



**NI Cancer Trials Network (NICTN) / Belfast Experimental Cancer  
Medicine Centre and  
NI Cancer Research Consumer Forum (NICRCF)**

**Evaluation of PPI in Cancer Research in  
Northern Ireland:  
Survey and Focus Group Results  
November / December 2017**

*'I cannot describe the input of the Forum more highly. They are a dedicated bunch who give depth and clinical relevance to research. What they have taught me about research....no book or lecture ever could.'*  
**Researcher**

**Final v 26.03.18**



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## **BACKGROUND**

### **PPI in Cancer Research in NI - Survey and Focus Group Rationale**

Since the launch of the [Strategy for PPI in Cancer Research in NI](#)<sup>1</sup> and establishment of the NI Cancer Research Consumer Forum (NICRCF) in 2011, an aim of the NI Cancer Trials Network (NICTN) has been to facilitate an accessible, systematic and integrated approach to PPI in cancer research across NI. While the NICTN has been the organisation providing the administrative support for the NICRCF, the strategy was that NICRCF was a resource approachable by any researcher/institution/organisation in NI or beyond. The criteria for NICRCF access was simply that research involved cancer patients/carers, or their data or tissue. The work of the NICRCF can be reviewed in their [annual reports](#). While informal feedback suggested the PPI strategy in cancer research was successful, the strategy was overdue a review, and a survey was conducted to enable groups of stakeholders to provide their perspectives about PPI and the strategy anonymously. A focus group was conducted to explore in more detail PPI experiences and recommendations from NICRCF members' perspectives. This was the only focus group conducted due to time and resource constraints.

## **SURVEY METHODS**

### **Survey Development**

NICTN senior management and the NICRCF had early awareness of the proposal to undertake a PPI survey. An outline of the survey themes was discussed with the NICRCF Chair, Margaret Grayson. Surveys were devised by the Ruth Boyd, NICTN/NICRCF PPI Professional Lead in consultation with Gail Johnston, HSC R&D Programme Manager and Sandra McCarry, Belfast HSC Trust Senior Manager Community Development and PPI, who then did not participate in the survey.

Questions were designed to ascertain information in the following categories:

- Evaluate existing experience of PPI in cancer research in Northern Ireland from a stakeholder perspective
- Evaluate if PPI objectives and standards are being met
- Identify areas for further development and gather recommendations to help inform a new cancer research PPI strategy

Each question was linked to a specific current or future objective e.g. evaluating achievement of objectives defined in the Strategy for PPI in Cancer Research in NI<sup>1</sup>, or achievement of NICRCF objectives, evaluation of PPI experience against current Public Health Agency PPI standards<sup>2</sup> and values.

Surveys were tailored for 3 key stakeholder groups:

- Cancer researchers in NI
- Personnel involved in cancer research management/strategy/conduct in NI
- Members of the NICRCF

Copies of the Researcher cover message and the Word version of the Researcher Survey are found in appendix 1 and 2 respectively. The Word surveys were transposed to SmartSurvey™ by Cillian McGinn, Digital Communications Officer, BHSCT. This format was utilised to assure participant anonymity, improve participant experience and facilitate collation of survey data.

## Survey Distribution

Participant e-mail distribution lists were generated pragmatically.

The aim was to target, not only researchers known to be involved with PPI, but incorporate potential researchers and cancer researchers over the past 6 years according to registration with NICTN and QUB, UU role profiles (e.g. Investigators and Research Fellows). It was noted all researcher e-mail addresses were within the public sector.

The research management/strategy/conduct survey mailing list was generated from NICTN staff and members of the NICTN Steering Group and HSC R&D Research Directors/Managers across HSC. *Note: for ease of reference in this document, this stakeholder category will be referred to as ‘**Research Support**’ for the remainder of the document.*

It is acknowledged that researchers, research support and, in particular, funders are not comprehensively represented through the survey process, however, due to time and resource constraints it was deemed unrealistic to source contacts across all charities, companies and relevant bodies. The intention of the survey was to focus on the practical delivery of PPI in cancer research across the research cycle. Wider engagement on PPI in cancer research in NI is planned through consultation on the new PPI strategy for cancer research in NI in 2018.

The survey was sent to all NICRCF current members.

## SURVEY RESULTS

### Survey Distribution and Participation

Surveys were distributed via a SmartSurvey™ link to the 3 stakeholder group mailing lists on 05 December 2017. A reminder e-mail was sent to all groups on 14 December 2017. The survey closing date was 21 December 2017.

Surveys were sent to:

- 175 cancer researchers
- 71 research support personnel
- 22 NICRCF members

Four 'Researcher' messages were returned 'undeliverable', and two further notifications were received stating the recipient was no longer in post. These were also classified as not delivered.

### Survey Response Rates

Response rates were **low**:

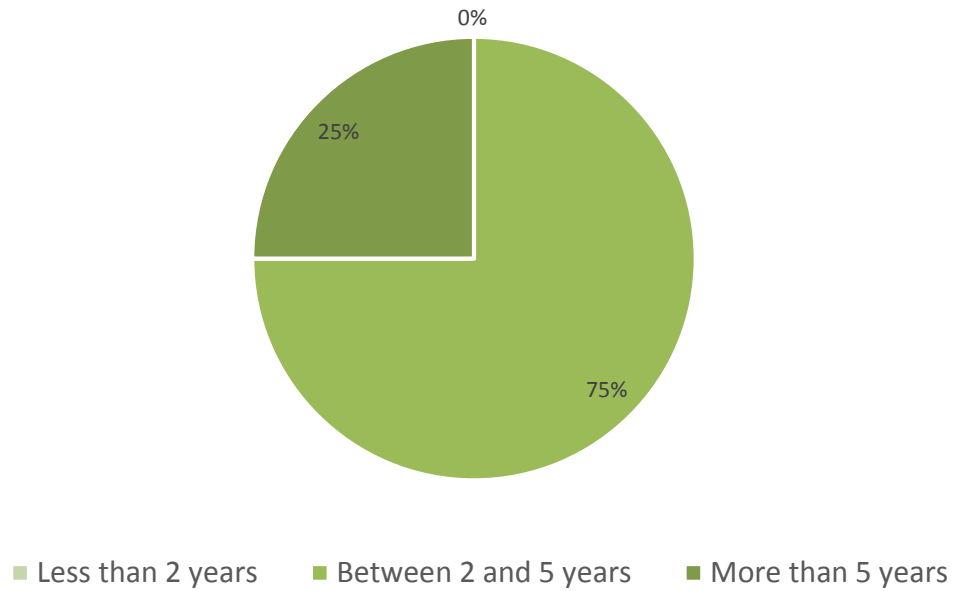
| Stakeholder Group  | Surveys Delivered | Number of Respondents | Response Rate % |
|--------------------|-------------------|-----------------------|-----------------|
| Cancer Researchers | 169               | 30                    | 17.8            |
| Research Support   | 71                | 10                    | 14.1            |
| NICRCF Members     | 22                | 8                     | 36.4            |
| <b>TOTAL</b>       | <b>262</b>        | <b>48</b>             | <b>18.3</b>     |

### Survey Responses

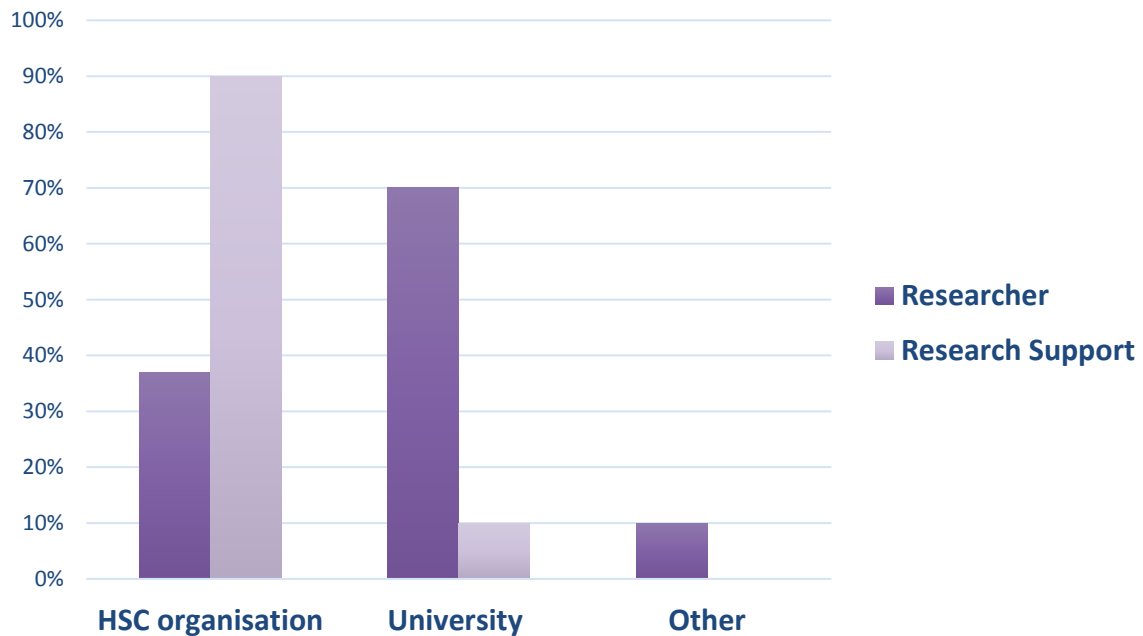
Below are the graphical representation of the results and comments for each of the questions in the survey. Where appropriate for evaluation-type questions, a 'thumbs-up' or a 'thumbs-down' is indicated at the topic title, demonstrating the perspective of the majority of the respondents.

