



A Strategy for Personal and Public Involvement (PPI) in Cancer Research in Northern Ireland 2019-2024

‘Patients, service users and the public are involved in the design, management, conduct and dissemination of research, unless otherwise justified.’

Principle 4

UK Policy Framework for Health and Social Care Research (2017)



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Alternative Formats

If you require this information in a different format for example, a minority language, Easyread, large print, Braille or electronic formats please contact us. Contact details are on page 42.

Abbreviations

BHSCT	Belfast Health and Social Care Trust
CCRCB	Centre for Cancer Research and Cell Biology
CRiPaCC	Centre for Research in Public Health and Community Care
DHSSPS	Department of Health, Social Services and Public Safety
ECMC	Experimental Cancer Medicine Centre
GDPR	General Data Protection Regulation
GRIPP	Guidance for Reporting Involvement of Patients and the Public
HSC	Health and Social Care
HSCB	Health and Social Care Board
NCRI	National Cancer Research Institute
NHS	National Health Service
NHSCT	Northern Health and Social Care Trust
NICRCF	Northern Ireland Cancer Research Consumer Forum
NICTN	Northern Ireland Cancer Trials Network
NIHR	National Institute of Health Research
PIER	Public Involvement Enhancing Research
PHA	Public Health Agency

Abbreviations cont.

PPI	Personal and Public Involvement
QUB	Queen's University Belfast
R&D	Research and Development
RMS	Research Management Service
SEHSCT	South Eastern Health and Social Care Trust
SHSCT	Southern Health and Social Care Trust
ToR	Terms of Reference
UU	University of Ulster
WHSCT	Western Health and Social Care Trust

Foreword

This strategy document is produced by the Northern Ireland Cancer Trials Network (NICTN) and the Northern Ireland Cancer Research Consumer Forum (NICRCF) partnership.

Back in 2011, when the NICTN published the first 'Strategy for Personal and Public Involvement (PPI) in Cancer Research in Northern Ireland' (NICTN, 2011), there was total conviction this was the right thing to do. Not only was it the right thing, but at the time, we did not anticipate just how far-reaching the positive impact of the strategy would be. Undoubtedly wider PPI policies have created a culture shift embracing or at the least increasing acceptance of PPI activity. However, our biggest asset has been the mixture of enthusiastic and dynamic researchers and the individuals who, over the years, have volunteered to become members of the NICRCF. Those individuals have been passionate in their support for cancer research and partnership working and have shared their valuable experience for the benefit of research and patients.

The model of a co-ordinated approach with access to NICRCF PPI resource for all types of cancer research activity received positive anecdotal feedback since the NICRCF was established. Now the results of the 2017 PPI focus group and survey (NICTN, 2018) confirms the success of the strategy. Does the PPI strategy need to change? While the fundamentals may remain, the focus group and survey results indicate there are still several areas that will benefit from further development. It is also crucial we recognise limitations as well as remain flexible within the evolving PPI landscape. Importantly, we want to keep in step with, for example, new national PPI standards in research (National Institutes of Health Research, 2018). We look forward to this future chapter of PPI in cancer research in Northern Ireland. We appreciate your valuable feedback about this strategy.

Ruth Boyd
NICTN PPI Lead

Margaret Grayson MBE
NICRCF Chairperson

March 2019

Strategy Background

Cancer in Northern Ireland

There are over 9,000 cases of cancer (excluding non-melanoma skin cancers) diagnosed in Northern Ireland each year. In the last ten years, primarily due to our aging population, the number of cancer cases has increased by 15% (Northern Ireland Cancer Registry, 2017). The most common cancers are breast, prostate, lung and colorectal cancer, accounting for around half of all cancers in men and women (Northern Ireland Cancer Registry, 2017). With over 4,000 deaths from cancer each year, the disease remains the leading cause of death (28%) in Northern Ireland (Northern Ireland Statistics and Research Agency, 2018). While overall survival rates in Northern Ireland are increasing (Northern Ireland Cancer Registry, 2017), cancer survival in the UK is lower than comparable countries (Cancer Research UK, 2018).

At the end of 2017 there were 63,413 people living in Northern Ireland who had been diagnosed with cancer within the previous twenty-five years (Northern Ireland Cancer Registry, 2017). Of these, 48% were aged 70 and over.

Cancer Research in Northern Ireland

Cancer research is vital to benefit the population and individuals affected by cancer (see Figure 1).

It helps us:

- increase our understanding of cancer
- identify and implement better ways to prevent, diagnose and treat cancer
- minimise the side-effects of cancer treatment
- improve the quality of life of people living with cancer
- improve cancer survival

Recent evidence (Downing *et al.*, 2017) also suggests that not only does cancer research in our hospitals have a value in its own right, in the treatment of research participants, but it also has a wider positive impact on quality within cancer services.

There are many people with an interest in cancer research in Northern Ireland, including the general population and those affected by the disease (see Figure 2).

The conduct of cancer research in Northern Ireland covers a wide spectrum of research methods by science and health researchers from various research and health institutions alongside the pharmaceutical and biotechnology industries. It should be noted that research undertaken in Northern Ireland is not confined to local projects. Cancer research is a global activity and Northern Ireland contributes as leaders, collaborators and participants in this arena.

