



**CANCER  
RESEARCH  
UK**

**Scotland  
Centre**

# **Patient and Public Involvement Strategy**

**2023 - 2028**

## **Foreword**

Established in 2022, the Cancer Research UK Scotland Centre brings together the very best in cancer research from Edinburgh and Glasgow. Our unifying mission is to translate cutting-edge discoveries into promising therapeutic opportunities, and to deliver novel options to prevent and detect cancer for the Scottish population.

To deliver this mission, the CRUK Scotland Centre facilitates partnerships with organisations across academia, NHS, industry, and the third sector. This supports research collaborations spanning over 80 teams, in the Universities of Edinburgh and Glasgow, including the Institute of Genetics and Cancer in Edinburgh, the School of Cancer Sciences and CRUK Beatson Institute in Glasgow. It also supports vital clinical research in Scotland's two largest cancer centres; Beatson West of Scotland Cancer Centre, and Edinburgh Cancer Centre.

Together, we aim to increase survival and prevent cancer, through a world-leading research programme which focuses on cancers that profoundly affect people in Scotland.

However, there is also a recognition that we must understand *what lies beneath* the narrative of Scotland's relationship with cancer if we are to fundamentally change it. That means harnessing the experiences and creativity of Scotland's people, to shape and extend the reach of our research endeavours, from board room, to study design, to bedside, to classrooms, and back again. We ultimately seek to reduce incidence and drive up outcomes by democratising the design and delivery of cancer research and services, carefully tailoring these to the diverse needs of the people we serve.

Here, we start as we mean to continue. The Centre's existing Patient and Public Involvement (PPI) groups, and other subject matter experts, have shared their experiences and vision for the future. Together, we have co-authored this strategy and will ensure it is implemented in full.

**Denise Calder**, Director of Strategic Partnerships  
Cancer Research UK Scotland Centre  
July 2023

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## 1. Strategic Work Packages

1.1 Vision	
<b>Lead</b>	<b>Denise Calder</b> , Director of Strategic Partnerships, CRUK Scotland Centre
<b>Group members</b>	Elspeth Banks, PPI Representative, CRUK Scotland Centre Linda Galbraith, PPI Representative, CRUK Scotland Centre
<b>Objective</b>	Articulate a clear vision that the PPI strategy will help to deliver

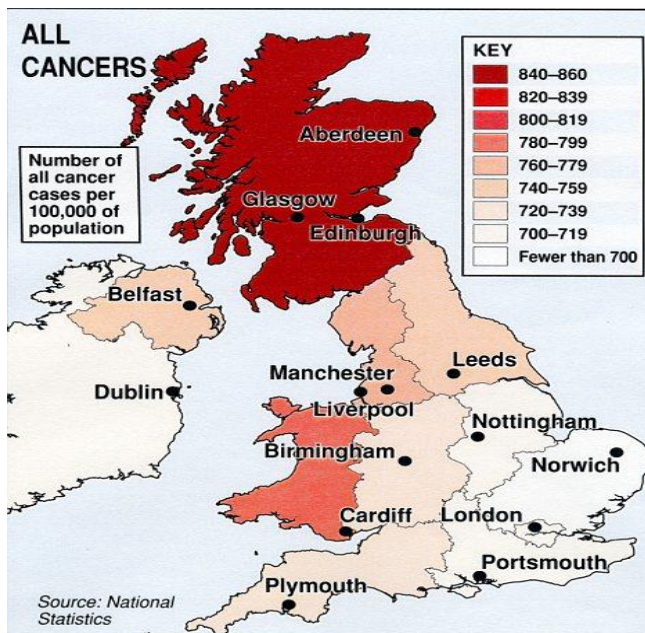
### Introduction

CRUK Scotland Centre’s unifying mission is to translate cutting-edge discoveries into promising therapeutic opportunities, and to deliver novel options to prevent and detect cancer for the Scottish population and further afield.

To this end, the Centre harnesses combined assets, which include world leading scientific and clinical expertise and highly engaged PPI groups, to drive scientific discovery and innovation faster than ever before.