## About Responders

### NICRCF: Length of NICRCF Membership

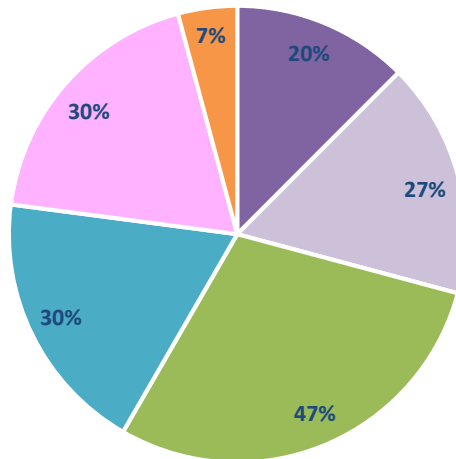


### Responder's Organisation (all that apply)



Researcher 'Other': Charity, AllHPC, Industry

### Researcher: Research Type (all that apply)

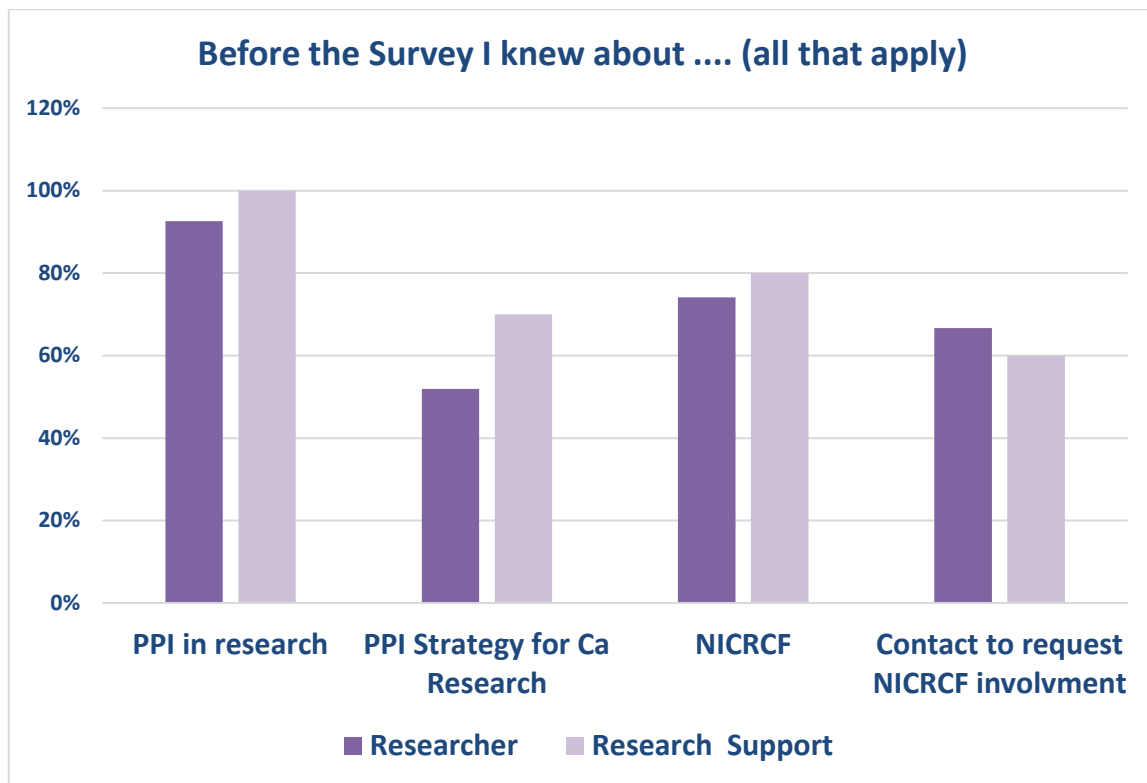


- Basic Research
- Clinical Trials
- Qualitative
- Translational research
- Population / Epidemiological
- Other

**Other:** Feasibility studies of clinical interventions, Knowledge Exchange



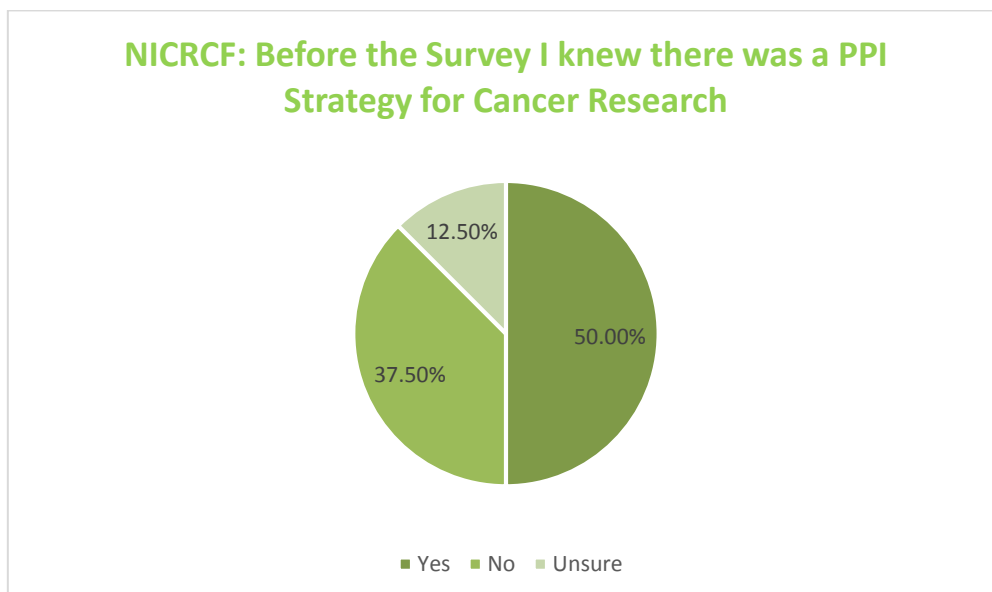
## PPI/NICRCF Awareness



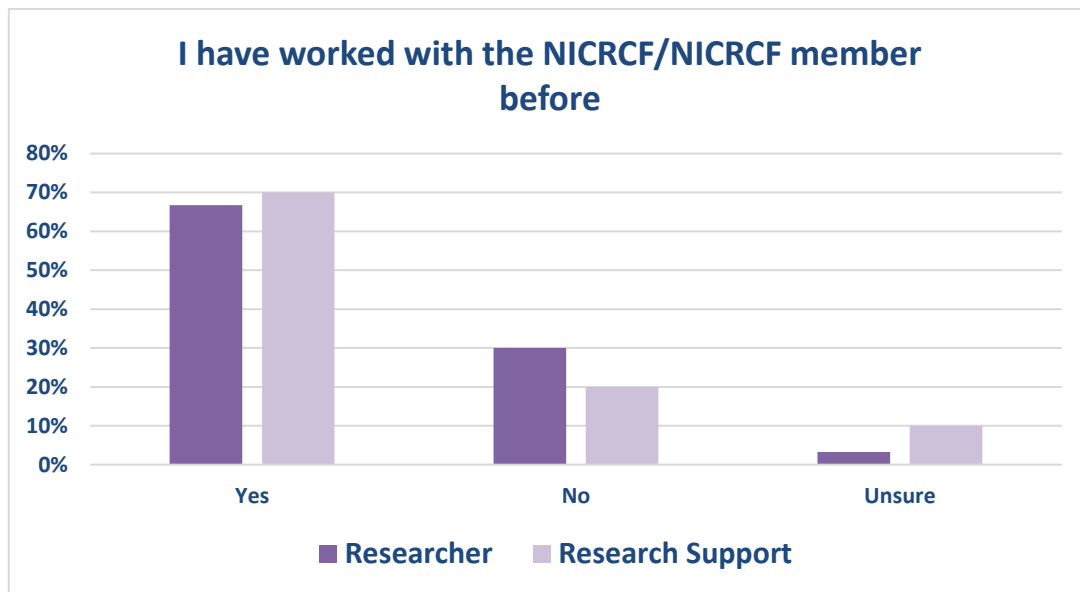
**Summary: Average awareness across all areas: 74.5%**

**Comment: Researchers** – ‘I have had the opportunity to work with the NICRCF on a number of occasions. Their input to our research projects was outstanding and provided a practical and real life look at research which we would have never got from academic papers.’

‘Within the charity we have a focus on service user involvement.’