Figure 1: The Benefits of Cancer Research

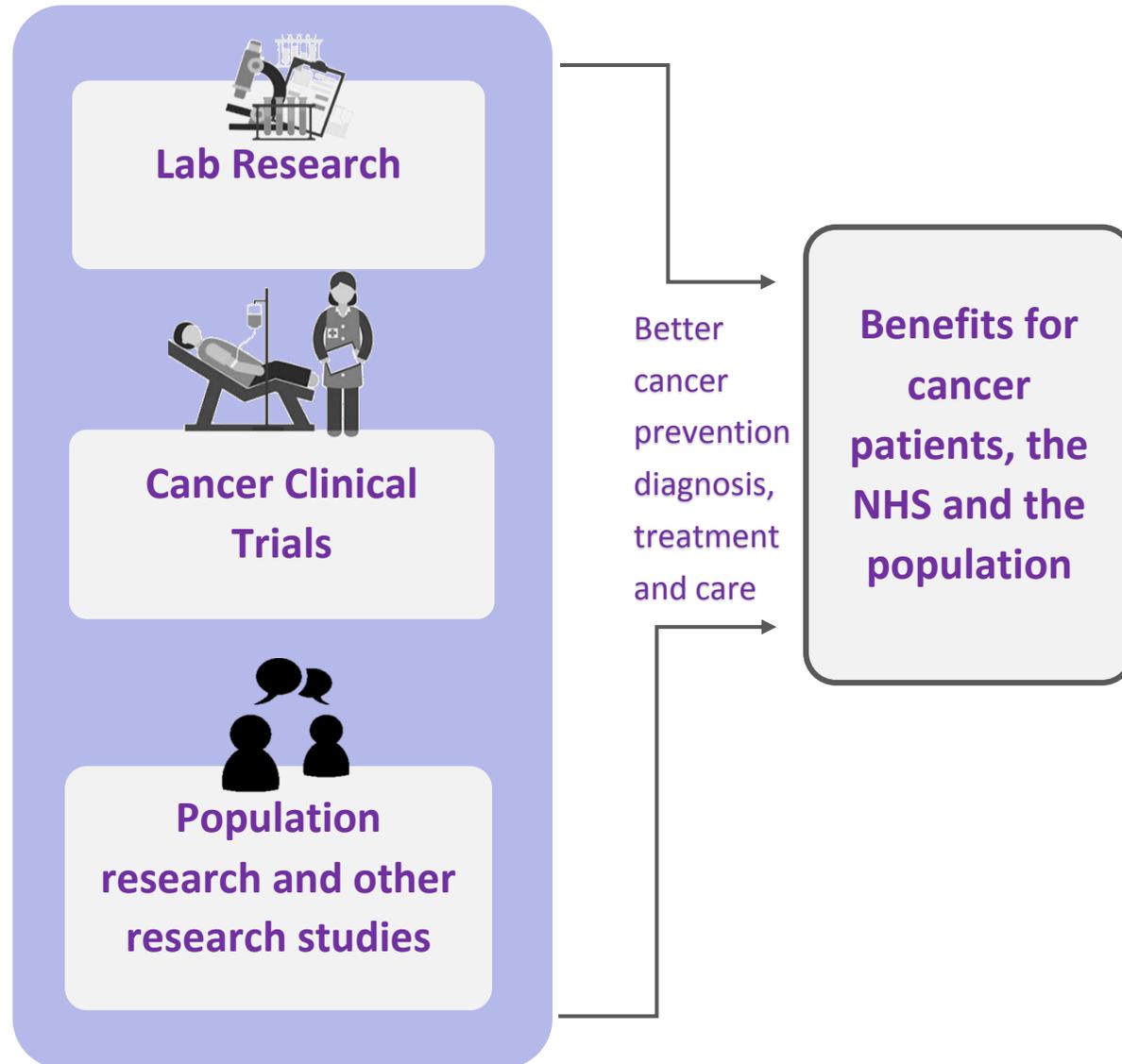
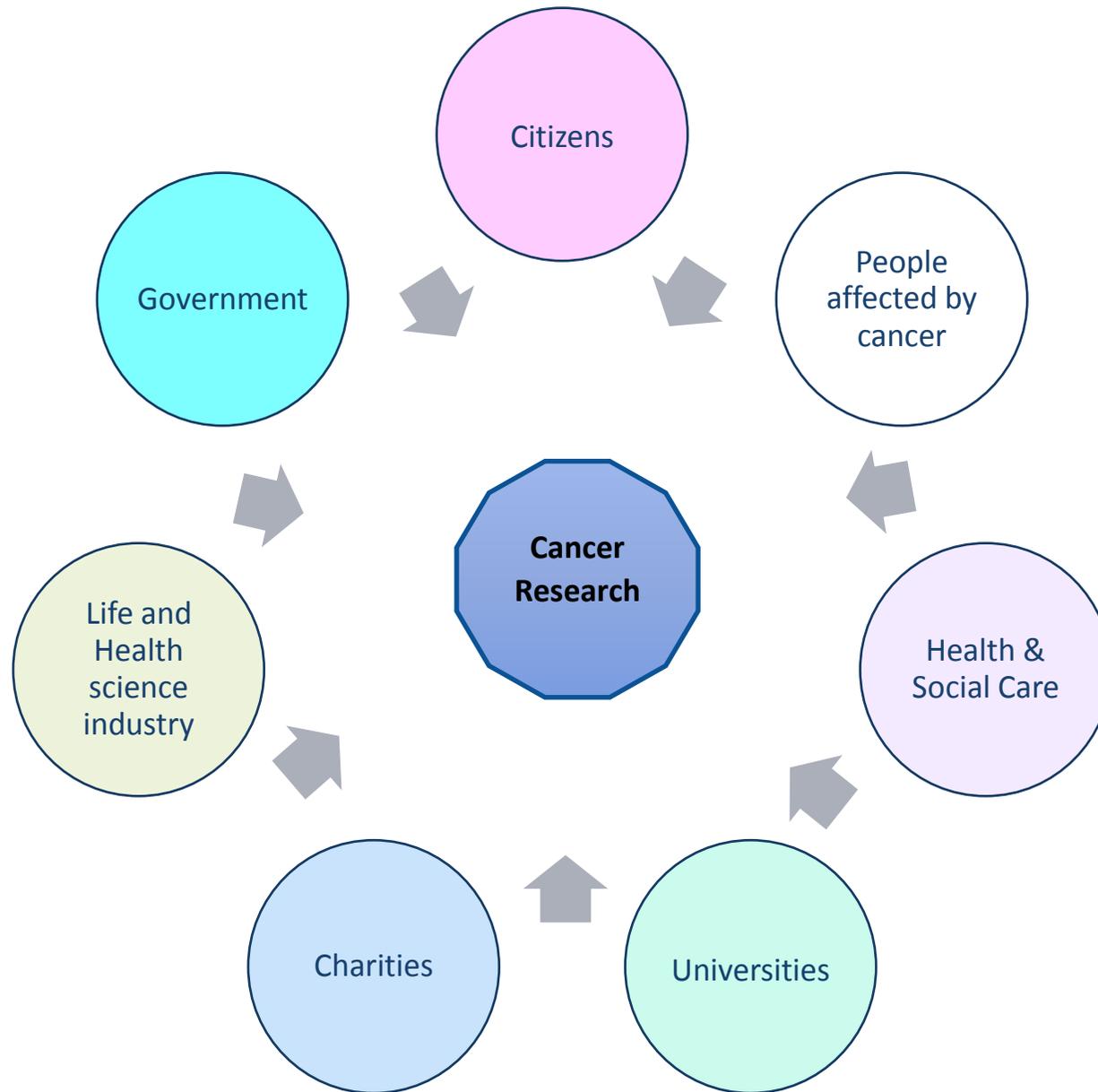


Figure 2: Stakeholders in Cancer Research



Personal and Public Involvement in Northern Ireland

Personal and Public Involvement (PPI) is a statutory duty within Health and Social Care (HSC) organisations (DHSSPS, 2007, Health and Social Care (Reform) Act (Northern Ireland), 2009) and it is a policy integral to delivering quality services (DHSSPS, 2012).

The elements of PPI are described as:

‘Personal - refers to service users, patients, carers, consumers, customers, relations, advocates or any other term used to describe people who use HSC services as individuals or as part of a group, e.g. a family.

Public - refers to the general population and includes locality, community and voluntary groups and other collective organisations. Individuals who use HSC services are also members of the general public.

Involvement - means more than consulting and informing. It includes engagement, active participation and partnership-working.’ (DHSSPS, 2007)

The PHA, in partnership with the HSC Board, launched a PPI strategy (PHA and HSCB, 2012) and standards for PPI within the HSC (PHA, 2015). A Co-Production Guide launched by the Department of Health in Northern Ireland (2018) describes co-production as involving ‘partnering with people from the start to the end of any change that affects them.’

The PHA and Patient and Client Council commissioned research to determine the impact of PPI in Northern Ireland and this work reported significant progress made and a number of recommendations, illustrating a need for PPI to be further embedded within the HSC (PHA, 2017).

Personal and Public Involvement in Research

There has been increasing momentum to ensure PPI is applied within the research setting. The National Institute of Health Research (NIHR) (2015) describe their involvement mission as *'The public as partners in everything we do to deliver high quality research that improves the health, wellbeing and wealth of the nation.'*

INVOLVE (2019) describe PPI in research as:

'An active partnership between patients and the public and researchers in the research process, rather than the use of people as 'subjects' of research.

Patient and public involvement in research is often defined as doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them. This would include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.'

The National Institutes of Health Research (NIHR) (2014) states:

The patients and public researchers actively involve... 'are contributing to the research process as advisers and possibly also as co-researchers.... Researchers and clinicians may not have first-hand experience of the illness, disease or health condition that they wish to research. PPI can therefore provide researchers with insights into what it is like to live with a particular disease, illness or health condition, and these insights can help to make health research more relevant to the needs of patients, carers and service users.'

The strategy for PPI within HSC research (HSC R&D, 2014) outlines the benefits and impact of PPI in research for both researchers and lay representatives (see Appendix 1). A recent systematic review and meta-analysis of a number of studies lends further evidence to the positive impact of PPI concluding that PPI was 'likely to improve enrolment of participants' (Crocker *et al.*, 2018).