The purpose of PPI in research is to help to set the research agenda, and to ensure patient interests and safety of research participants are always at the forefront. This is of particular importance in Scotland, where it is most clear that *beating* cancer is not just about *treating* cancer.

The Chief Medical Officer’s Annual Report published in March 2021 stressed that ‘*We urgently need to address health inequalities here in Scotland, which are the worst in western and central Europe*’. Cancer inequalities are stark, even in relation to the rest of the UK, as illustrated below.



## Approach

By working more closely with communities, patients, and partner institutions, we will improve our understanding of the drivers of cancer inequalities in Scotland. This will facilitate the co-design of an ambitious and far reaching research programme, tailored to the needs of Scotland's people.

Through this approach, we expect to improve the balance of the research portfolio, with greater emphasis on developing new approaches to the identification and management of cancer risks, and improved participation across the full spectrum of research spanning prevention, early detection, diagnosis, and development of novel therapies.

Expertise and access to PPI groups will also be shared with other University and NHS partners to help fast-track access to new treatments through the expansion of trials.

PPI will therefore be part of the research we do, but also the way we organise and deliver that research. Accordingly, PPI will be routinely sought and valued by researchers, and be firmly embedded in all aspects of work in the Centre. All research programmes will therefore be required to demonstrate PPI engagement.

To facilitate this, we will create conditions and supporting infrastructure which allow PPI groups to be easily accessed and research to be coproduced. Use of the Centre's excellent but sometimes fragmented PPI resource will then be optimised across traditional boundaries to this end.

We will build on current strengths, as set out in the next section, by ensuring PPI Groups better reflect the makeup of our communities. They will include people with a lived experience of cancer, a higher risk of developing cancer (e.g. participants of screening programmes), and/or extensive experience of living or working within hard to reach communities.

No strategic decisions will be made without PPI partners. PPI representatives will be empowered with roles in the development and delivery of the Centre's strategies, and voting rights in decision making committees. They will also be routinely involved in the Centre's seven theme meetings, the design and oversight of research projects, along with the core business of involvement in clinical trials as collaborators.

The Centre operates within a wider science and health community which spans academia, the NHS, government, industry, and the third sector. We depend on partners across Scotland to create favourable conditions for high quality research. Naturally, our partners strive to provide patient centred services, but they sometimes experience difficulties in gaining access to PPI groups. The Centre will therefore design an exemplary model of PPI which is accessible to all partner organisations. In so doing, we will extend the reach of Scotland's people, empowering them to help design world leading cancer research and services.

High level actions related to delivery of this vision are provided below. These will be expanded upon in the following sections.

## Actions

- Identify and develop opportunities to work more closely with communities
- Ensure PPI groups reflect the makeup of our communities and develop the necessary monitoring arrangements to ensure this is the case.

- Secure representation from hard to reach communities, and people who have been identified as at high risk of developing cancer
- Develop a culture in which PPI contributions are valued and routinely embedded in all parts of a pro-active operating model
- Ensure that all strategies, programmes, and projects demonstrate PPI engagement
- Provide PPI representatives with voting rights on key strategic committees, and open access to centre theme meetings / AGMs
- Build infrastructure and capacity to flexibly meet the needs of CRUK Scotland Centre, and its key partners, on a self-sustaining basis
- Design and conduct research projects which aim to formally establish patient priorities, particularly within hard to reach communities

1.2 Baseline assessment	
<b>Lead</b>	<b>Jackie Beesley</b> , Centre Manager, CRUK Scotland Centre
<b>Group members</b>	Elspeth Banks, PPI representative, CRUK Scotland Centre Susan Crate, Senior Research Nurse, Breast Cancer
<b>Objective</b>	Provide a baseline assessment to identify current PPI assets, challenges, and opportunities

Patient and public involvement (PPI) is already a key component of research activities within the CRUK Scotland Centre, particularly those that are clinically facing. In addition, PPI reps work across the UK where their experience and skills are utilised in groups such as National Cancer Research Institute (NCRI), Experimental Cancer Medicine Centre (ECMC) network, Independent Cancer Patients' Voice (ICPV) and a range of other organisations, including regulators.

