A Strategy for Personal and Public Involvement (PPI) in Cancer Research in Northern Ireland

PPI — "It's about developing collaborative partnerships with researchers to improve research. It's about making sure research is relevant to the patient. It's about making a real difference to the patient experience. Ultimately it's about making sure that the research is applied in the NHS. It's not just about patients sitting on boards."

Derek Stewart, Clinical Research Network's Associate Director for Patient and Public Involvement ¹



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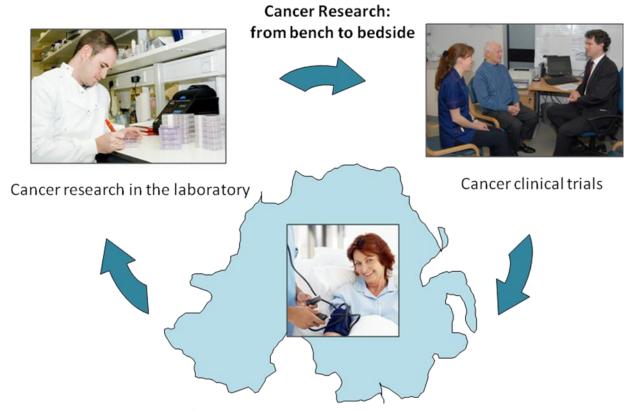
Abbreviations

HSC	Health and Social Care
NICTC	Northern Ireland Cancer Trials Centre
NICTN	Northern Ireland Cancer Trials Network
PPI	Personal and Public Involvement
QUB	Queen's University Belfast

Why Cancer Research?

The goal of cancer research is to improve health and benefit patients (see Figure 1).

Fig. 1 Benefits of Cancer Research



Benefits for cancer patients and the population:

better cancer prevention, diagnosis, treatment and care

Research is conducted through the partnership of various *stakeholders* such as government, Health and Social Care (HSC) Trusts, universities, charities, research bodies and drug and technology industries. Key stakeholders in cancer research are also the public and cancer patients who need the best possible health information, treatment and services.

Why Personal and Public Involvement (PPI) in Cancer Research?

The 'Strategy for Personal and Public Involvement in Health and Social Care Research' was launched by the HSC Research and Development Division of the Public Health Agency in 2010. This strategy advocates that Personal and Public Involvement (PPI) should be embedded within HSC research.

What is Personal and Public Involvement?

'Personal refers to any individual with a specific condition who uses or has used a service. This will include patients, carers, parents, clients or their advocates.'²

'Public refers to the general population and includes locality, community and voluntary groups and other collective organisations.'
Involvement means 'active partnership between the public and researchers in the research process....... Active involvement may take the form of consultation, collaboration or user control.'
'Involvement in research is different from simply taking part in a research study. For example, it can mean:

- helping researchers to identify and ask the right questions in the right way
- making sure that health and social care research is relevant to patients, people using services and the public
- getting involved in the research process itself, whether designing, managing, undertaking or disseminating research.' 5

There are multiple benefits of cancer research. The increasing growth of cancer research studies originating in Northern Ireland, and the expansion of *clinical research* activity and co-ordination across Northern Ireland, points to a vital need for a strategic approach to increase PPI in cancer research. While PPI in cancer research in Northern Ireland may be at an early stage, this provides the opportunity for PPI during the development of the strategy, as well as involvement across the future evolution of PPI in this arena. In the journey to develop this initial strategy for PPI in cancer research in Northern Ireland, it has been apparent there is a wealth of support, experience and resources available, regionally and nationally, from which to draw on, to enhance the potential effectiveness of the PPI strategy.







Cancer Centre, Belfast City Hospital

There is an existing track record of PPI in cancer research within the UK.

PPI in cancer research was formalised within the National Cancer Research

Institute with the establishment of the Consumer Liaison Group in 2001. A

number of Consumer Research Panels have been established within some

of the regional networks of the National Cancer Research Network.