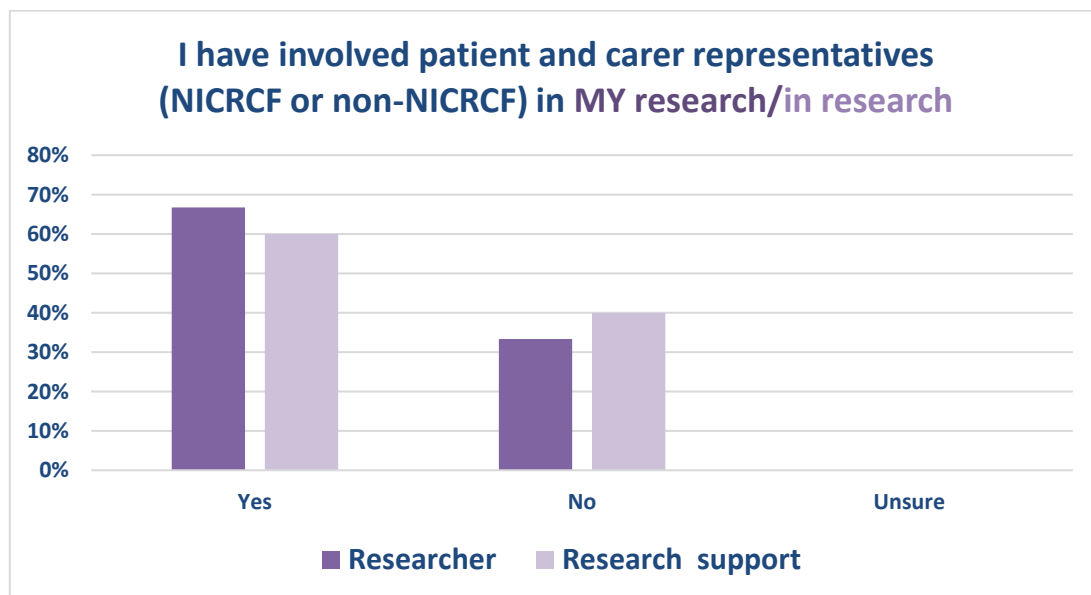


## Researcher/Research PPI/NICRCF Activity



**Summary: Average involvement with NICRCF 68.5%**

**Comment: Researcher** - *'I have had different PPI representatives inputting to aspects of my research from design through to dissemination.'*



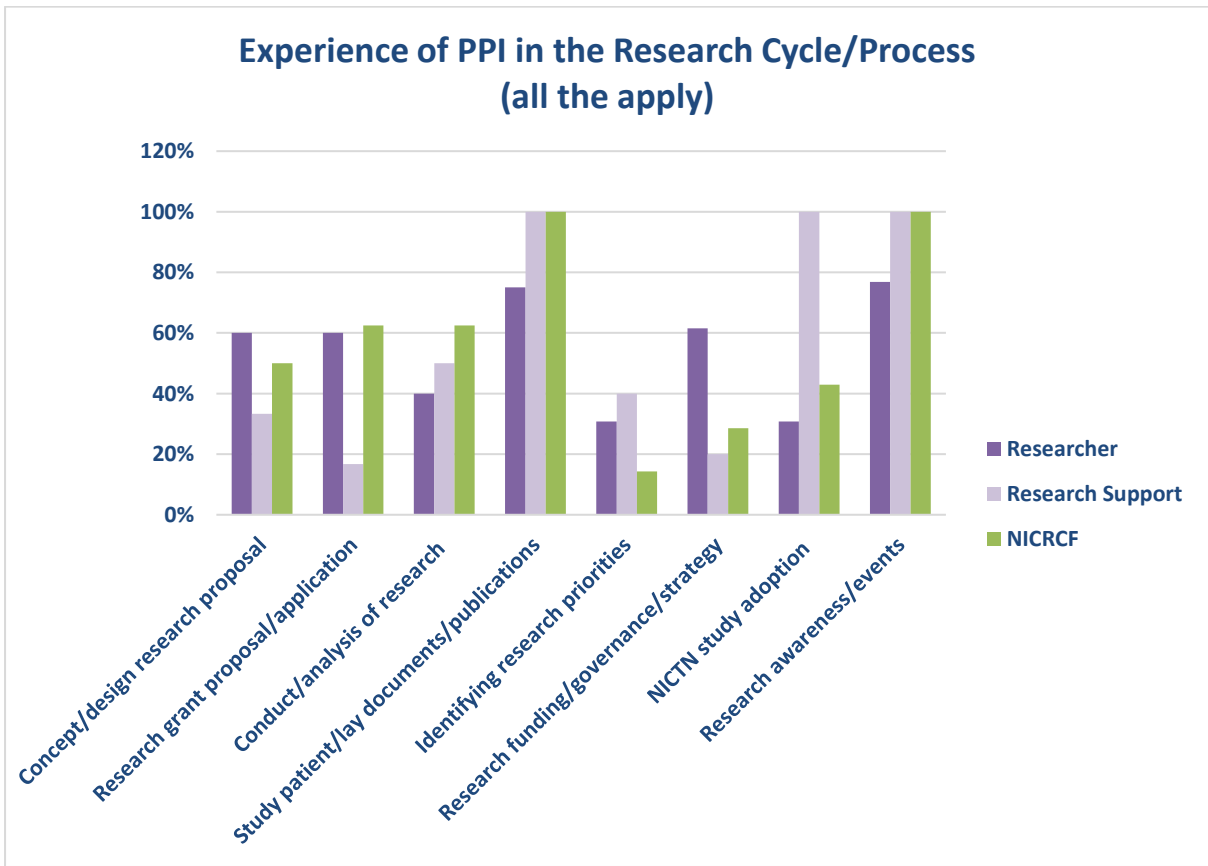
**Summary: Average NICRCF/non-NICRCF involvement in research 63.5%**

**Note:** Respondents who stated **'No'** to this question did not receive questions about their PPI activity or evaluation of PPI / NICRCF

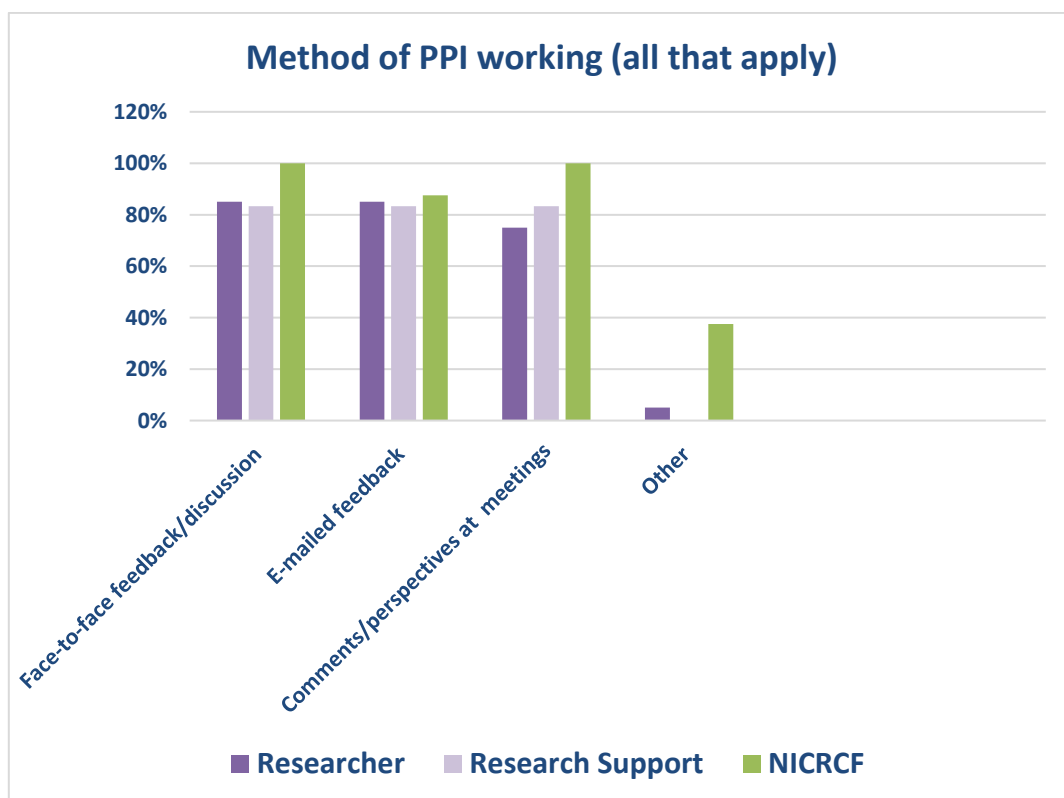
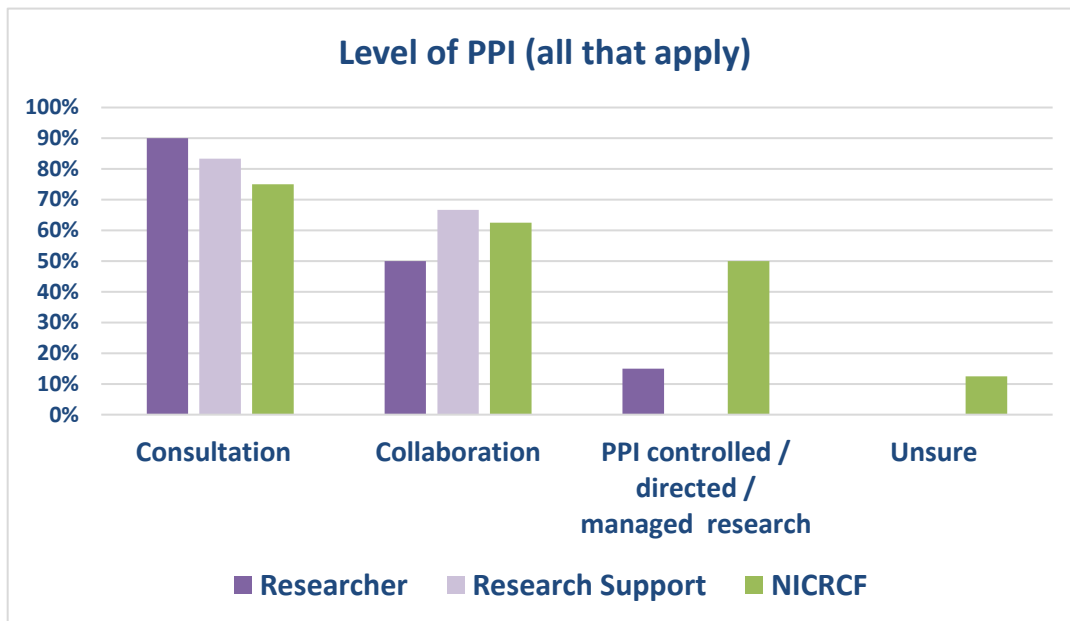
**Non-NICRCF** patient/carer representatives that researchers had worked with:

|  |   |
|--|---|
| Patient/carer/parent representatives         | Charitable Groups                                 |
| Patient student educators                    | Support Groups                                    |
| PPI Representatives on national trial groups | National Cancer Research Institute Consumer Forum |
| Young adult survivors                        | Voices4Care (AllHPC)                              |