There are several PPI groups (Table 1), many of which focus on the Centre's key tumour types. Broadly, these groups provide comment and insight into grant, trial, and ethics applications prior to submission. PPI groups also can take an active role as a key part of study management groups, guiding and coproducing research. In addition, PPI reps share their personal cancer experiences at research conferences or via press and social media.

**TABLE 1. CRUK SCOTLAND CENTRE PPI GROUPS**

**Brain Cancer Patient Advocacy Group:** facilitated by Sara Erridge, Clinical Neuro-oncologist and Paul Brennan, Neurosurgeon; works with other patient advocacy groups including the Brain Tumour Charity and Brainstrust

**Edinburgh Oncology Research PPI Group** 6 sitting members; facilitated by Lois Eddie, CRUK Senior Research Nurse and Susan Crate, Senior Research Nurse for Oncology Clinical Trials

**Glasgow Oncology Clinical Trials Unit (GOCTU) PPI Oversight Group:** chaired by Elspeth Banks, PPI Lead and **PPI Panel** managed by Karen Bell, Senior Research Nurse. Patient representation on In-House Trials Advisory Board, Umbrella Trials Steering Groups, Clinical Trials Executive Committee and all GOCTU Clinical Trial Management Groups

**Precision-Panc Patient Public Advisory Group:** 7 sitting members; facilitated by CRUK and Pancreatic Cancer UK with training provided by pancreatic cancer clinicians; also, patient representation on the Precision-Panc Steering Committee and Scientific Advisory Board; plan to include a patient representative on each Precision-Panc Trial Management Group

**PREDICT-Meso Network PPI Group:** formed with input from a mesothelioma specific PPI group in Surrey and the [Scottish Mesothelioma Network](#); For Meso-ORIGINS a named PPI representative is included on the protocol and attends study management group meetings; network lead Kevin Blyth, Consultant Respiratory Physician has strong links to patient advocacy groups such as the June Hancock Mesothelioma Research Fund and Clydebank Asbestos Group

**RadNet Glasgow PPI Group:** for those who have experienced radiotherapy treatment; 8 sitting members; has drafted a recruitment pack with an application form and information/training slides to share with other PPI groups in the Centre

**Beatson West of Scotland Cancer Centre/University of Glasgow PPI Group:** ECMC and BCRF draw on for representatives – membership overlaps with GOCTU PPI Group (above)

## Challenges

- We have some baseline information but are there groups missing from this list? Are some patients underrepresented?
- What do these groups get involved in and how would they want to be involved in the Centre?
- How can these activities be networked with those of the North of Scotland?
- What other 'overarching PPI structures exist or are being develop that include cancer along with other diseases? (e.g.: liver disease)
- How are PPI reps in each of these groups recruited, trained, involved, and rewarded/recognised for their contributions? The GOCTU Group has a policy, which could be share and used as best practice.
- What existing strategies, resources, training, best practice and policies do these groups already have?
- How do these groups and PPI reps use virtual platforms, social media and/or websites?
- How do these groups measure compliance and success (against their key objectives if they have these), and are there any barriers to this?
- How do Centre employees currently involve patients in their work and strategic decisions?  
How do researchers, senior decision makers and policy makers interact with PPI reps and vice versa? (e.g. the Centre's work with the CRUK policy team on liver cancer)
- How many research studies have PPI representatives on the study management groups?
- Where are our exemplars and how do we share learning and best practice? Could there be facilitators to bridge groups?

### Opportunities

There is a wealth of high-quality PPI activity within the Centre, which has been commented on/recognised by several funding review panels. This is a strong base on which to build and there is potential to make these PPI groups more than the sum of their parts. There is also an opportunity to share best practice, internally and externally, and think about the use of different platforms/resources.