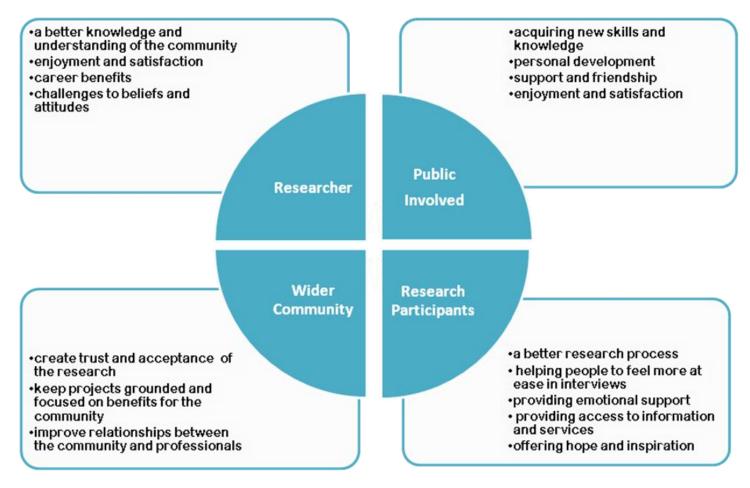
Within this strategy document, in the context of the PPI process, the individuals involved in this process, the PPI *representatives*, will be referred to as *consumers*. This reflects the term used within the national cancer research networks.

Benefits of PPI

PPI can benefit research. Consumers can be involved in research across the various stages of the research cycle, from design to conduct and dissemination. Consumers can also be involved across the strategic decisions about our research priorities and funding. This involvement has the potential to have a positive impact on those involved, and the wider community (see Figure 2). As Derek Stewart (Clinical Research Network's Associate Director for Patient and Public Involvement) puts it:

"Patients are experts in their own illnesses. They provide a personal insight into a disease or condition and bring additional knowledge that only they have. They challenge assumptions that medical professionals may make and identify problems that researchers might not have anticipated. But not only that, they sometimes come up with solutions that researchers would not expect. Again and again we see evidence of this throughout the Networks." ¹

Fig. 2 Some Benefits of Consumer Involvement



Text taken from Staley, 20094

The Need for a Strategic Approach to Personal and Public Involvement in Cancer Research in Northern Ireland

As the 'user involvement route map'⁶ (see Figure 3) illustrates, an infrastructure is necessary to support consumer involvement in research. This document aims to set out the plans to develop this infrastructure, to formalise and promote consumer involvement in cancer research in Northern Ireland.

Fig. 3 User involvement in research: a route map⁶



We know there are factors which appear to maximize the impact of consumer involvement including:

- involvement throughout a research project
- long-term involvement
- training and support for the people involved
- linking involvement to decision-making⁴

We also acknowledge that, for those involved, there are challenges associated with consumer involvement.

For researchers these challenges can be:

- Increased demand on resources and a slower pace of research
- Loss of power
- Forced changes in working practice
- Challenges to values and assumptions³

For the public these challenges can be:

- Emotionally burdened
- Overloaded with work
- Exposed through the media
- Frustrated at the limitations of involvement³

An important objective of this PPI strategy is to maximize the potential impact of consumer involvement and also incorporate the appropriate support and infrastructure to minimize the potential burden or challenges for those involved.

A Strategy for Personal and Public Involvement in Cancer Research in Northern Ireland

There are several aims of the PPI strategy. A priority is to develop the appropriate infrastructure⁶ needed to support PPI, to be able to sustain and support effective consumer involvement within cancer research management and research projects.

The Aims of the Strategy for PPI in Cancer Research in Northern Ireland

- 1. PPI in cancer research in Northern Ireland will be adopted by the research community as a routine standard process
- PPI will be integrated into local and regional cancer research strategy, management and projects
- 3. Opportunities for consumer leadership, partnership, and collaboration will be promoted
- 4. Consumers will have a clear pathway for finding out how they can be involved in influencing research
- 5. Researchers will have a clear pathway for accessing PPI
- 6. Consumers will be supported appropriately to maximize the impact of their involvement
- 7. The experience of consumers and the impact of PPI will be monitored and fed back into the process of on-going PPI strategy development
- 8. Continued learning and development about PPI will be supported through regional and national networking

What's needed to help achieve these aims?