The UK Policy Framework for Health and Social Care Research (Health Research Authority and UK Health Departments, 2017) also enshrines PPI within its principles, which are 'a benchmark for good practice that the management and conduct of all health and social care research in the UK are expected to meet.' Principle 4 - Patient, Service User and Public Involvement states 'Patients, service users and the public are involved in the design, management, conduct and dissemination of research, unless

otherwise justified.’ This emphasises how integral PPI is within research and how this meaningful partnership is throughout the duration of a research project.

Research is conducted utilising a range of research methods within a variety of health and research settings / organisations. The ‘research cycle’ describes a process that reflects common aspects of conducting research. Figure 3 illustrates how PPI can enhance research throughout the research cycle.

UK wide National Standards for Public Involvement, devised in conjunction with the PHA, were launched by the National Institute of Health Research (NIHR) (2018). These standards (see Figure 4) sit comfortably with HSC PPI standards. The NIHR described the aim of the standards to ‘provide people with clear, concise benchmarks for effective public involvement alongside indicators against which improvement can be monitored. They are intended to encourage approaches and behaviours which will support this: flexibility; partnership and collaboration; a learning culture; the sharing of good practice; effective communications.’ The standards also highlight the importance of PPI, not only in research conduct, but in research governance.

These standards **will be adopted within this strategy action plan** in both defining processes to meet standards and where standards need strengthening, driving actions to address gaps.

A Note about Research Engagement

The value of research engagement activities (sharing research information and raising awareness), distinct from involvement (active partnership), is acknowledged. Both approaches are vital within a patient / public-focused research culture. The key purpose of **this strategy** is to grow and develop **involvement in research**.

Figure 3: PPI in the Research Cycle ([Health Research Board](#) website)

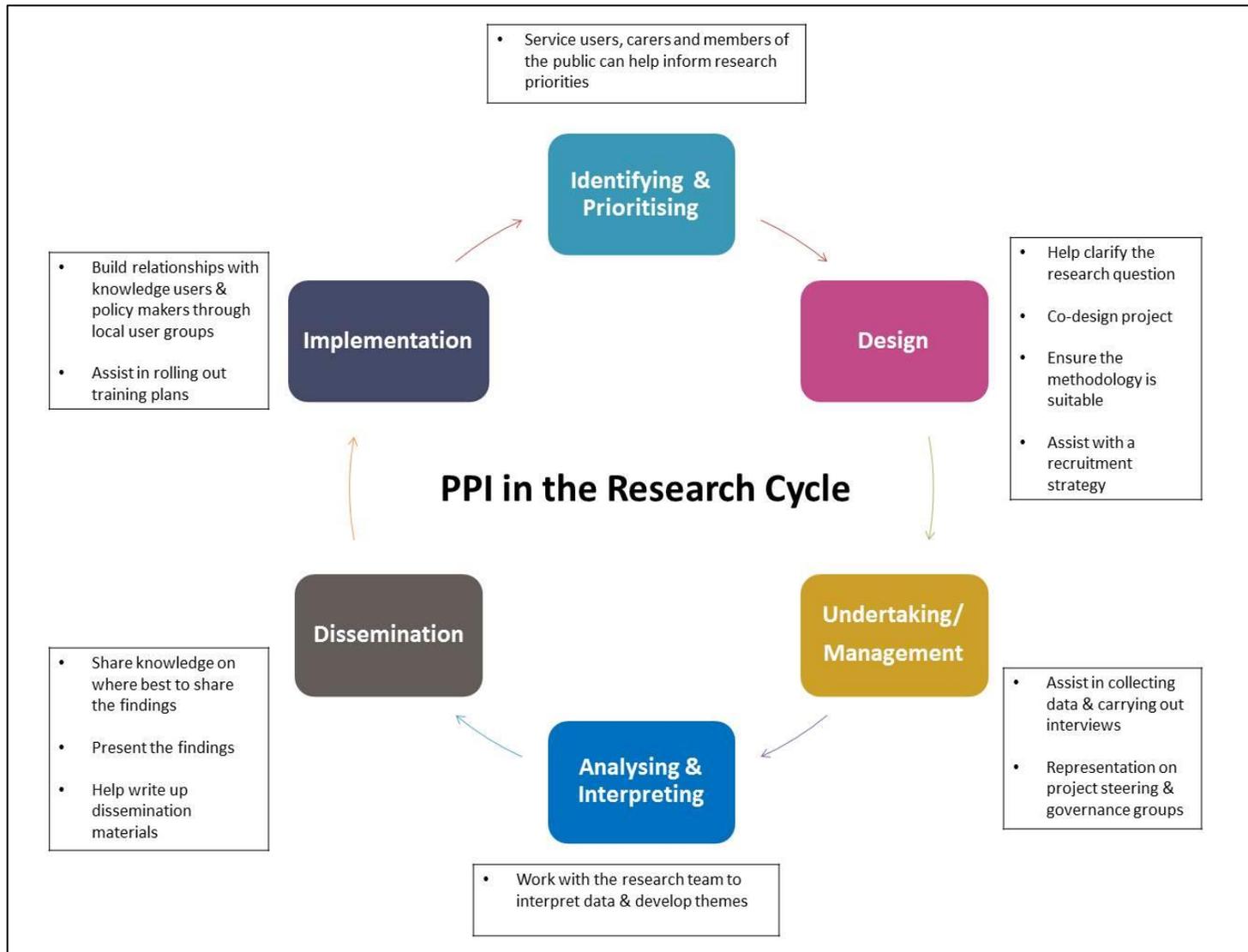
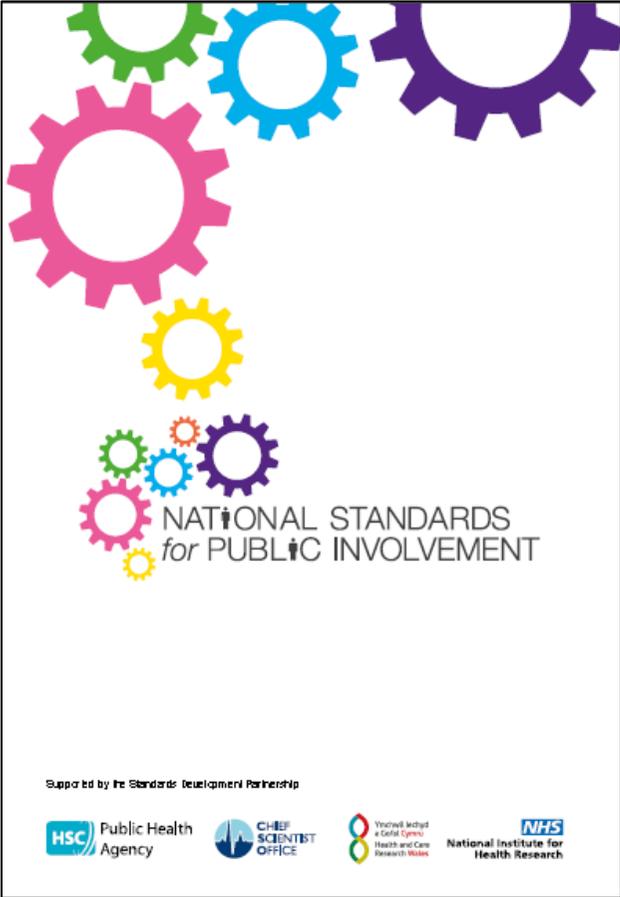


Figure 4: National Standards for PPI in Research (NIHR, 2018)



The graphic features a cluster of colorful gears (green, blue, purple, pink, yellow) in the upper left corner. Below the gears, the text reads "NATIONAL STANDARDS for PUBLIC INVOLVEMENT". At the bottom left, it says "Supported by the Standards Development Partnership" and lists logos for HSC Public Health Agency, Chief Scientist Office, and NHS National Institute for Health Research.