### Actions

1. Gather answers to the remaining unanswered questions regarding the baseline position as outlined above. To establish a clearer baseline, the Centre Manager will ask groups to answer the following - what do they do, how do they add value, what help do they need. PIs will also be asked for examples of about their work with PPI groups
2. Create a comprehensive list of local and national PPI groups and key contacts
3. Map activity, experience, knowledge and best practice for each of these groups
4. Survey PPI groups and reps on how they would like to be involved in the Centre (will require a lay summary of the Centre)
5. Identify compelling narrative examples of PPI work within the Centre  
Survey researchers, particularly early researchers, on when/how they currently involve PPI reps in their work and what ambitions they have to do this in the future. This should be supplemented by PPI led workshops.
6. Articulate the supporting infrastructure required to keep information current following completion of the baseline assessment, and to allow these assets to be fully leveraged, supported, shared, and coordinated across boundaries
7. Identify how to progress current PPI functions and the scope of these. It is essential to move to a model where research is co-developed and coproduced with PPI.



This baseline assessment has provided a snap shot of current provision. Many of the themes identified here, and related actions, will be further expounded in the following sections, and ultimately within the strategic implementation plan.

<b>1.3 People</b>	
<b>Lead</b>	<b>Carol Porteous</b> , Patient and Public Involvement Lead, ECRC
<b>Group members</b>	Dee Davison, IGC Public Engagement Manager Dr Laura Richmond, Lecturer, University of Glasgow Linda Galbraith, PPI Representative, CRUK Scotland Centre CRUK Senior Research Nurse, Lead Research Nurse SE-SCRN
<b>Objective</b>	Identify the key enablers, challenges, and opportunities to develop a culture which values and routinely accesses PPI groups

### **Support and Training**

It is vital that staff are appropriately trained and supported in order to feel confident and competent to involve PPI partners in research. CRUK Scotland Centre expects its staff to undertake appropriate training to support the involvement of PPI partners. Accordingly, PPI training will in future be included in the Centre’s mandatory training programme.

Additionally, it is vital that we offer the mutually agreed support and training for our PPI partners, to enable them to take part in PPI activities. This may be through informal support or via training courses and other upskilling activities. Research Teams should be mindful that PPI partners may need formal training for specific activities including assessing grant applications or attending a Research Ethics Committee (the need for formal training should happen through discussion between PPI partners and Research Teams)

### **Existing Training Provision**

#### **CRUK**

Cancer Research UK have useful resources in their Cancer Research UK Public Involvement Toolkit <https://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers>

#### **University of Edinburgh**

The University of Edinburgh provides an array of PPI Training for researchers - including:

- Introduction to PPI
- PPI in Funding Applications
- PPI in Clinical Trials
- Creating and Running PPI Groups
- PPI Summer School
- PPI for Lab based researchers.
- Communication Skills – How to talk to anyone about research.

- Communication Skills – Listening & Facilitation skills.
- Ethical & Social Implications of Research – Understanding public expectations & concerns (The Civic Duty of Researchers)
- PPI – Engaging with people living with Genetic Conditions & Cancer, their relatives & carers, Patient Advocates & Charities - Working in Partnership
- Equity, Respect & Safeguarding (EDI) in PE - Accessibility & Disability Awareness

## University of Glasgow

CRUK CTU group are developing training materials / compendium

MVLS - [PPIE Group](#)

MVLS – [Public Engagement training](#)

<https://www.gla.ac.uk/colleges/mvls/researchinnovationengagementsupport/issf/ppie/>

## Canadian Institutes of Health Research

The Canadian Institutes of Health Research (CIHR) also have an online training module developed between staff and PPI partners. This online training module is designed for those new to PPI in research and is available for anyone to do at their own pace <https://cihr-irsc.gc.ca/e/27297.html>

## Actions

1. Promote availability of training already available and ensure it is accessible to all working under the auspices of CRUK Scotland Centre, and its partners
2. All staff across the centre to have at least undertaken Introductory PPI training course, including PPI training courses during induction for new members of staff.
3. Lab based researchers undertaking PPI for Lab-based Researcher training
4. Offering training courses to new PPI partners who join our PPI activities.  
Ensuring ongoing support and training opportunities are offered to existing PPI partners
5. All post-doctoral staff who are applying for funding to undertake specific training on PPI in Funding Applications

## Equality, Diversity, and Inclusion

As explained in the opening section, to optimise the quality, reach, and power of our research we must develop research studies in collaboration with diverse communities. There is a particular need to develop our public involvement activities in collaboration with those underserved by research.