1. Core Values (Aims 1-8)

The 'core values underpinning the behaviour and attitude of HSC staff in their interactions with individuals and the public' will be the foundation values of PPI activity:

'Dignity and Respect

Each person is treated with dignity and respect. This includes individual responsibility to respect the views of all participants be they individuals, communities or HSC staff.

Inclusivity, Equity and Diversity

The PPI process should facilitate the inclusion of all those who need to be involved and who chose to do so. It must be sensitive to the needs and abilities of each individual. Each person's background, culture, language, skills, knowledge and experience will be valued, accommodated and respected.

Collaboration and Partnership

The PPI process is based on collaboration and partnership working. Each person has a responsibility to build constructive relationships with others involved in the process.

Transparency and Openness

The PPI process should be open and transparent and each person has a

responsibility to be open and honest in their interactions and relationships with others.' 3

2. PPI in cancer research strategy, management, and projects (Aims 1 - 5)

It is now recognised that the various committees related to cancer research in Northern Ireland require two consumer members, to ensure that the quality and value of research is maximised. Table 1 describes the purpose of the various bodies that currently exist, or are in development, and where and how frequently they meet.

Individual *clinical trials* and other research projects developed by researchers in Northern Ireland will require PPI across the research cycle (see Figure 4), as appropriate, as ideas are generated, *protocols* developed, and research conducted and disseminated.

Fig. 4 The research cycle⁷

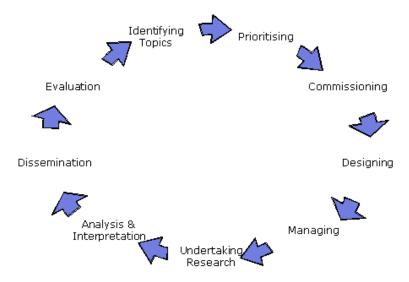


Table 1 Cancer Research Committees in Northern Ireland

Name	Key Purpose	Venue	Frequency
NI Cancer Clinical Trials Co-ordinating Committee	Peer review of all new cancer clinical trials proposed for NI and monitoring the existing portfolio of clinical trials in NI	Cancer Centre, Belfast	Monthly
NI Cancer Trials Centre (NICTC) Executive Committee	Strategic and developmental planning and monitoring of the NICTC	Cancer Centre, Belfast	Monthly
NI Cancer Trials Network (NICTN) Steering Committee	To ensure NI-wide integrated working in clinical cancer research across all 5 HSC Trusts	Cancer Centre, Belfast	Twice a year
Belfast Cancer Research UK Centre Governance Board	To oversee and review the progress of the Belfast Cancer Research UK Centre	Centre for Cancer Research and Cell Biology, Queen's University Belfast (QUB)	3 – 4 times per year
NI Experimental Cancer Medicine Centre (ECMC) Steering Group	To oversee and review progress of the NI ECMC	Centre for Cancer Research and Cell Biology, QUB	4 times per year
Western Trust NICTN Implementation Committee	(Committee in development)	Altnagelvin Hospital	(Committee in development)
Southern Trust NICTN Implementation Committee	(Committee in development)	Craigavon Hospital	(Committee in development)
South Eastern Trust NICTN Implementation Committee	(Committee in development)	Ulster Hospital	(Committee in development)
Northern Trust NICTN Implementation Committee	(Committee in development)	Antrim Hospital	(Committee in development)
NI Biobank Scientific Committee	(Committee in development)	Centre for Cancer Research and Cell Biology, QUB	(Committee in development)

See 'Jargon Explained'

The level of consumer time and involvement needed for each study will relate to attributes of the study such as the study's patient/public implications, size, patient information sheets, outcome measures and study management requirements.