**PPI across the Research Cycle/Process**

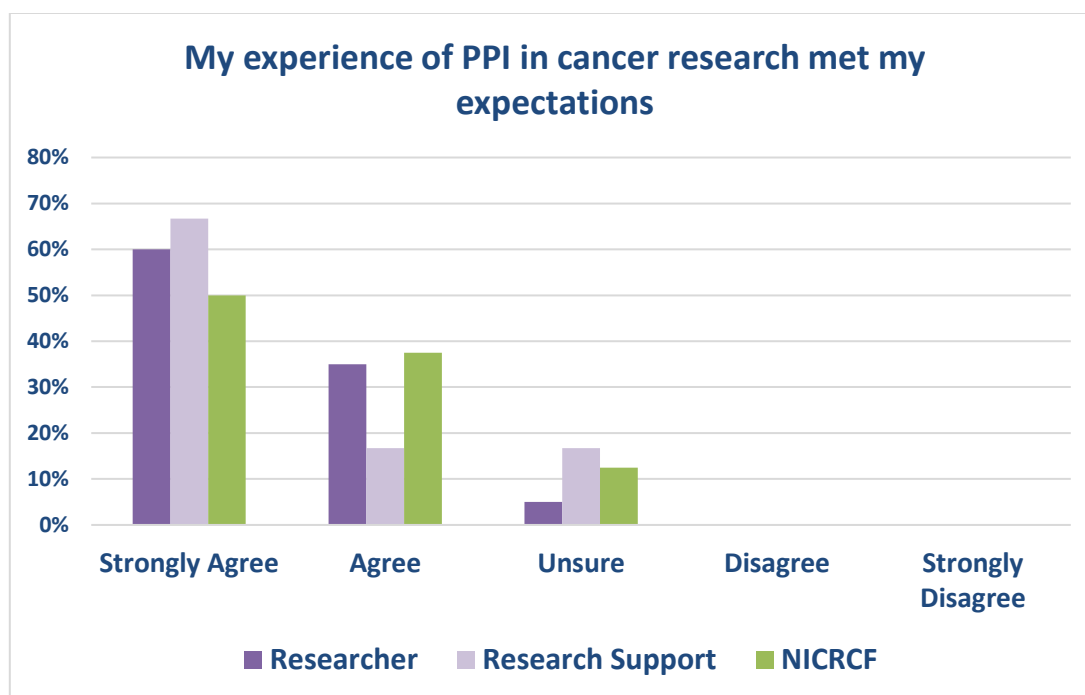


## Level and Methods of Involvement



**Other:** Researcher - 'Being supported by encouragement and advocacy to conduct clinical trials.'  
 NICRCF not described.

## Did Experience of PPI Meet Expectations?



**Summary: Average Agree 89%, Unsure 11%, Disagree 0%**

**Comments: NICRF Members** – *‘As I really had no idea what would be involved, I have been happy with the amount of involvement I have had.’*

*‘Would like more feedback when we review documents etc. by email. You never know if you are doing a good job or not and whether it has any impact.’*

**Research Support** – *‘Even more valuable than originally would have anticipated.’*

**Researchers** – *‘It has far exceeded my expectations and has had profound effects on my thinking towards research in general.’*

*‘Exceeded my expectations. I met a wide range of interesting and diverse individuals who really taught me a lot, even as an experienced healthcare professional.’*

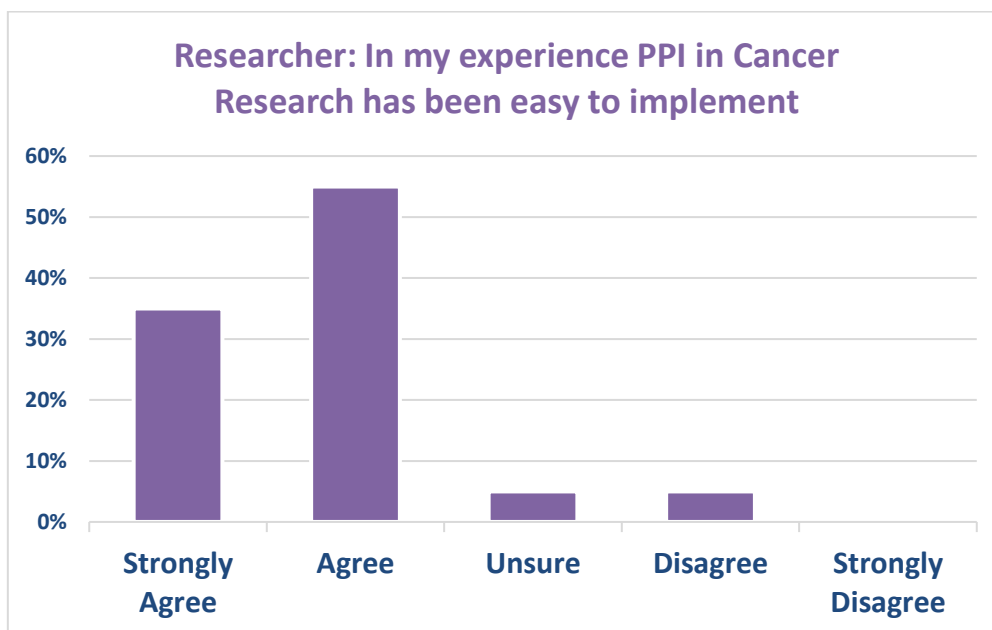
*‘I think that it's hard for PPI group members to give feedback to researchers - I guess I would like more guidance as to research priorities and what matters most.’*

*‘I cannot describe the input of the Forum more highly. They are a dedicated bunch who give depth and clinical relevance to research. What they have taught me about research .. no book or lecture ever could.’*

*‘I think I have more of a responsibility to work collaboratively with PPI representatives to develop research agendas which may lead to funded applications rather than in a consulting capacity.’*

*‘PPI involvement was key to my research project and it was on my agenda from the beginning, but the contribution they made to the wording and structure was invaluable.’*

## Did Researchers find PPI Easy to Implement?



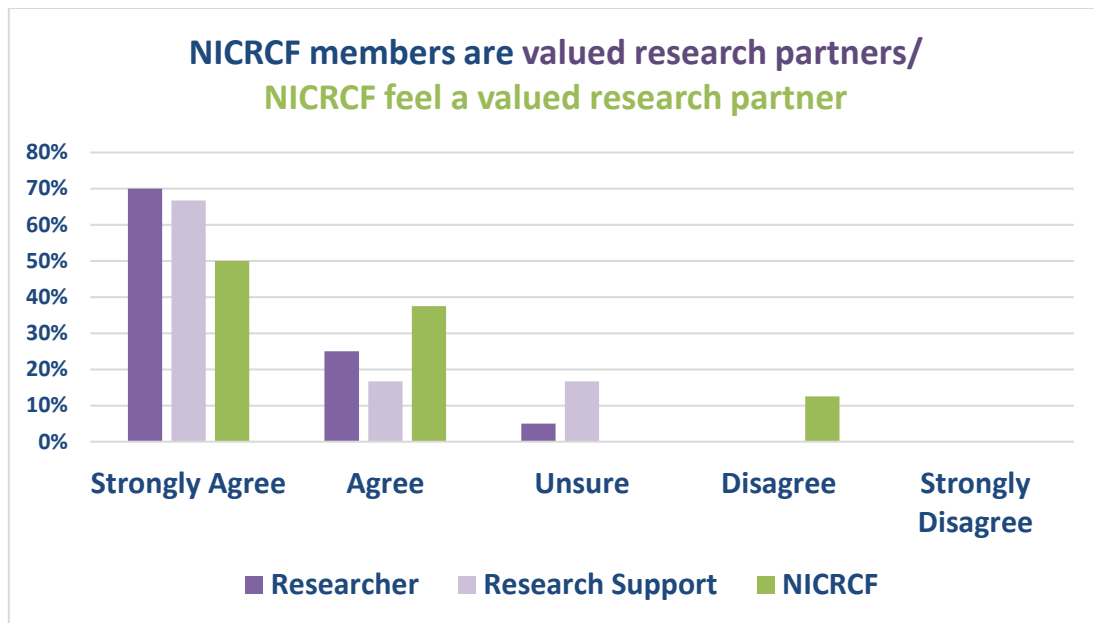
**Comments:** *'The NICRCF are extremely committed to supporting researchers.'*

*'The forum are easy to work with and committed. Ruth , Margaret and the team make it easy.'*

*'Not from the perspective of not being able to contact/not being useful - its just that we work mostly with secondary analysis of existing datasets and so there are fewer opportunities to develop collaborative rather than consultative PPI interactions.'*

*'Our young people are heavily involved in participation within the charity and we have representatives from NI sit on a Young Person's Reference Group in London. There is a keen interest within this age group to 'give back' and 'be involved'. We also promote PPI as a great skill to mention in job and university applications.'*