This does present some challenges, both in terms of the time commitment required to engage and develop trust with communities, but also because our different research projects will by virtue of the cancer under investigation affect different underserved communities.

Scotland is not as ethnically diverse as other parts of the UK. Scotland's population is 96% Caucasian, 2.6% Asian, Asian Scottish or Asian British, 0.5% African, 0.4% other ethnic groups, 0.3% mixed or multiple ethnic groups and 0.1% Caribbean or Black (ref).

While ethnicity is important in terms of who is underserved by research, there are also other categories of being underserved by research which affect our population. For example, around **one fifth** of Scotland's population lives in poverty and seventeen percent of our population lives rurally – the majority of whom are aged 45 and over.

The NIHR INCLUDE project in 2020, explored who is underserved by research and suggested over 30 different groups that are underserved by research, individuals may occupy multiple groups and we need to as part of our long-term plans work with those who are underserved by cancer research currently.

Other groups which are underrepresented include those experiencing social deprivation and poverty, often associated with poor outcomes in certain cancers e.g., head and neck, age - young and old, and mental health. A review of reviews on PPI by Josephine Ocloo et al (2021) found that established strategies to avoid stigmatisation and discrimination were not always effective. Findings included the need for a change in attitudes and for health professional relationships with patients to be conducted in a non-paternalistic way in a spirit of equal partnership, ensuring people do not feel subordinate to clinicians or professional staff and valuing all people. Beyond that report, the timings of meetings are also significant, often excluding younger working people, who cannot attend meetings within working hours. Mental Health conditions raise issues of adequate assessment of an individual's capacity to consent to their participation, which mandates the input of appropriately trained professionals.

To increase the diversity of our PPI partners and the composition of our PPI Groups, we will:

#### Actions

1. Create and develop a plan for engaging and involving those in particular who are underserved by cancer research
2. Involve diverse PPI partners, ensuring the makeup of our PPI groups adequately reflect the makeup of the communities they represent
3. Work with specific underserved communities to include them within our research activities (including but not limited to rural communities, deprived and disadvantaged communities, vulnerable people, families and carers, different faith groups and ethnic minority backgrounds)
4. Gather diversity data on the PPI partners we involve – with the intention this diversity increases over time as relationships with communities develop.

1.4 Finance	
<b>Lead</b>	<b>Dorothy Boyle</b> , Service Manager, Southeast Scotland Cancer Research Network
<b>Group members</b>	Andrea Harkin, Cancer Research UK Glasgow Clinical Trials Unit Gerard Lynch, Project Manager, Beatson WoSCC
<b>Objective</b>	Identify the key enablers, challenges, and opportunities, to provide appropriate financial support to PPI groups

#### Overview

Patient and Public involvement representatives can provide researchers with valuable insights, skills and experiences, which can help to make health research more relevant to the needs of patients, carers and service users.

If PPI Groups are to work effectively and a group is to be maintained, it is only right that the individuals are not disadvantaged financially, and their valuable contribution acknowledged.

#### Resourcing PPI

All research projects and clinical studies that require Patient and Public Involvement (PPI) should first start with drafting a PPI plan. The purpose of this plan is to document the scope and scale of the PPI activities for the proposed study or research project and therefore ensure that these activities can be resourced appropriately.

This plan can then be resourced from a variety of sources, including grant funding from charities, Scottish and UK government research councils, overseas funding bodies, and investment from the private sector, including pharmaceutical industry and biotech. Funding is not only essential to establish the infrastructure required for PPI activities but should also make sure that these activities are both impactful and sustainable.

When budgeting for PPI activities, things that need to be considered include patient expenses, patient honorarium, carer costs, venue hire, food, cost of an external facilitator, training and learning, advertising costs and staff costs (e.g., administrative support, coordinator, researchers, and facilitators).

For early career researchers within the centre (pre or post-doctoral), who often do not have access to research funding, seed funding will be allocated to allow PPI activities to be undertaken in preparation for external grant funding. Funding of PPI activities should be comprehensively costed into all grant applications from the centre and will form part of the internal checking and grant submission process.