3. The Northern Ireland Cancer Research Consumer Forum (Aims 3 - 8)

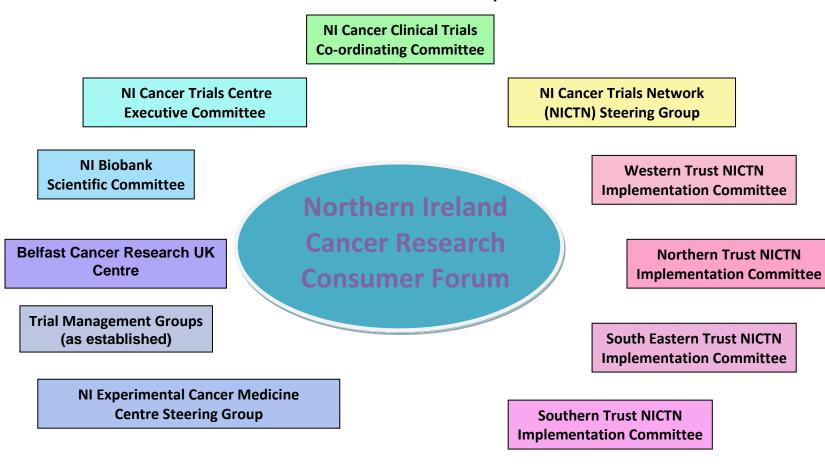
A Northern Ireland Cancer Research Consumer Forum will be established to bring together consumers involved in cancer research as part of the infrastructure to support and sustain PPI in cancer research.

Membership of the Forum will primarily to be made up of consumer members, who will also be involved in cancer research groups or committees (see Figure 5). If not involved within a specific group, these consumers will have a research interest in a particular cancer type and may be involved in specific study projects or *Trial Management Groups*.

The Forum will meet four times a year. The purpose of formal meetings will be to:

 Provide a forum for consumers who are involved in the various aspects of cancer research in Northern Ireland to come together to network

Fig. 5
Northern Ireland Cancer Research Consumer Forum Membership Involvement in Cancer Research



Northern Ireland Representative,
National Cancer Research Network
PPI Steering Group

See 'Jargon Explained'

- Provide a forum to facilitate communication about news and developments in PPI, and offer support, additional to regular e-mail communications
- Provide a forum for the delivery of consumer training, training evaluation and identification of training needs
- Provide a forum for researchers to formally liaise with the cancer research consumer community
- Provide a visible focus of PPI in cancer research in Northern Ireland
- Provide a forum to review and evaluate consumer involvement in cancer research across the various research groups, and consultation processes
- Provide a forum to generate new ideas and strategic planning regarding PPI in cancer research in Northern Ireland

The first Chair of the Forum is Mrs Margaret Grayson, who has pioneered consumer involvement within the Northern Ireland Cancer Trials Centre (NICTC), the Northern Ireland Cancer Trials Network (NICTN), and the Northern Ireland Experimental Cancer Medicine Centre. She is the Northern Ireland representative on the National Cancer Research Network PPI Steering Group.

Miss Ruth Boyd, Cancer Research UK Senior Nurse, a Deputy Director and the PPI lead for the NICTC, will be the professional link within the Forum.

Administrative support will be provided to support Forum meetings and the on-going activity of the Forum members.

Consumer members of the Forum will be active throughout the year. They will be involved as members of the research committees or groups, and/or by consultation regarding various cancer research communications, including researcher's new requests for consumer involvement in developing studies.

4. Consumer Access and Support Pathway in Cancer Research in Northern Ireland (Aims 4, 6, 8)

To ensure that effective PPI in cancer research in Northern Ireland is sustainable and not over-burdensome for individuals, a number of factors are required:

- Appropriate outreach and engagement with the public to promote the opportunity for PPI
 - The NICTC website will contain information for the public to access regarding
 - 1. The process of registering interest (see Leaflet Appendix 1)
 - Public open evenings about PPI in cancer research in Northern Ireland (see Registration of Interest Form Appendix 2)
 - 3. Consumer application documentation
 - Networking with existing cancer consumer groups will be ongoing to promote public information