## Are NICRCF Members Valued?



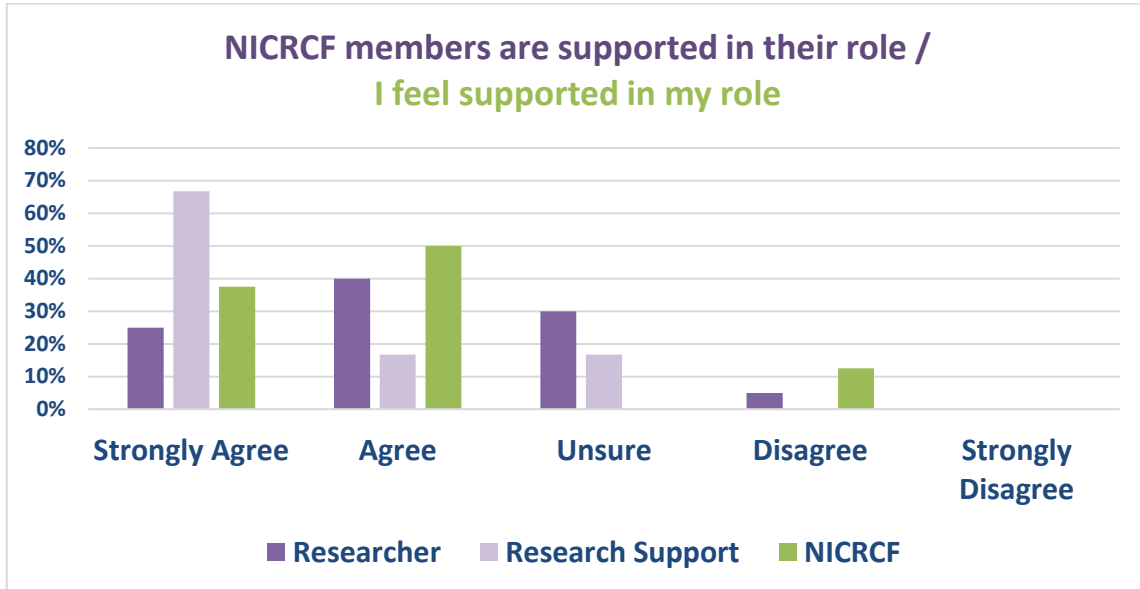
**Summary: Average Agree 89%, Unsure 7%, Disagree 4%**

**Comments: Researchers** – *‘Highly supportive group!’*

*‘NICRCF and other PPI representatives are highly valued by myself and my colleagues yet I do feel that their skills are still underutilised by many.’*

*‘I think I need to do more work on involving them more in the early stages of research development.’*

## Are NICRCF Members Supported in the Role?

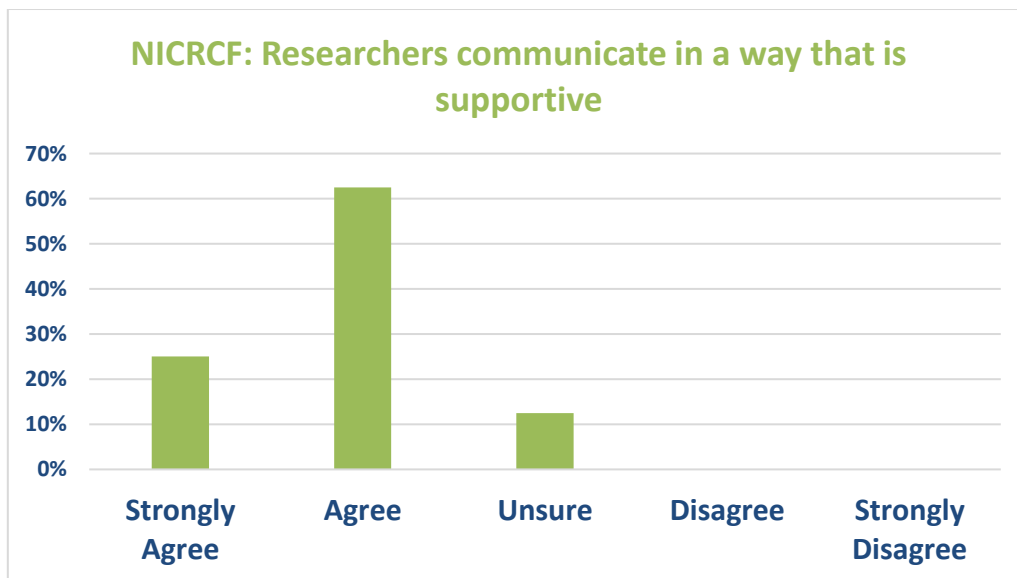


Summary: Average Agree 79%, Unsure 16%, Disagree 5%

**Comments: Researchers** – ‘NICRCF needs more direct support and an increased membership.’

‘Ruth and Margaret are fantastic ambassadors for PPI and it is their leadership and enthusiasm that makes the NICRCF such a success in my view.’

‘I’m afraid I don’t know for this one - do they feel supported?’

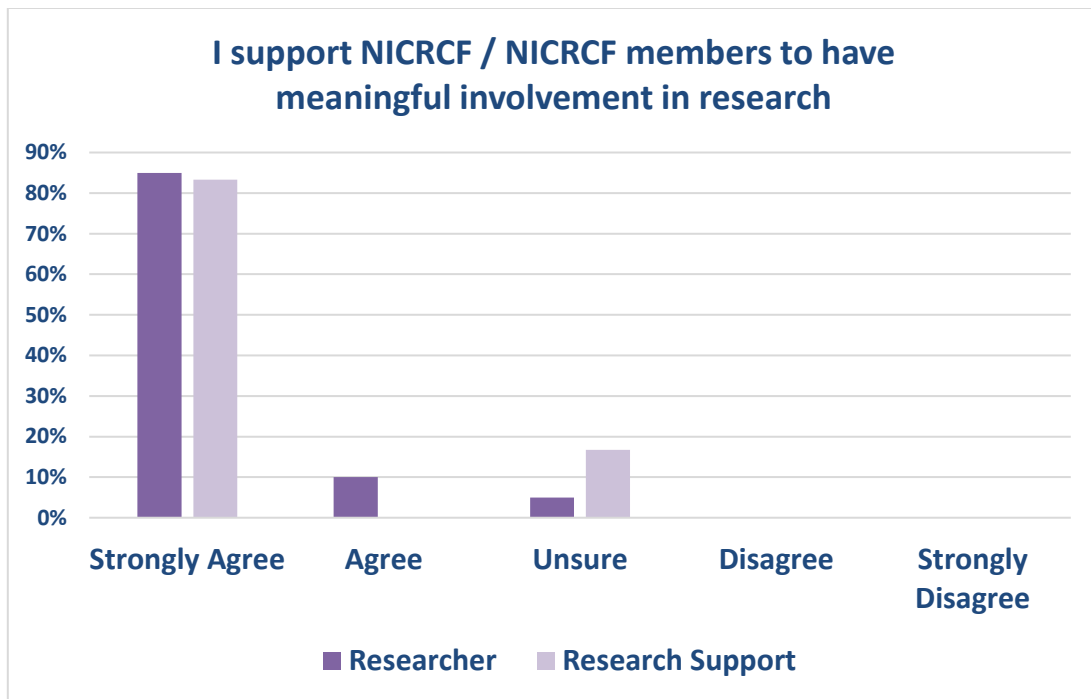


**Comments:** ‘I have found this to be so.’

‘Sometimes.’