Standard 1: INCLUSIVE OPPORTUNITIES
We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Standard 2: WORKING TOGETHER
We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Standard 3: SUPPORT & LEARNING
We offer and promote support and learning that builds confidence and skills for public involvement in research.

Standard 4: COMMUNICATIONS
We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

Standard 5: IMPACT
To drive improvement, we capture and share the difference that public involvement makes to research.

Standard 6: GOVERNANCE
We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

Northern Ireland Cancer Trials Network (NICTN)

The NICTN is part of the research infrastructure supported by the Health and Social Care (HSC) Research and Development (R&D) Division of the Public Health Agency (PHA). As this document is published, conclusion of a HSC R&D Division infrastructure review is underway and the NICTN will move to a closer structural alignment with the existing Northern Ireland Clinical Research Network.

The NICTN also receives support from multiple charities, most significantly from Friends of the Cancer Centre and Cancer Research UK. There are forty-two whole-time-equivalent staff within the NICTN across a range of roles incorporating research clinical, data, administrative, laboratory, quality and management functions.

While the co-ordinating hub of the NICTN is located at the Northern Ireland Cancer Centre, Belfast City Hospital, the regional network promotes clinical research activity across cancer services in Northern Ireland (see Figure 5).

The objectives of the NICTN are to:

- provide high quality care through delivery of cancer clinical trials and other high quality studies
- co-ordinate cancer clinical trials and translational research activity throughout Northern Ireland, particularly phase III trials and epidemiology studies
- facilitate delivery of locally designed or adopted multi-centre studies
- manage an academic early phase clinical trials unit running a portfolio of academic, charity, pharmaceutical industry and local investigator-initiated experimental cancer medicine studies
- promote collaboration with relevant research institutions and bodies
- promote and support effective partnership working with the NI Cancer Research Consumer Forum

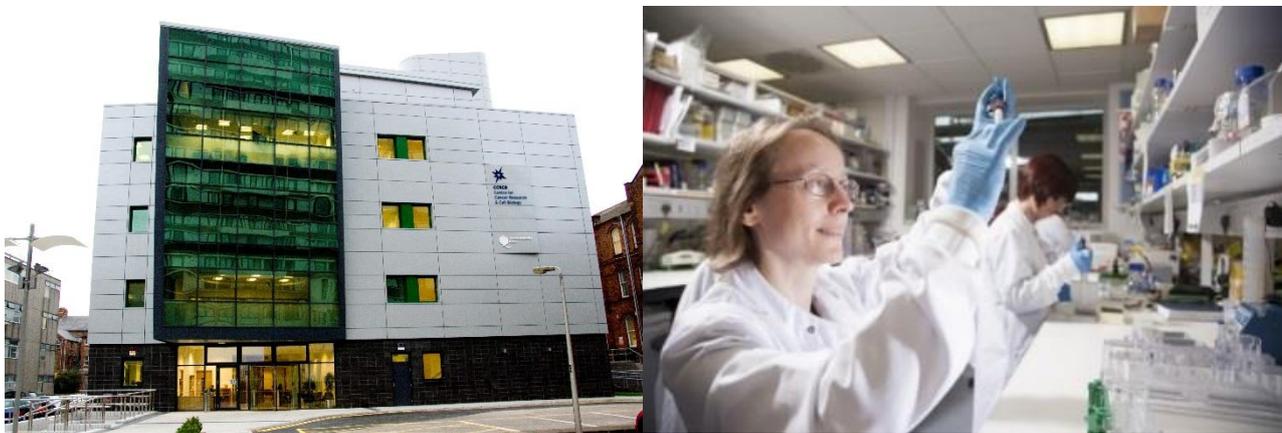
Figure 5: Location of NICTN Activity in Northern Ireland



The NICTN also incorporates the clinical research activity of the Belfast Experimental Medicine Centre (EMC), which is a collaboration with the Centre for Cancer Research and Cell Biology (CCRCB), Queen's University Belfast (QUB). This is co-funded by the HSC R&D Division and Cancer Research UK.

The Belfast EMC aims to:

- advance the discovery and implementation of novel biomarkers
- identify and validate novel targets for therapeutic intervention
- develop a comprehensive radiation oncology translational research programme
- prioritise patient recruitment to innovative clinical trials
- contribute fully to the development in the UK of a world-class EMC network



Centre for Cancer Research and Cell Biology, Queen's University Belfast

The NICTN collaborates with both QUB and UU in the conduct of cancer research.

NICTN data indicates that during the ten years between April 2008 and the end of March 2018, 12,269 people participated in a cancer research study in Northern Ireland. Last year (2017/18) there were 106 active clinical studies across a range of cancers including; breast, colorectal, gynaecological, haematological, head and neck, lung, prostate, upper gastrointestinal, studies not specific to a tumour type and children's cancers.

Northern Ireland Cancer Research Consumer Forum (NICRCF)

The NICRCF was established in 2011, aligned with the initial NICTN strategy for PPI in cancer research in Northern Ireland (NICTN, 2011). The NICRCF is a partner group of the NICTN, but all members are volunteers and involvement activities are not confined to research undertaken within the NICTN. The operational approach of the NICTN / NICRCF has been to welcome opportunities for involvement where research involves **cancer** and **people / tissue / data**.

From an initial group of 17 people affected by cancer, interested in shaping cancer research, the NICRCF now maintains a membership of over 20 people.

The objectives of the NICRCF are:

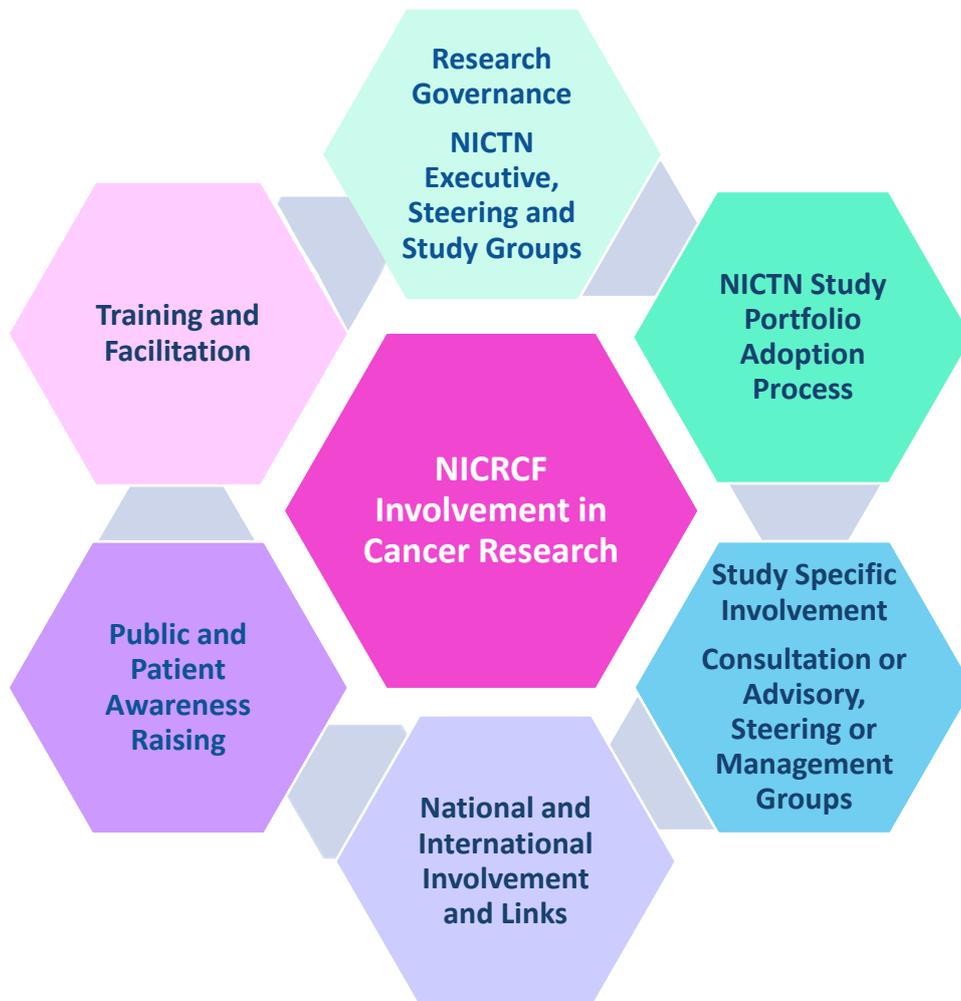
- To promote effective consumer involvement in cancer research both regionally and as appropriate, nationally and internationally
- To promote effective consumer involvement in cancer research across all applicable stages of the research process and as appropriate, act as an advisory group for researchers
- To promote consumer membership of relevant committees such as research committees, steering groups, trial management groups and National Cancer Research Institute Cancer Groups
- To provide a forum for identification of consumer training needs and training delivery and evaluation
- To provide a forum to facilitate and maintain communication pathways and networks about news and developments in research and personal and public involvement
- To provide a forum for researchers to formally liaise with the cancer consumer community
- To promote the role of PPI in cancer research
- To promote awareness of cancer research in Northern Ireland
- To monitor and evaluate the contribution of consumer involvement in cancer research in Northern Ireland and generate recommendations and plans