The National Institute for Health Research (NIHR) [INVOLVE Cost Calculator](#) can help with costing PPI activities.

#### Public, Charity and Industry funders

Engagement with patients and public is a strategic priority for many of the funders of medical research and excellent resources are available to help the Centre provide a clear costing for PPI activities for grant application (e.g., [Medical Research Council](#), [Cancer Research UK](#) and [NIHR](#)).

Another source of funding for PPI is from industry. There are a number of challenges that we must consider when accepting support from industry:

- Is this support to fund specific activities? If so, it must be clear and transparent which activities are funded by industry and we also must also ensure that patients/public are happy to be partner with these activities.
- Support from industry comes with risks including potential scrutiny from the media and the wider public, reputational risks by being associated with a particular partner and potential conflicts of interest.
- Do we have a policy in place which describes the principles, rules and guidelines for working with industry on PPI?
- Contracts and agreements are required. These agreements must cover defining the activity to be performed and timescale, confidentiality, IP rights, finance, exploitation, conflicts of interest, limits of liability, publications, exclusivity clauses etc. A one-off fee to cover the cost for drafting these agreement should also be included.

These issues are not always straightforward. To ensure consistency, the Centre will provide protocols, training, support, and checks to guide researchers on comprehensive costing.

### Building PPI Capacity

As well as the direct PPI costs listed above, we must also consider the indirect costs in developing impactful and sustainable PPI. For example, there should be a standard overhead contribution to strategy development and wider public engagement, particularly with hard to reach communities.

Furthermore, if PPI is to have a meaningful role in developing a research proposal, it may be necessary to engage a PPI group in the development and writing of the application and the costs associated with this support would have to be covered from elsewhere.

It is also necessary to coordinate activity across the CRUK Scotland Centre, to build upon our current PPI capacity and maximise the impact that PPI can have on framing and steering our research. To do this effectively, we must build the personnel and resources required to support this PPI activity across the centre.

Whilst the implementation plan of this strategy will require pump-prime funding, it should ultimately become self-sustaining. This will primarily be through provision of comprehensive and systematic costing of PPI in all grant applications and commercial trials. Costs will include PPI expenses plus a percentage contribution to cover the whole cost of access to PPI expertise, training, and support. These costs will be systematically recouped and reinvested into providing the capacity required to deliver this strategy.

### PPI Expenses and Honorarium Policy

There is a need to agree principles of a PPI expenses policy for the Centre with all stakeholders and adopt within our own local processes. Learning could be taken from the Glasgow Oncology CTU PPI Expenses Policy

- This should cover:
  - Out of pocket expenses (travel, accommodation, subsistence, overheads (e.g. stationery) for PPI and, if needed, those for accompanying carers or alternative care costs to allow participation. Have an agreed list of costs that will be covered and what will not be covered, and rates of pay in line with national guidelines (car mileage, meals, accommodation).
  - Honorarium payments to cover preparation time, activity time and any post activity time required by the PPI representative. Agree payment rates in line with national guidelines.

- It will be expected that each stakeholder/partner will have their own local policy and process for payment of expenses and honorariums but there should be alignment between all partners in terms of what can be claimed and the rates.

#### Actions

- Determine the number and types of posts required within Cancer Research UK Scotland Centre to support the delivery of the strategy
  - Provide comprehensive costings to allow full costs to be recouped in future
  - Write a PPI costing protocol and provide support for its implementation
  - Identify a suitable funding stream for pump priming delivery of this strategy
  - Create a central fund to which PPI partners working across Scotland can access support for training, and attendance at conferences.
  - Created a shared and accessible training programme to improve cost effectiveness and ensure that costs per delegate are covered by the employer or PPI sponsor
  - Identify opportunities to further centralised PPI activities to minimise cost and optimise availability of resource across traditional boundaries
- Create a service model to offer access to PPI to partner organisations on a fee paying basis, thereby covering costs, and building capacity required for an extensive offering which benefits all stakeholders. Develop a shared PPI expenses policy for the Centre