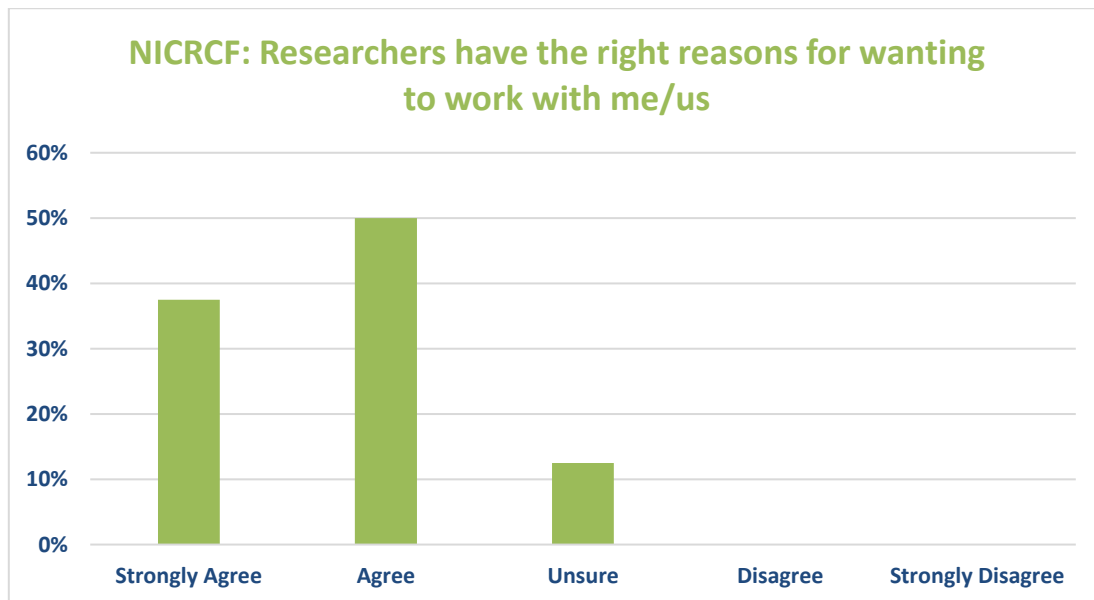


## Is Involvement Meaningful?



Summary: Average Agree 89%, Unsure 11%, Disagree 0%

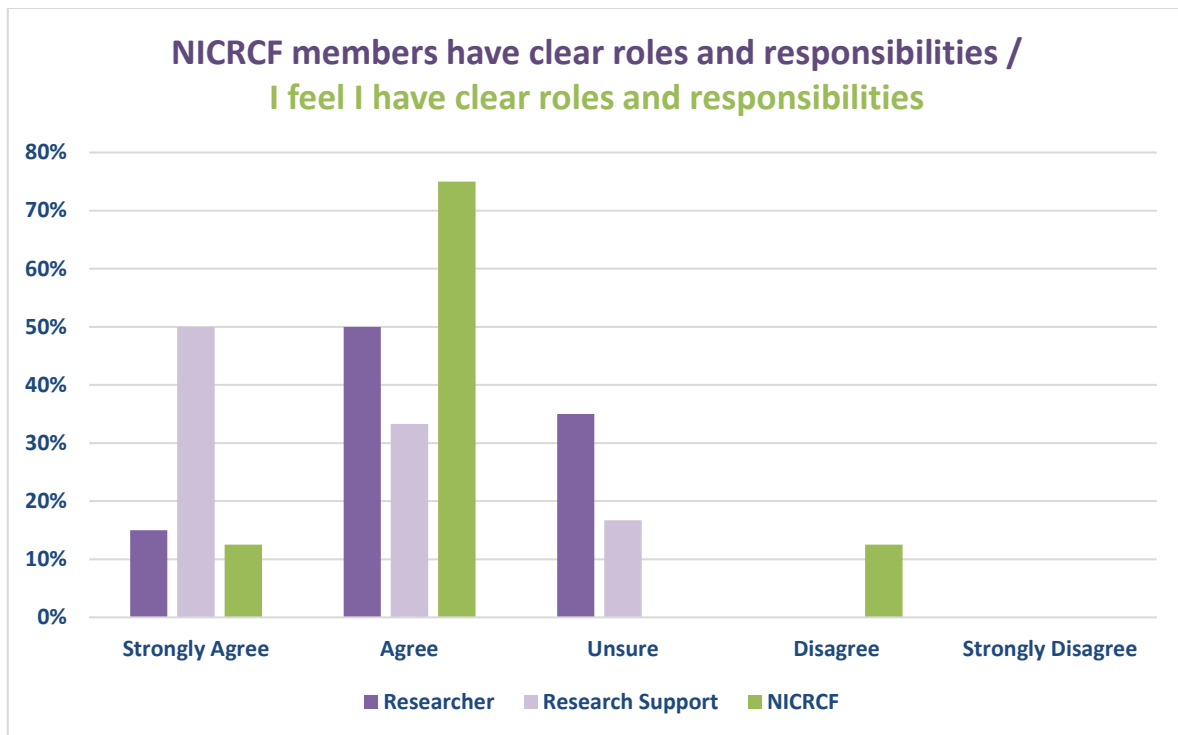
**Comment: Researcher** – ‘I could make more effort to work collaboratively rather than in a consulting relationship.’



**Comments:** ‘They genuinely seem to be interested in what we have to say and can improve their research as a result of consulting us.’

‘Some do some don’t in many cases they now have to do this to get grant funding but they don’t really see how it might benefit them.’

## Do NICRCF Members have Role Clarity?



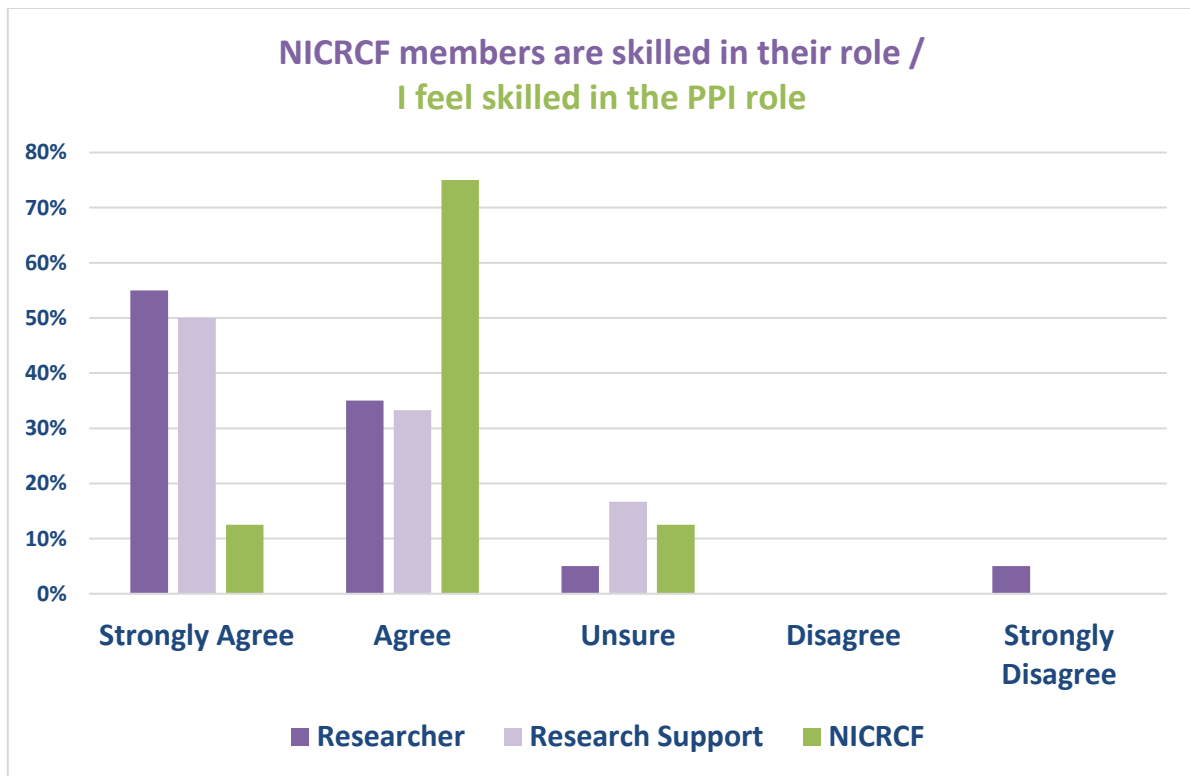
**Summary: Average Agree 79%, Unsure 17%, Disagree 4%**

**Comments: NICRCF Member** – *‘When you work on a specific project its fine otherwise it can be very woolly.’*

**Research Support** – *‘Some members have a clearer understanding regarding their role than others. But through training and support these roles do become clearer.’*

**Researcher** – *‘I haven’t seen the current NICRCF member guidance to be able to comment on this.’*

## Are NICRCF Members skilled in their role?



**Summary: Average Agree 87%, Unsure 11%, Disagree 2%**

**Comments: NICRCF Member** – *‘I do my best and hope that it is useful.’*

**Research Support** – *‘The vast majority of NICRCF clearly are skilled in their role.’*

**Researchers** – *‘Members of the NICRCF who I have had the opportunity to work with have all been highly effective and skilled in their roles.’*