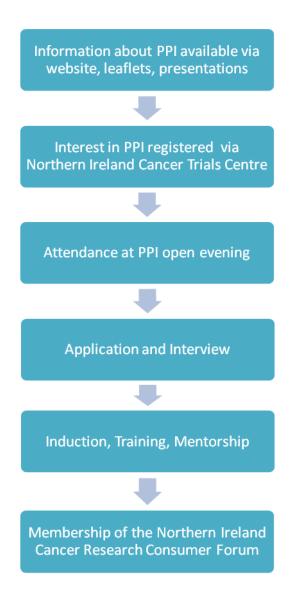
- The media will be utilised to promote public information where possible
- Information for patients/carers attending cancer facilities will be available via the NICTC
- Appropriate interview and induction processes, mentorship and training will enable consumers to maximise the impact of their involvement
 - An interview process will be conducted by members of the NICTC Executive Committee to clarify the consumer role and maximise realistic expectations
 - The NICTC lead for PPI will co-ordinate induction and mentorship according to individual's needs
 - Training opportunities within the local cancer and research communities within Northern Ireland, and other national training providers for PPI, will be utilised
 - Training sources found to be beneficial to date are:
 - Health and Social Care (HSC) Research and Development
 Division, Public Health Agency
 - National Cancer Research Network Consumer Liaison
 Group
 - Experimental Cancer Medicine Centres Network
 - INVOLVE
 - Macmillan Cancer Support
- Dealing with consumer expenses and other practicalities
 - Expenses Claim Forms will be provided for all consumers

Consumers will be able to liaise with the PPI lead,
 administration team, and fellow-consumers for practical
 support and advice as required

Figure 6 is a summary of the access and support pathway.

Fig. 6

Consumer Involvement Access and Support Pathway



5. Researcher Pathway for PPI in Cancer Research in Northern Ireland (Aims 1, 2, 5)

To ensure effective PPI in cancer research, researchers need to be aware of PPI requirements and processes. Information will be disseminated across the cancer researcher community in Northern Ireland via presentations, the leadership of the various committees, the NICTC website, and e-mail communications. PPI will be integrated into the NICTC quality management processes, and information provided for Principal Investigators. Figure 7 is a summary of the Researcher Access Pathway for PPI in cancer research in Northern Ireland.

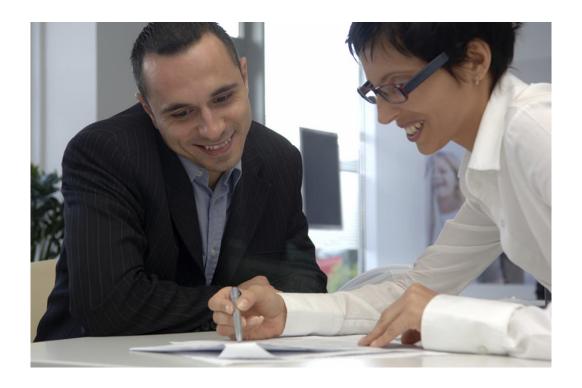
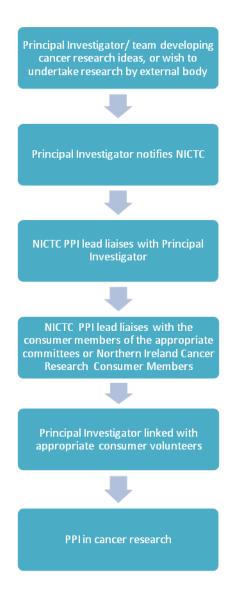


Fig. 7
Researcher Access Pathway for PPI in cancer research in Northern Ireland



6. Evaluation of PPI in Cancer Research in Northern Ireland (Aim 7-8)

As the culture of PPI expands across healthcare and research, and a growing body of research and evaluation in the field is being established, it is vital to ensure that the PPI process in cancer research in Northern Ireland is responsive to evolving evidence about strategies to enhance PPI effectiveness, and approaches to support consumers' needs within the process. Maintaining best practice will be supported through networking and formal and informal training for researchers, PPI facilitators and consumers.

To ensure that the PPI process is responsive to need, and evaluated, consumer, researcher, and other *stakeholder* perspectives will be sought formally, as a minimum, on an annual basis.

