is at stake.

The maturity of the Forum is demonstrated by the volume, breadth and reach of PPI activity that members are involved in, extending the impact the Forum. We are very fortunate to work so closely with the amazing individuals in the Forum. We gain so much from all their strengths and experience. Similar to previous years, the work of the Forum Chairperson, Margaret Grayson, must be highlighted as it is quite staggering in both its scale and influence. Both the NICTN and Forum members are especially indebted to Margaret, for her PPI leadership, capacity for PPI activity and unfailing support and enthusiasm.

We look forward to another very busy year!

Ruth Boyd, NICTN PPI Lead, Cancer Research UK Senior Nurse, on behalf of the NICTN Executive Committee

Financial Summary

September 2015-August 2016

NICRCF Expenses	Sept 2015- Nov 2015	Dec 2015- Feb 2016	Mar 2016- May 2016	June 2016- Aug 2016	Annual total
Catering	Funded informally				
Travel expenses	£96.48	£48.20	£120.00		£264.68
Subsistence			£19.15		£19.15
Breast and Ovarian Cancer Public Information Evening			£178.25		£178.25
Chair administration costs	£19.50*	£19.50*	£19.50*	£19.50*	£78.00*
Quarterly totals	£115.98	£67.70	£336.90	£19.50	
Total NICRCF expenses paid by NI Cancer Trials Network					£540.08

*paid retrospectively

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*

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