*‘Some are highly skilled.’*

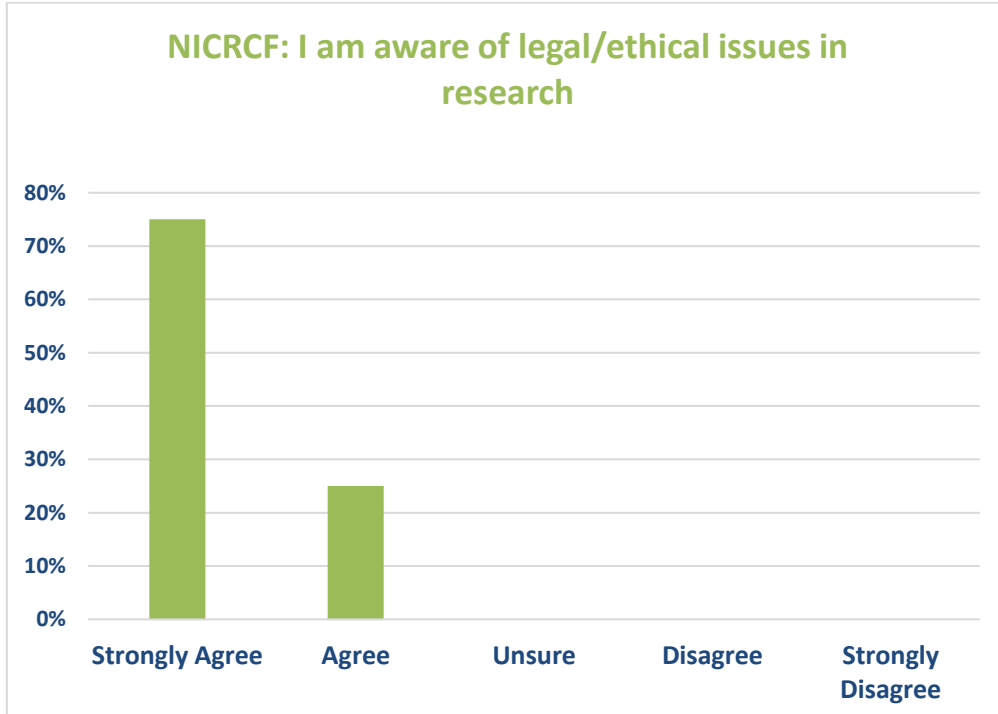
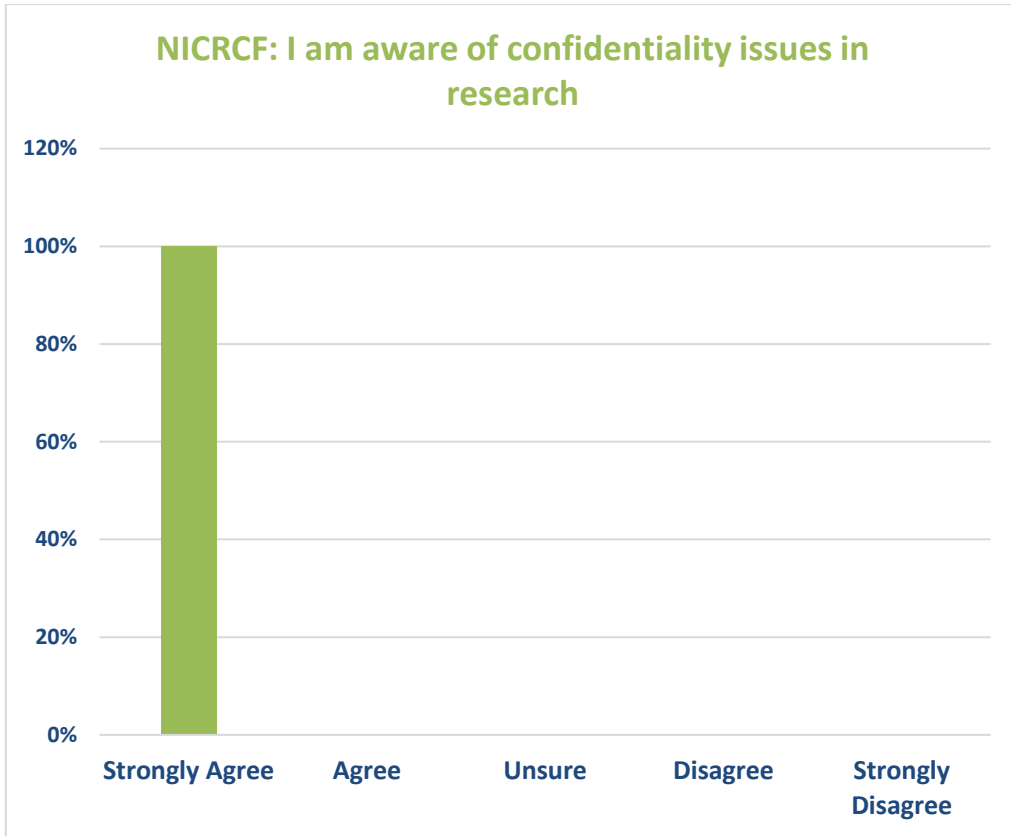
## NICRCF Member Awareness of Research Issues



**Summary: Average Agree 76%, Unsure 24%, Disagree 0%**

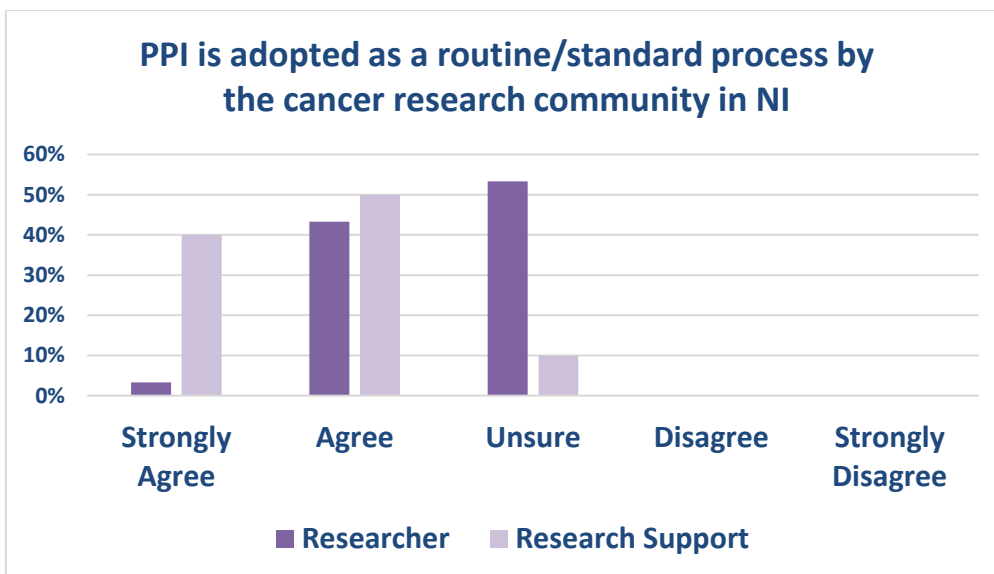
**Comments: Researchers** – *'I have had no concerns about any breaches in confidentiality or ethical issues in relation to any dealings with NICRCF.'*

*'I personally always make sure that they are very informed of these issues.'*



**Comment:** *'However I would welcome training in law and ethics in relation to all of this.'*

## Is PPI Embedded into Practice?



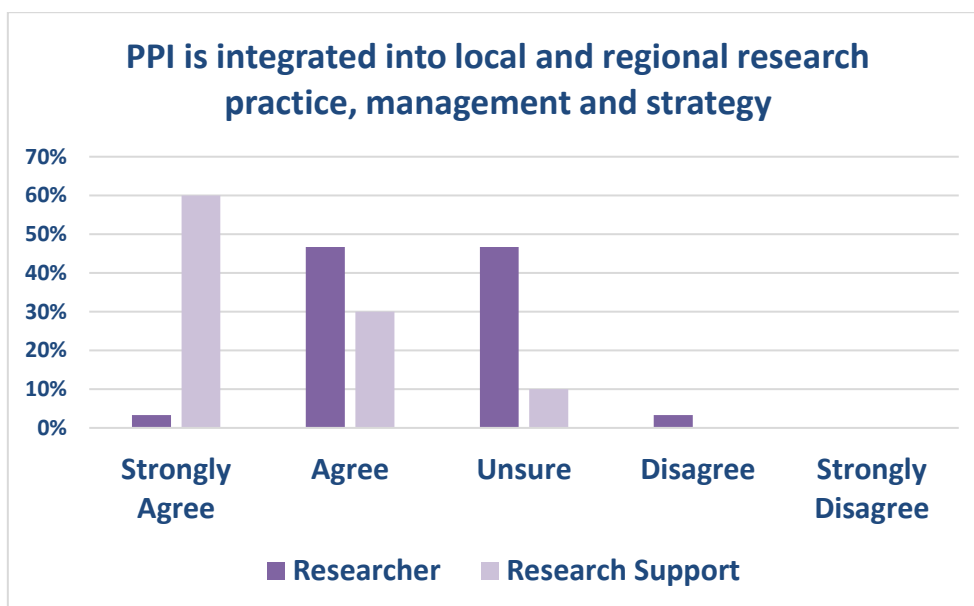
**Summary: Average Agree 68%, Unsure 32%, Disagree 0%**

**Comments: Researchers** – *‘It is overwhelmingly adopted by some groups, but rather ignored by others (usually those who have never seen the benefits of it)’*

*‘I think it varies by research group as to how much collaboration exists with PPI.’*

*‘From my understanding, NI seems to take a strong lead in encouraging PPI involvement in research.’*

*‘It is getting there but I am not sure it is fully implemented throughout cancer research.’*



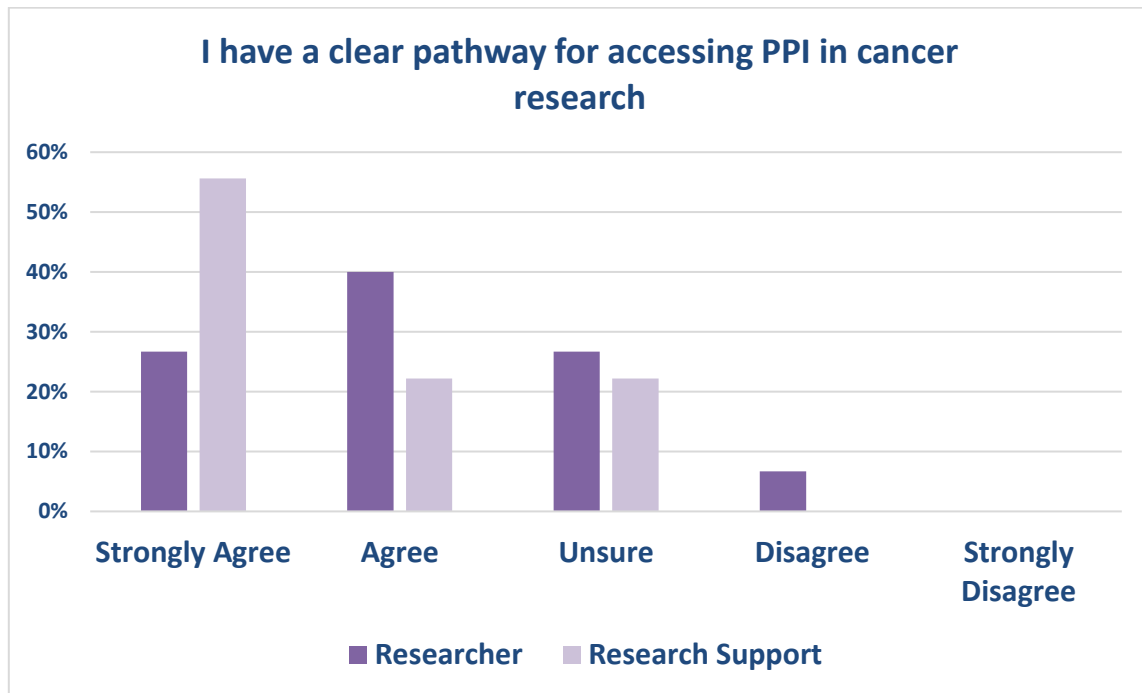
**Summary: Average Agree 70%, Unsure 29%, Disagree 1%**