The Northern Ireland Cancer Research Consumer Forum will provide an annual report summarising PPI activity and evaluation.

7. Funding and Administration (Aims 1-8)

There is no formal funding for the PPI in cancer research in Northern Ireland. However, consumers volunteer their time and experience, therefore comprehensive, timely reimbursement of their travel or other expenses will be promoted.

The activities and consumer expenses generated by the Northern Ireland Cancer Research Consumer Forum will be met by the NICTC. Consumer expenses incurred within specific committees will be met from the appropriate budget relating to the committee. Administration of expenses will be co-ordinated by the NICTC PPI lead and undertaken by the finance offices of the Belfast HSC Trust or Queen's University Belfast, as appropriate.

Administrative support for meetings and correspondence will be designated through the NICTC.

Jargon Explained

Collaboration	Collaboration involves active, on-going partnership with members of the public in the research process. For example, members of the public might take part in an advisory group for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project. 8
Consultation	Consultation involves asking members of the public for their views about research, and then using those views to inform decision-making. This consultation can be about any aspect of the research process – from identifying topics for research, through to thinking about the implications of the research findings. Having a better understanding of people's views should lead to better decisions. 8
Consumer	(See also Personal and Public Involvement) Individuals with a specific condition who use or have used a service, including patients, carers, parents, clients or their advocates, or representatives of locality, community and voluntary groups and other collective organisations.
Clinical Research	Clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes comparing them with healthy people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records, or the data from health and lifestyle surveys. ⁴
Clinical Trial	Clinical trials are research studies involving people who use services, which compare a new or different type of treatment with the best treatment currently available. They test whether

	the new or different treatment is safe, effective
	and any better than what already exists. No
	matter how promising a new treatment may
	appear during tests in a laboratory, it must go
	through clinical trials before its benefits and risks
	can really be known. ⁴
Outcome	Outcome measures are measurements of the
Measures	effects of a treatment or service. They might
	include physical measurements - for example
	measuring blood pressure, or psychological
	measurements - for example measuring people's
	sense of well-being. So if someone takes part in
	research, they may be asked questions, or may be
	asked to have extra tests to assess how well the
	treatment or service has worked. 4
Patient	Researchers must provide a patient information
Information	leaflet to everyone they invite to take part in a
	research study, to ensure people can make an
Sheet	informed decision about this. The leaflet explains
	what taking part will involve and should include
	details about:
	 why the research is being done, how long it will
	last, and what methods will be used.
	the possible risks and benefits
	what taking part will practically involve e.g.
	extra visits to a hospital or a researcher coming
	to interview someone at home
	 what interventions are being tested, or what
	topics an interview will cover
	 how the researchers will keep participants'
	information confidential
	what compensation is available to people if they are harmed as a result of taking part in the
	are harmed as a result of taking part in the
	research
	who to contact for further information
	 how the results will be shared with others.

	(- U 6
Personal and	'Personal' refers to any individual with a specific
Public	condition who uses or has used a service. This will
Involvement	include patients, carers, parents, clients or their advocates. ¹²
(PPI)	'Public' refers to the general population and includes
	locality, community and voluntary groups and other collective organisations.' 3
	'Involvement' means 'active partnership between
	the public and researchers in the research
	process Active involvement may take the form
	of consultation, collaboration or user control.' 4
Protocol	A protocol is the plan for a piece of research. It
	usually includes information about:
	 what question the research is asking and its
	importance/relevance
	 the background and context of the research,
	including what other research has been done
	before
	 how many people will be involved
	•who can take part
	the research method
	 what will happen to the results and how they will
	be publicised.
	A protocol describes in great detail what the
	researchers will do during the research. Usually, it
	cannot be changed without going back to a
Donnesontative	research ethics committee for approval. 4
Representative	As a representative, you are expected to speak on
	behalf of a larger group of people. If you've been
	asked to get involved in research as a representative of a particular group, you may want to think about
	how you can be confident that you are representing
	a wider range of people's views, rather than just
	offering your own perspective. 8
	onemia your own perspective.