The activities of the NICRCF are summarised in their [Annual Reports](#). These illustrate that the NICRCF has become embedded into NICTN structures and processes. For example, since its inception, NICRCF members have been involved in the NICTN study portfolio adoption process, annually reviewing 22-35 clinical trials or other types of research study. The HSC R&D funded Building Research Partnership workshop has been the designated PPI core training for members.

Undoubtedly NICRCF members have demonstrated skill in PPI and dedication to PPI activity and many have been involved in PPI beyond NICTN and beyond Northern Ireland, undertaking roles within national cancer research bodies involvement in national and international activities. This breadth and depth of involvement further

strengthens skills and confidence and enriches the work of the NICRCF across all areas.

Figure 6: Summary of Types of NICRCF Involvement in Cancer Research



Why Do We Need a New NICTN / NICRCF PPI Strategy for Cancer Research in Northern Ireland?

Given the significant changes in the PPI landscape over the past 8 years, the need for a strategy 'refresh' was self-evident. However, much has already been achieved in PPI in cancer research in Northern Ireland during the intervening years. The key to the original 2011 strategy (NICTN, 2011) was the establishment of the NICRCF as a working partner in cancer research, facilitated by the NICTN. This model has now been endorsed by the positive track-record of the NICRCF and results of the 2017 evaluation process (NICTN, 2018). The results of the surveys across researchers, research support staff, NICRCF members and a NICRCF focus group, all pointed to an overwhelmingly positive experience of PPI. Expectations were met and there was satisfaction with the NICRCF structure and function across respondents. Among researcher respondents there was relatively good awareness of the NICRCF and there was evidence of PPI throughout the research cycle. However, scope for improvement was acknowledged across various dimensions. Funding was a significant area of concern. The full summary of recommendations from the report are presented in Appendix 2.

A key thrust of the new strategy is to ensure resilience of the NICRCF and increase capacity and support. A further dimension of the strategy is to enhance and demonstrate impact. Alongside this is a commitment to appropriately acknowledge the time, experience and energy contributed by NICRCF members, given entirely voluntarily. As this document is published, a HSC consultation process regarding PPI reimbursement and remuneration is underway and thus any change of policy in this, will be of significance in the delivery of this strategy.

The Strategy for PPI in Cancer Research in Northern Ireland (2019-2024)

Scope

This strategy is devised by the NICTN / NICRCF partnership and will incorporate consultation with the wider cancer / research / PPI community. While the 'open-access' approach to NICRCF involvement is an abiding principle of the PPI model, the NICTN and NICRCF acknowledge certain guidance and constraints outlined below.

- Strategy implementation will take place across the NICTN (all HSC Trusts) and Belfast ECMC (Belfast HSC Trust / CCRCB collaboration)
- The values and approach embedded within this strategy aim to act as a guide for researchers / stakeholders from other organisations who interface with the NICTN and NICRCF
- The strategy aims to be consistent with HSC R&D and other relevant regional and national PPI guidance
- The co-ordinating centre of the NICTN is based in the Belfast HSC Trust, thus in regard to the administration of the NICRCF, where applicable, the policies and procedures of the Belfast HSC Trust apply

Vision

Our vision is to **facilitate opportunities for effective PPI in cancer research by NICTN and NICRCF partnership working to enhance cancer research for maximum patient benefit.**

Values

The values which underpin this strategy are those described in *Setting the Standards* (PHA, 2015) (see Figure 7).

Figure 7: Values Underpinning PPI

Dignity and Respect Each person is treated with dignity and respect.
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.
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.

Goals

A. A culture of partnership working and PPI in cancer research will be supported and further embedded into research governance, training and practice
B. Provision of sustainable support for the NICRCF and its members will enable the NICRCF and PPI in cancer research to grow
C. PPI impact will be maximised through on-going adoption of best practice and PPI standards in research

Objectives

Objectives identified to support each goal are listed below:

Goal A	Objective
<p>A culture of partnership working and PPI in cancer research will be supported and further embedded into research governance, training and practice</p>	A1. PPI embedded into NICTN governance structures and processes will be sustained and developed
	A2. PPI resources and training will be more accessible to NICTN staff and cancer researchers
	A3. Cancer researchers will continue to be facilitated to access partnership working with the NICRCF
	A4. Early PPI in research will be promoted – from concept and throughout the research cycle
Goal B	Objective
<p>Provision of sustainable support for the NICRCF and its members will enable the NICRCF and PPI in cancer research to grow</p>	B1. Sustained administrative support will be provided for communications and co-ordination of NICRCF PPI activities
	B2. A NICTN budget will be available for the reimbursement of PPI expenses and where HSC policy indicates, remuneration of NICRCF members, for the conduct of PPI within the HSC / NICTN setting
	B3. Opportunities for NICTN to facilitate ease of access to reimbursement and remuneration and minimise barriers to claiming, will be explored
	B4. Opportunities to access designated funding for PPI in research will be utilised
	B5. Membership of the NICRCF will be sustained and supported to grow enabling the NICRCF to continue to be a hub for PPI in cancer research
	B6. The training needs of the NICRCF collectively and of its individual members, will be met to ensure role understanding, confidence and development
	B7. NICRCF members' development will be promoted to maximise their potential and leadership in PPI activity, according to individual wishes
	B8. The NICRCF Chairperson will be supported to undertake the requirements of the role
	B9. Collaboration with relevant international/ national PPI groups and awareness of evolving resources, training, publications and peer support will be promoted to advance shared learning and best practice
	B10. The work of the NICRCF will be acknowledged and celebrated
	B11. Public / Patient awareness about cancer research, PPI and the NICRCF will be maximised

Goal C	Objective
PPI impact will be maximised through on-going adoption of best practice and PPI standards in research	C1. Effective partnership working will be promoted through effective NICTN / NICRCF PPI communications and activity
	C2. Measures will be adopted to assess positive or negative impact of PPI
	C3. Relevant national, regional and local PPI (or other relevant) policy, guidance, research will be adopted into PPI processes of the NICTN / NICRCF
	C4. NICTN / NICRCF experience will be utilised for learning and sharing

Responsibilities

The Strategy Action Plan identifies the person or group with lead responsibility for the actions outlined. Only the NICTN Executive Committee members and NICRCF are named in this section, however it is acknowledged that many actions will require the collaboration of wider personnel and other stakeholders in cancer research and PPI.