1.5 Communication and stakeholder engagement	
<b>Lead</b>	<b>Jennifer Hay</b> , Head of Glasgow Tissue Research Facility, University of Glasgow
<b>Group members</b>	Heather Moffitt, PPI Representative, Trustee, Make 2nds Count Lesley Stephen, PPI Representative, Make 2nds Count
<b>Objective</b>	Identify the key enablers, challenges, and opportunities, to appropriately support communications and stakeholder engagement

## Introduction

Effective communication will be crucial to the success of this pan-Scotland, networked approach to PPI. The table below identifies key audiences that the team will need to engage and coproduce research with, including communication objectives, examples of top-line messages and channels which will be developed in more detail as part of the implementation plan.

Audience	Comms objectives	Key messages	Channels
<b>PPI</b>			
<i>New PPI</i>	Attract new patients, families, carers, and key members of the public (i.e., from high-risk groups or underrepresented EDI groups) to get involved in PPI	PPI is a great way of learning about research, and getting involved means you will benefit cancer research. You will be trained, expenses covered and given all the tools you need	Online patient forums; charities; existing PPI members; social media; posters/leaflets in clinic; focus group and qualitative data collection
<i>Existing PPI</i>	Encourage existing patients to stay and support a more integrated approach to PPI	An integrated Scotland PPI will deliver greater benefit to patient studies, and be a more interesting role for you mentoring new patients, families, and carers.	Existing channels used for Glasgow and Edinburgh PPI
<b>Research</b>			
<i>Early Career Researchers (ECR)</i>	Provide practical information on how to use PPI and its benefits to you and your research.	What PPI is, and why it's becoming increasingly important. It will help with funding and to deliver the best research. The centre will support ECRs to undertake PPI as part of grant applications.	Conferences, University led training, integrated into Centre training and information for research applications, integrate PPI into presentations

<b>Audience</b>	<b>Comms objectives</b>	<b>Key messages</b>	<b>Channels</b>
<i>Professors/Principal Investigators (PIs)</i>	Raise awareness and support for PPI as a core element of your trial/study; provide links to access a pool of PPI reps	PPI is becoming a core part of research and has many benefits to you as a PI, such as ease funding. We want to encourage more leadership from senior HCPs in this area. New grants need to have PPI costs comprehensively factored in and be checked and approved by Centre Management before submission.	Conferences, University led training, integrated into Centre training and information for research applications, integrate PPI into presentations
<i>Students</i>	Explain where PPI is required, why and its overall benefits	What PPI is, and why it's becoming important. It will help you to get funding, design and deliver the best research. The centre will support students to undertake PPI as part of grant applications.	Incorporate a lecture/seminar into modules for MSC, BSC, Medicine etc
<b>NHS</b>			
<i>Clinicians</i>	Raise awareness of what PPI in Scotland is, and how best to direct potential patients to it	What PPI is, and why it's becoming increasingly important. It can help to deliver the best research for patients and we would value your proactive support for it	Build into existing societies (eg RCPATH, PathSoc, Royal Soc of Medicine), NES training
<i>Nurses</i>	Raise awareness of what PPI in Scotland is, and how best to direct potential patients to it	What PPI is, and why it's becoming increasingly important. It can help to deliver the best research for patients and we would value your proactive support for it	Existing channels pulling together a more integrated Scotland PPI strategy, NES training
<i>HCPs</i>	Raise broad awareness of PPI	What PPI is, and why it's becoming increasingly important. It can also provide benefits for your patients, and here is where interested patients can find more information.	HCP Conferences (eg SAH), linked to students (as HCPs often do MSCs through job) local engagement in hospital atriums, grand rounds, NES training

## Challenges

We have identified a number of challenges that the team responsible for communication will face. These include:

- NHS staff are busier than ever – how will they find the time or inclination to engage with any PPI proposals?
- Potential new PPI representatives will likely need extensive awareness building and jargon-free explanations (i.e., what even is PPI?). They will also need training opportunities to support the co-development and co-production of research.
- Also need to consider how to reach geographically diverse and EDI cohorts who tend to be underrepresented in PPI, both in messaging and channels.