User Control	User controlled research is research that is actively research/user controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. The service users will run the research advisory or steering group and
Stakeholder	may also decide to carry out the research. 8 In the context of this strategy a stakeholder is
	anyone who has an interest in cancer research and PPI.
	It includes the people and organisations who are actively involved, as well as the people who might
	be affected by the outcomes. 4
Trial	The Trial Management Group normally includes
Management	those individuals responsible for the
Group	day-to-day management of the trial, such as the chief investigator, statistician, trial manager,
	research nurse, data manager. The role of the group
	is to monitor all aspects of the conduct and progress
	of the trial, ensure that the protocol is adhered
	to and take appropriate action to safeguard
	participants and the quality of the trial itself. 9

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Appendix 1: Consumer Information and Invitation Leaflet



Do you want to get involved in helping to influence cancer research in Northern Ireland?

If you are living with or beyond cancer, or are a relative, or carer of someone with cancer, you may want to consider getting involved in helping to influence cancer research. We are looking for people with an experience of cancer to join the Northern Ireland Cancer Research Consumer Forum. An interest in cancer research is important, but you do not need to have taken part in a clinical trial.

Cancer Research in Northern Ireland

Cancer research is important because it helps us find new ways to prevent, diagnose, and treat cancer. In 2010, over 1000 people in Northern Ireland took part in cancer clinical trials, or other high quality research studies. This type of research is expanding, and it is taking place at the Cancer Centre in Belfast, the Royal Belfast Hospital for Sick Children, Altnagelvin, Antrim, Craigavon and Ulster Hospitals.

What is the Northern Ireland Cancer Research Consumer Forum?

The Northern Ireland Cancer Research Consumer Forum has been established to increase personal and public involvement in cancer research across Northern Ireland. Members of the Forum will be involved in one or some the following:

- Reviewing and advising on clinical trial protocols and patient information leaflets
- Membership of a research steering group or committee

- Membership of a Trial Management Group of a specific clinical trial
- Advising on the best methods and information to raise patient and public awareness about cancer clinical trials available in Northern Ireland
- Promoting personal and public involvement in cancer

The members of the Forum will meet together four times a year. Training and support will be available to members.

Are you interested in getting involved?

We encourage everyone interested to attend a meeting to hear more what is involved, to help you decide if you want to apply. Details of how to let us know you may be interested are available at www.qub.ac.uk/nictc or by email at nictc@belfasttrust.hscni.net or by telephoning or writing to the address below.

We look forward to hearing from you.

Contact Address and Telephone Number

Ruth Boyd
Cancer Research UK Senior Nurse
NICTC
East Podium
C-Floor
Belfast City Hospital
Lisburn Road
Belfast
BT9 7AB

Telephone: 028 9026 3903

Appendix 2: Request for More Information



I am interested in finding out more about helping to influence cancer research in Northern Ireland.

Name	
Address	
Telephone	
e-mail address (optional)	

Post or e-mail this form to:

Ruth Boyd
Cancer Research UK Senior Nurse
NICTC
East Podium, C-Floor
Belfast City Hospital
Lisburn Road
Belfast
BT9 7AB

Telephone: 028 9026 3903

e-mail: nictc@belfasttrust.hscni.net

Contact Ruth about any questions you have. Ruth will contact you about the next available cancer research open evening at the Belfast City Hospital/Centre for Cancer Research and Cell Biology.

Acknowledgements:

This strategy has been developed by Miss Ruth Boyd and Mrs Margaret Grayson on behalf of the NICTC, in consultation with:

Mrs Helen Barnes, Senior Local Engagement and Development Manager, Cancer Research UK

Mrs Sally Campalani, Senior Cancer Nurse, Cancer Services PPI Lead, Belfast Health and Social Care Trust

Dr Gail Johnston, Programme Manager (PPI), HSC Research and Development Division of the Public Health Agency

Mrs Janis McCulla, PPI Co-ordinator, Northern Ireland Cancer Network

Mrs Margaret McManus, Information Manager, Macmillan Information and Support Unit, Belfast City Hospital

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