NICTN Executive Committee members are:

- Clinical Director
- Operational Director
- Clinical Leads: Experimental Cancer Medicine, Haematology, Oncology, Radiotherapy, Surgery
- Cancer Research UK Senior Nurse / PPI (Professional) Lead
- Manager / Lead Clinical Research Nurse
- NICRCF Chairperson

The accountability for delivery of the Strategy Action Plan will be undertaken by NICTN and NICRCF and progress recorded in annual reports. Objectives which align with organisational and funder requirements will also be reported externally.

Strategy Action Plan

Goal A - A culture of partnership working and PPI in cancer research will be supported and further embedded into research governance, training and practice

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
A1. PPI embedded into NICTN governance structures and processes will be sustained and developed	Any change in NICTN governance structure or process is subject to review of PPI representation	1. Inclusive opportunities 2. Working together 6. Governance	NICTN Directors / NICTN PPI Lead	NICRCF representation is throughout NICTN governance structures and key agreed processes	On-going as required
	Maintain NICRCF representation within NICTN Executive Committee and relevant steering groups	1. Inclusive opportunities 2. Working together 6. Governance	NICTN Directors / NICTN PPI Lead	NICRCF representative committee / steering group membership	Review annually
	Maintain NICRCF representation within ECMC Steering Committee	1. Inclusive opportunities 2. Working together 6. Governance	NICTN Operational Director	NICRCF representative committee membership	Review annually
	Sustain or expand NICRCF representation within developing range of NICTN portfolio adoption processes	1. Inclusive opportunities 2. Working together 6. Governance	NICTN Operational Director / NICTN PPI Lead	NICRCF representation with relevant groups / portfolio adoption processes	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
A1. PPI embedded into NICTN governance structures and processes will be sustained and developed <i>cont.</i>	Identify relevant personnel, who will be PPI champions within cancer research in BHSCT, SEHSCT, SHSCT, NHSCT, WHSCT and establish regular liaison to facilitate NICRCF membership and NICTN partnership working across all Trusts and relevant hospitals	1. Inclusive Opportunities 2. Working together	NICTN Operational Manager / NICTN Manager / NICTN PPI Lead NICRCF Chairperson and members	Established contacts across all Trusts re PPI Regional communications re NICTN PPI	By end 2019/20 and review annually
A2. PPI resources and training will be more accessible to NICTN staff and cancer researchers	PPI training will be a core aspect of NICTN staff induction	3. Support and learning	NICTN PPI Lead	NICTN staff induction programme	On-going as required
	Training and succession planning for PPI lead responsibilities / delegated roles will be on-going to ensure continuity and consistent PPI support functions e.g. dual attendance at meetings	3. Support and learning	NICTN PPI Lead	NICTN staff member	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
A2. PPI resources and training will be more accessible to NICTN staff and cancer researchers <i>cont.</i>	The NICTN / NICRCF website will reviewed and refreshed on monthly basis and will signpost to PPI resources (relevant websites, publications, resources such as Cancer Research UK toolkit for researchers) including current information on training opportunities such as HSC R&D Building Research Partnerships Workshop	3. Support and learning 4. Communications	NICTN PPI Lead	NICTN website contains current PPI content for researchers	Initial content in place by end 2019/20 Review annually
	Opportunities to raise awareness of / educate about PPI in research across healthcare professionals and researchers will be sought / utilised	3. Support and learning	NICTN PPI Lead / NICTN Executive Committee and staff	Number of awareness / education opportunities per year	Review annually
	Identification / designation of PPI champions / link personnel / researchers within QUB, UU and relevant organisations to promote cross communications and training / mentoring opportunities	3. Support and learning 4. Communications	NICTN PPI Lead	Two-way communications about PPI between NICTN and designated PPI link personnel	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
A2. PPI resources and training will be more accessible to NICTN staff and cancer researchers <i>cont.</i>	Opportunities to provide awareness / education to healthcare professionals and researchers in training , including PhD students, will be utilised to promote a sustained and future culture of PPI in cancer research	3. Support and learning	NICTN PPI Lead / NICRCF Chairperson and members	Number of awareness / training opportunities delivered by NICTN / NICRCF members	Review annually
A3. Cancer researchers will continue to be facilitated to access partnership working with the NICRCF	NICTN / NICRCF communications, plasma screens and websites signpost researchers to contact the NICTN with PPI requests	1. Inclusive opportunities 2. Working together 4. Communications	NICTN PPI Lead	Number of PPI opportunities requested through researchers	Review annually
	Opportunities for expanding awareness of access to PPI / NICRCF (materials and events) across researchers / organisations will be utilised	4. Communications	NICTN PPI Lead	Nature and number of PPI awareness raising materials and events accessible by researchers	Review annually
A4. Early PPI in research will be promoted – from concept and throughout the research cycle	Early involvement of the NICRCF will be promoted within training and awareness opportunities	3. Support and learning 4. Communications 5. Impact	NICTN Director / NICTN PPI Lead / NICTN staff / NICRCF members	Number of PPI opportunities involving PPI representation in on-going capacity for research project duration	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
A4. Early PPI in research will be promoted – from concept and throughout the research cycle <i>cont.</i>	NICTN Research Management Service (RMS) incorporates PPI within study management pathway and patient document templates are devised in partnership with NICRCF	1. Inclusive opportunities 2. Working together 5. Impact	NICTN Operational Manager / NICTN PPI Lead / NICRCF members	RMS pathway incorporates PPI through study processes Partnership working on any new patient document templates	Review annually
	The experience of the NICRCF / members will be profiled in communications and NICTN / NICRCF website researchers information sources to emphasise relevance to cancer research	2. Working together 5. Impact	NICTN PPI Lead	Number of PPI opportunities	Review annually

Goal B - Provision of sustainable support for the NICRCF and its members will enable the NICRCF and PPI in cancer research to grow

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B1. Sustained administrative support will be provided for communications and co-ordination of NICRCF PPI activities	NICTN will identify an annual budget for support of PPI administrative functions and support appropriate work plan allocation	2. Working together 4. Communications	NICTN Operational Director	NICRCF participation in PPI opportunities, training or reimbursement etc. indicate communications were delivered in a timely way NICRCF Annual Report dissemination is within the following financial year	Review annually
B2. A NICTN budget will be available for the reimbursement of PPI expenses and where HSC policy indicates, remuneration of NICRCF members, for the conduct of PPI within the HSC / NICTN setting	NICTN complies with HSC policy in regard to remuneration and reimbursement policy and processes and communicates policy to NICRCF members	1. Inclusive opportunities 2. Working together	NICTN Operational Director / NICTN PPI Lead	NICRCF Annual Report indicates expenses and payments to NICRCF members	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B3. Opportunities for NICTN to facilitate ease of access to reimbursement and remuneration and minimise barriers to claiming will be explored	NICTN / NICRCF participate in relevant consultations and explore barriers to claiming and methods of facilitation	1. Inclusive opportunities 2. Working together	NICTN Operational Director / NICTN PPI Lead / NICRCF members	NICRCF Annual Report indicates expenses and payments to NICRCF members	Review annually
B4. Opportunities to access designated funding for PPI in research will be utilised	Relevant applications submitted as and when funding opportunities arise	1. Inclusive opportunities 2. Working together	NICTN Operational Director / NICTN PPI Lead / NICRCF Chairperson	NICRCF Annual Report indicates any NICTN designated PPI budget	Review annually
	<p>Researchers will be encouraged to identify PPI expenses and remuneration costs at time of initial research project grant submission</p> <p>Researchers sign-posted to relevant expenses / rates</p> <p>Where PPI funding is awarded, this achievement will be acknowledged / communicated</p>	1. Inclusive opportunities 2. Working together 4. Communications	NICTN Operational Director / NICTN PPI Lead / NICRCF Chairperson	<p>Researcher feedback</p> <p>Communication and acknowledgement of funding achievement</p>	Review quarterly