- Many existing PPI representatives are also very busy and may not have sufficient time to get involved. How can messaging feel supportive rather than oppressive (i.e., possible social media groups rather than loads of emails)?
- PPI isn't yet embedded in the NHS - this culture exists in pockets and will be a challenge to shift, requiring strong leadership. That leadership strategy will inform how the comms plan can be shaped and delivered.
- How do we resource the communications plan? Who is overall responsible for its ownership, management and implementation? This will require dedicated time and funding.
- PPI groups require administration (i.e. scheduling meetings, expenses claims), there will need to be someone who support this on a day to day basis

### **Opportunities**

We have also identified a number of opportunities that the team responsible for communication can build on. These include:

- There is an existing PPI network and plans that we can leverage and build on
- As evidenced at the workshop, there is strong commitment from senior HCPS to help drive the changes forward
- We believe that ECRs and younger professionals will be very open to PPI development, and they have the energy to help make this happen
- There are existing funding opportunities that we can access

### **Key action points**

1. Identify the baseline for communication in order to identify any gaps and to develop this skeleton plan in more detail. This will help identify the existing PPI and what communication channels are already available to us.
2. To identify who will be leading and accountable for PPI communications and engagement, who will be actively coordinating this on a daily basis, and what are the timescales.

## 1.6 Governance and benefits evaluation

<b>Lead</b>	<b>Anna Morris</b> , Programme Manager, CRUK RadNet Glasgow Centre
<b>Group member</b>	Professor Rob Jones, Director, Glasgow Oncology Clinical Trials Unit Paul Brennan, Reader, Honorary Consultant and Clinical Director for Neurosurgery, University of Edinburgh and NHS Lothian
<b>Objective</b>	Identify the key enablers, challenges, and opportunities, to provide appropriate governance and benefits evaluation

### Overview

It is important that CRUK Scotland Centre has the necessary governance arrangements in place to ensure effective oversight of PPI work. This can be provided through the creation of a PPI Governance Group (GG) with a clear mandate and Terms of Reference.

The GG would be responsible for ensuring that the goals of the vision for PPI are being achieved, that PPI is being incorporated appropriately and that PPI members are supported to maximise their involvement across areas of research. This includes both activities at a strategic level and for project/ clinical trial specific PPI. This GG would address issues of concern regarding PPI implementation across the Centre and contribute to ensuring PPI makes a meaningful impact on the Centre's strategic focus and direction.

This Group can be used to make recommendations for improvements or address issues that are of concern for PPI as a whole across the Centre.

A comprehensive baseline assessment, building on the work outlined in section 1.2 above, will serve as a marker for performance.

Key Performance Indicators that will be assessed by the GG are:

- Increased PPI representation across diverse groups
- Increased attendance at PPI training sessions
- Increase in score from baseline Evaluation Questionnaire
- Increase in impact- how many projects/ trials now have input from a PPI representative compared to baseline.
- Diversity of PPI representation across the groups it oversees.

### Challenges

- Finding volunteers to take up positions on the Group- extra time commitment over and above PPI representation or research role.
- Sourcing a PPI Coordinator to help the Group- funded, volunteer, any previous experience of similar roles? Could this be a member of staff supported by the Centre?
- If recommendations are made, how to ensure these are carried out- level of seniority and commitment to PPI strategy?
- Encouraging existing PPI Groups to 'sign up' to the oversight programme and work with the GG to make the PPI vision a reality.

## **Actions**

- Establish a PPI governance committee with clear Terms of Reference and representative membership, reporting to CRUK Scotland Centre Governance Board via the Centre's Senior Management Team. The scope of this group should encompass two work streams:
- 1) Delivery of the overarching strategy implementation plan

AND

- 2) Operational delivery and performance, including:
  - Establishing priorities
  - Creating new PPI groups, activities, and work streams where needs and/or opportunities arise
  - Agreeing operational / project level metrics
  - Measuring performance against these metrics
  - Agreeing corrective action plans where necessary
  - Allocating/reallocating resource to PPI activities from the capacity fund where necessary in support of the above