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
<p>B5. Membership of the NICRCF will be sustained and supported to grow enabling the NICRCF to continue to be a hub for PPI in cancer research</p>	<p>Active awareness and recruitment to the NICRCF will be promoted on an on-going basis taking account of representation of the population of cancer patients and carers:</p> <ul style="list-style-type: none"> • Experience across a range of cancer types and stages • Range of age, gender and ethnicity • Experience across a range of geographic / cancer hospital locations 	1. Inclusive opportunity	NICTN PPI Lead	New membership of the NICRCF reported	Review annually
	<p>Where outreach activities do not attract new NICRCF members NICTN / NICRCF will explore barriers to involvement and adapt processes and activities accordingly</p>	1. Inclusive opportunity	NICTN PPI Lead / NICRCF members	New membership of the NICRCF reported	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B5. Membership of the NICRCF will be sustained and supported to grow enabling the NICRCF to continue to be a hub for PPI in cancer research <i>cont.</i>	PPI representation / NICRCF membership will be identified across all HSC Trusts linked with NICTN / cancer research	1. Inclusive opportunity	NICTN Operational Director / NICTN Manager / NICTN PPI Lead	PPI representation across each Trust within NICRCF	Review annually
	Opportunities for expanding awareness of access to PPI / NICRCF (materials, websites, plasma screens and outreach events, including liaison with cancer charities) across patients / carers / public will be utilised	1. Inclusive opportunity 4. Communications	NICTN PPI Lead NICRCF members	Nature and number of PPI awareness raising materials and events accessible by patients / carers / public	Review annually
	Potential NICRCF members will have easy access to information and a clear pathway to membership Contact details on materials and NICTN / NICRCF website form enables additional application / enquiries to the NICRCF	1. Inclusive opportunity 4. Communications	NICTN PPI Lead	Web application / enquiry form developed	By end 2019/20

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B5. Membership of the NICRCF will be sustained and supported to grow enabling the NICRCF to continue to be a hub for PPI in cancer research <i>cont.</i>	Wallet cards and logo pens will be utilised by NICRCF members and at awareness events to raise the profile of NICRCF and promote new membership	1. Inclusive opportunity 4. Communications	NICTN PPI Lead / NICRCF members	Wallet cards and pens available	Review at least annually
	Annual anonymous satisfaction survey conducted and evaluated across NICRCF members Action plan devised according to outcome	3. Support and learning 4. Communications	NICTN PPI Lead	Retention of NICRCF members Satisfaction survey devised / conducted by end 2019/20 and annually thereafter with action plan following results	Review annually
B6. The training needs of the NICRCF collectively and of its individual members will be met to ensure role understanding, confidence and development	An on-line induction pack will be provided to new NICRCF members with additional face-to-face opportunities to promote role clarity, review IT / communication requirements, address training needs / visits / tours will be supported and new members encouraged to attend the Building Research Partnerships Workshop	3. Support and learning	NICTN PPI Lead / NICRCF Chairperson	Provision of induction to new NICRCF members NICRCF members attend Building Research Partnership Workshops	On-going and review at least annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B6. The training needs of the NICRCF collectively and of its individual members will be met to ensure role understanding, confidence and development <i>cont.</i>	Annual survey undertaken to review member's training needs and identify resources or training based on results	3. Support and learning	NICTN PPI Lead / NICRCF members	Survey of training needs Training agreed and delivered according to need and available resources	Annually
	Group training opportunities (internal or external) will be maximised to promote peer learning and role confidence	3. Support and learning	NICTN PPI Lead / NICRCF members	Training activities conducted	Review quarterly
B7. NICRCF members' development will be promoted to maximise their potential and leadership in PPI activity, according to individual wishes	Opportunities for PPI training or conference attendance disseminated to the NICRCF as they arise with sharing of knowledge and experience encouraged within NICRCF meetings	3. Support and learning	NICTN PPI Lead / NICRCF members	Value and Impact Metrics (adapted from National Cancer Research Institute (NCRI) Consumer Forum)	Review quarterly
	Opportunities for national and international cancer research strategy / management / projects disseminated to the NICRCF as they arise and sharing of knowledge and experience encouraged within NICRCF meetings	3. Support and learning	NICTN PPI Lead / NICRCF members	Value and Impact Metrics (adapted from NCRI Consumer Forum)	Review quarterly

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B8. The NICRCF Chairperson will be supported to undertake the requirements of the role	The NICRCF Chairperson role will be rotated on a 3-5 year basis with training needs / training opportunities identified as part of role 'induction' and on-going	3. Support and learning	NICTN PPI Lead / NICRCF Chairperson	Training and development opportunities open to NICRCF Chairperson Value and Impact Metrics	Review annually
	Opportunities for NICRCF members to participate in training, presentations and other non-PPI activities will also be promoted	3. Support and learning	NICTN PPI Lead / NICRCF members	Satisfaction survey results	Review annually
B9. Collaboration with relevant international / national PPI groups and awareness of evolving resources, training, publications and peer support will be promoted to advance shared learning and best practice	Nurture links with other PPI groups / PPI representatives (via NICTN / NICRCF or NICRCF members) e.g. Patient Involvement Enhancing Research (PIER), BHSC Cancer Services PPI Group, Voices4Care (All-Ireland Institute of Hospice and Palliative Care), Cancer Trials Ireland Patient Consultants, NCRI Consumer Forum, Independent Cancer Patient Voices, Cancer Research UK Involvement	3. Support and learning	NICTN PPI Lead / NICRCF members	Meetings with PPI counterparts / organisations or shared training	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B10. The work of the NICRCF will be acknowledged and celebrated	The work of the NICRCF members will be acknowledged annually through a 'thank you' event	2. Working together	NICTN Operational Director / NICTN PPI Lead	'Thank you' event	Review annually
	The NICRCF Annual Report will acknowledge PPI activities and members involved NICRCF Annual Report dissemination plan will include circulation to the Trust PPI Leads and relevant Trust Directors	2. Working together 4. Communications	NICTN Operational Director / NICTN PPI Lead	NICRCF Annual Report Dissemination plan includes Trust PPI Leads and Directors	Review annually
	The work of NICRCF will be acknowledged in annual reports to NICTN funders	2. Working together 4. Communications	NICTN Operational Director / NICTN PPI Lead	NICTN annual reports	Review annually
	Opportunities for NICRN / NICRCF news items, other media sources, poster, publications and presentations will be utilised to acknowledge and share information about the work of NICRCF	2. Working together 4. Communications	NICTN staff / NICTN PPI Lead / NICRCF members	Number of NICTN / NICRCF website items, publications, presentations, awards per year	Review annually

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
B11. Public / Patient awareness about cancer research, PPI and the NICRCF will be maximised	Utilise existing patient / public activities, such as International Clinical Trials Day, CCRCB Open Day, to raise awareness of cancer research, PPI and the NICRCF	1. Inclusive opportunity 4. Communications	NICTN Operational Director / NICTN PPI Lead NICRCF	Number of patient / public activities Number of new enquiries about the NICRCF	Review annually
	Host NICTN / NICRCF patient / public activity annually which will raise awareness of cancer research, PPI and the NICRCF	1. Inclusive opportunity 4. Communications	NICTN Operational NICTN PPI Lead NICRCF	Number of patient / public activities Number of new enquiries about the NICRCF	Review annually

Goal C - Provision of sustainable support for the NICRCF and its members will enable the NICRCF and PPI in cancer research to grow

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
C1. Effective partnership working will be promoted through effective NICTN / NICRCF PPI communications and activity	All PPI opportunities / researcher requests / activity will receive timely and co-ordinated communication and responses	1. Inclusive opportunities 2. Working together 4. Communications	NICTN PPI Lead	Number of PPI opportunities received resulting in PPI Administrative reasons for non-involvement	Review annually
	NICRCF will review Terms of Reference (ToR) annually NICRCF will produce Annual Report	6. Governance	NICTN PPI Lead	NICRCF minutes reflect review of ToR NICRCF Annual Report produced	Review annually
C2. Measures will be adopted to assess positive or negative impact of PPI	All researchers / projects requested to provide feedback (CRiPaCC, 2018) for evaluation, learning, impact assessment and recognition Provision of timely individual and / or collective feedback where possible and researchers encouraged to attend NICRCF meetings to share results	2. Working together 3. Support and learning 5. Impact	NICTN PPI Lead	Collation of researcher feedback Summary in Annual Report Identification of learning	Review quarterly

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
C2. Measures will be adopted to assess positive or negative impact of PPI <i>cont.</i>	Researchers will be encouraged to acknowledge PPI within specific project publications according to current best practice guidance (e.g. GRIPP2 – Staniszewska <i>et al</i> , 2017)	3. Support and learning 5. Impact	NICTN PPI Lead NICTN / NICRCF	Number of publications acknowledging NICRCF / NICRCF member involvement	Review annually
	All NICRCF members will have opportunities to feedback experience of PPI representation within NICRCF, for shared experience and onward sharing of learning	3. Support and learning 5. Impact	NICTN PPI Lead / NICRCF members	Minutes of NICRCF meetings	Review quarterly
	NICRCF PPI activities will be captured by NICTN according to NCRI Consumer Forum Value and Impact Metrics	5. Impact	NICTN PPI Lead / NICRCF members	Value and Impact Metrics tables published for each NICRCF meeting	Review quarterly

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
C3. Relevant national, regional and local PPI (or other relevant) policy, guidance, research will be adopted into PPI processes of the NICTN / NICRCF	Effective communications will be maintained with PPI Leads in HSC R&D Division and Belfast HSC Trust and via NIHR / NCRI / ECMC and CRUK Involvement Team communications to promote NICTN / NICRCF awareness and compliance with current applicable policy and guidance	4. Communications 6. Governance	NICTN Directors / NICTN PPI Lead	NICTN implementation of national / regional / local PPI policy and guidance	On-going review
	National NIHR standards for PPI in research or subsequent revisions, will be utilised as guide and benchmark devising PPI management, training, processes and delivery, communication and evaluation	1. Inclusive opportunities 2. Working together 3. Support and learning 4. Communications 5. Impact 6. Governance	NICTN PPI Lead	Reference to PPI standards in research in staff and NICRCF member training and PPI strategy, training, processes, activities and evaluation	Review annually
	NICTN will comply with GDPR and other relevant regulations regarding NICRCF members' information	6. Governance	NICTN PPI Lead	Communication of management of personally identifiable information to all members	On-going

Objective	Action	Applicable Standard	Person/Group with lead responsibility	Measure	Timeline
C4. NICTN / NICRCF experience will be utilised for learning and sharing	Experience / past feedback to researchers will be utilised to inform training / tools and local templates or guidance for cancer researchers, minimising need for repetition	2. Working together 3. Support and learning	NICTN PPI Lead / NICRCF members	Development / delivery of local training / tools / guidance for researchers	On-going as required
	Research and PPI success stories / case studies will be shared / utilised to raise awareness and understanding of PPI	2. Working together 4. Communications	NICTN Operational Director / NICTN PPI Lead / NICRCF members	Number of publications / presentations that promote awareness and understanding of PPI in cancer research	Review annually

Consultation and Further Enquiries

A final version of this strategy will be issued following a 3 month consultation period up to the end of June 2019.

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Appendix 1

Benefits and Impact of Personal and Public Involvement in Research

(reproduced from *Strategy for Personal and Public Involvement in Health and Social Care Research*, HSC R&D, 2014)

Impact on Study design

- Identification of more meaningful research topics and questions
- Greater ethical integrity
- Improved reliability of research tools
- More practical research methods
- Increased numbers of patients participating in clinical trials
- Improved access to groups or services that may be difficult to reach
- Richer data
- More relevant and accessible findings
- Quicker dissemination and translation into appropriate and timely interventions

Benefits to Researchers

- Greater knowledge and understanding of service users
- Greater satisfaction and enjoyment
- Career benefits
- Increased credibility

Benefits to PPI representatives

- New skills and knowledge
- Sense of empowerment and achievement
- Support and friendship
- Enjoyment and satisfaction
- Employment and financial reward

Benefits to wider communities

- Greater trust in and acceptance of research
- Projects grounded and focused on benefits for the community;
- Improved relationships between communities and professionals
- New and improved services
- Changes in practice
- Partnerships to effect change

Appendix 2

Evaluation of PPI in Cancer Research in Northern Ireland: Survey and Focus Group Results November / December 2017 - Future Recommendations (NICTN, 2018, Page 53)

1	Provide dedicated PPI funding and expenses processes	<ul style="list-style-type: none"> • <i>Provide ring-fenced funding for PPI</i> • <i>Review processes for payment of expenses to maximise respect for PPI representatives</i>
2	Enhance support structures	<ul style="list-style-type: none"> • <i>Research institutions integrate PPI into research / proposals and provide PPI roles</i> • <i>Provide clerical support for PPI</i> • <i>Provide support for NICRCF leadership</i> • <i>Provide relevant IT support/guidance to PPI Representatives to facilitate electronic PPI activities/input</i> • <i>Corporate recognition for PPI volunteers</i>
3	Expand PPI Representative numbers and networking	<ul style="list-style-type: none"> • <i>Expand the number of patients and carers involved in PPI - increasing Trust and cancer type representation</i> • <i>Provide experiences that incentivize young people to get involved</i> • <i>Increase engagement with local charities</i> • <i>Increase opportunities for PPI representatives to network and collaborate with other groups</i>
4	Enhance training	<ul style="list-style-type: none"> • <i>Integrate PPI training into graduate, post-grad and cancer researcher education</i> • <i>Provide researcher mentorship support</i> • <i>Provide researcher training/workshops about developing patient / lay information in plain English</i> • <i>Utilise group training approaches in NICRCF to build confidence and clarify expectations</i> • <i>Provide on-going NICRCF training and mentorship and assure role clarity</i> • <i>Provide on-line PPI training for PPI representatives</i>

cont.

Evaluation of PPI in Cancer Research in Northern Ireland: Survey and Focus Group Results November / December 2017 - Future Recommendations (NICTN, 2018, Page 53) *cont.*

5	Raise researcher and public PPI awareness	<ul style="list-style-type: none"> • <i>Increase awareness/culture of PPI benefits to research</i> • <i>Provide on-going researcher awareness</i> • <i>Develop and utilise researcher PPI champions</i> • <i>Increase PPI access awareness.</i> • <i>Devise PPI on-line register / resource / experience register</i> • <i>Promote awareness of PPI role opportunity</i>
6	Increase PPI opportunities	<ul style="list-style-type: none"> • <i>Promote wider adoption of PPI in research</i> • <i>Promote early PPI in research projects</i> • <i>Facilitate face-to-face researcher / PPI opportunities</i> • <i>Increase opportunities for more researcher / clinician / PPI meaningful collaboration. Sandpit events.</i>
7	Share PPI impact	<ul style="list-style-type: none"> • <i>Provide feedback about PPI impact</i> • <i>Annual public PPI events</i> • <i>Share success stories</i>