**Comments: Research Support** - *'If some of the cancer research community don't then they should!'*

**Researchers** – *'Again, similar to previous comment, I think there are opposing extremes to this answer.'*

*'As above.'*

*'Within our charity yes, but not sure within the management of HSC.'*

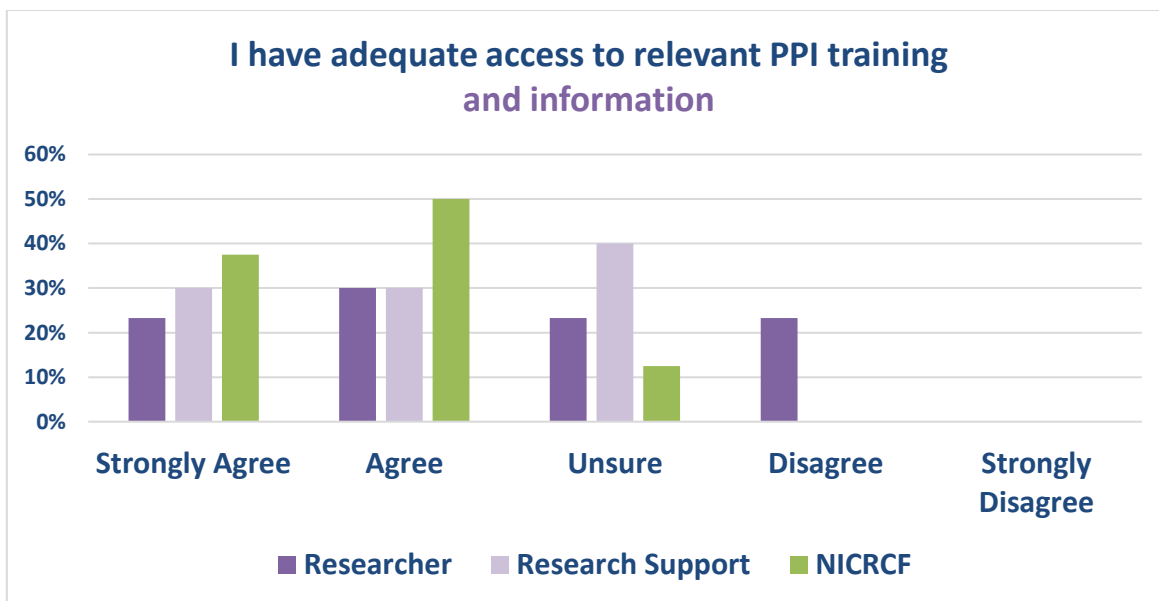


**Summary: Average Agree 72%, Unsure 25%, Disagree 3%**

**Comment: Researcher** - *'Gripp2\* used.'*

\*Guidance for Reporting Involvement of Patients and Public<sup>3</sup>

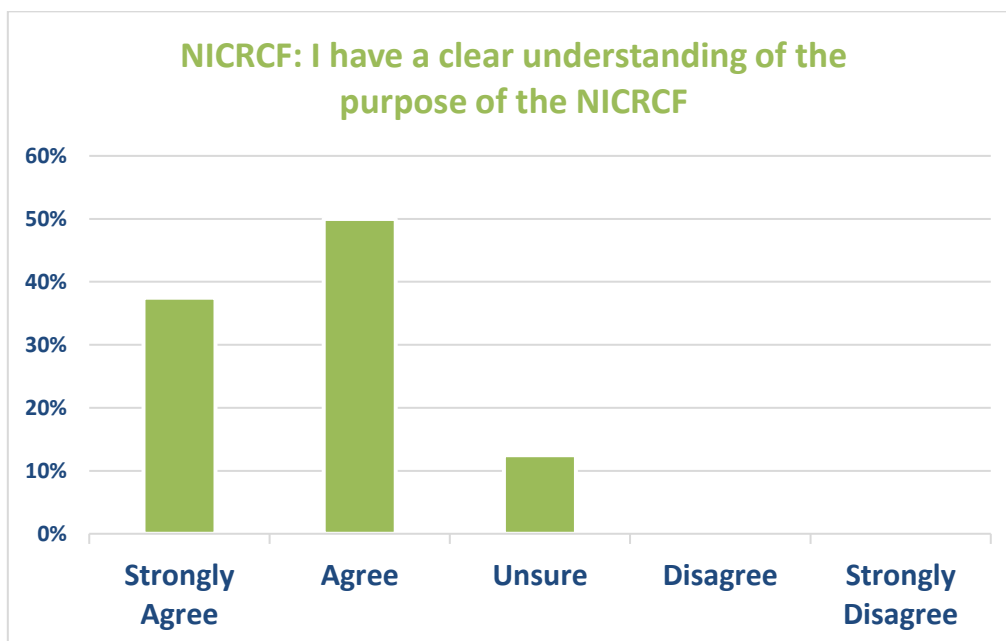
## Is PPI training adequate?



**Summary: Average Agree 67%, Unsure 25%, Disagree 8%**

**Comments: NICRCF Member** – ‘I would be really interested in some training now that I would be free to attend such.’

**Researcher** – ‘Given associations with an existing PPI network, I have accessed information in this way.’

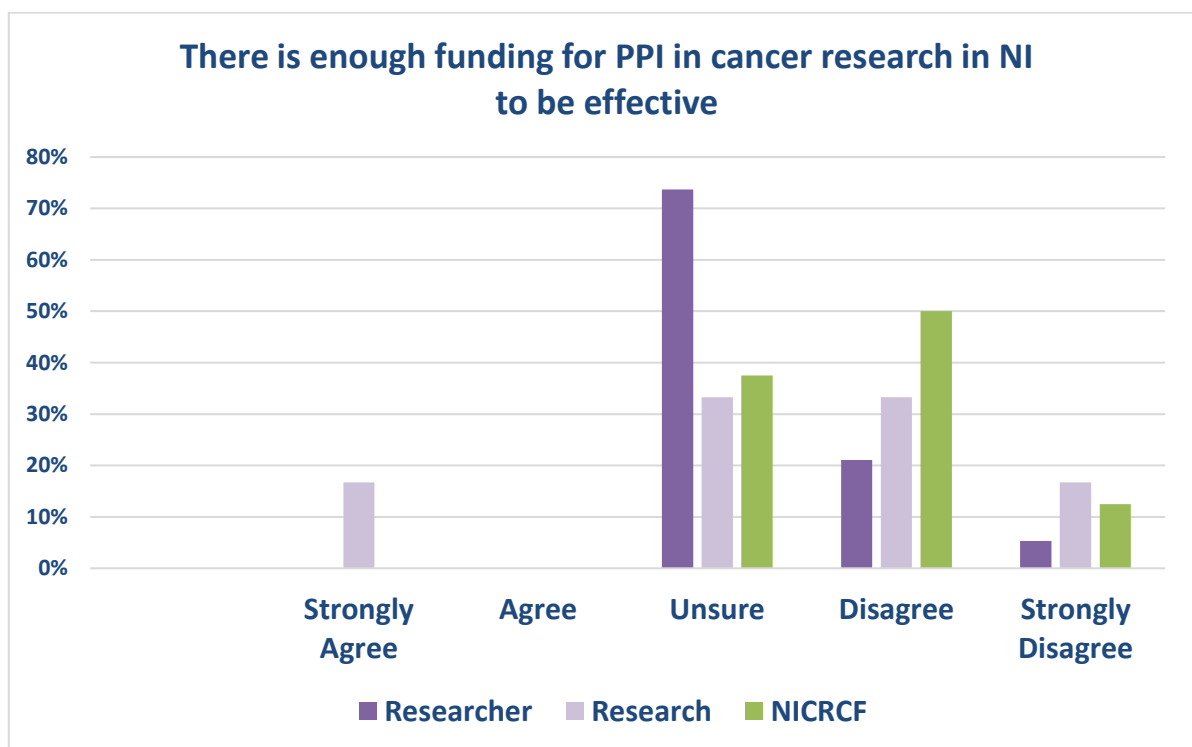


**Comments:** ‘I think we all do and even that grows with every meeting because we see all the different aspects.’

‘I know what we do but I'm not clear what is expected of us... the hierarchy.’



## Is there Enough Funding for PPI?



**Summary: Average Agree 6%, Unsure 48%, Disagree 46%**

**Comments: NICRCF Members** – *‘There is a distinct lack of funding. Our chair had no vice chair and has to take on so many commitments. There is a bit of a lack of understanding as to just how much a person who has previously suffered with cancer can physically take on!’*

*‘I hope so as it has been proved that PPI fulfills an essential role. I believe that although many members do not claim expenses this should be changed and all members attending meetings, training etc, should be paid expenses. Having to claim demeans the function of PPI.’*

*‘We need some sort of clerical support. a senior nurse should not have to spend so much time doing mundane administration. Emails are regularly sent at unsociable hours and at weekends - this should not be the norm nor should it be expected.’*

**Research Support** – *‘This hasn’t impacted on the contribution which they have provided, but more directed funding would help to develop further what could be achieved.’*

*‘Although NICRCF is highly effective, it is underfunded (not funded) and this needs to be addressed to allow continuation of the type of meetings/work they host and support.’*

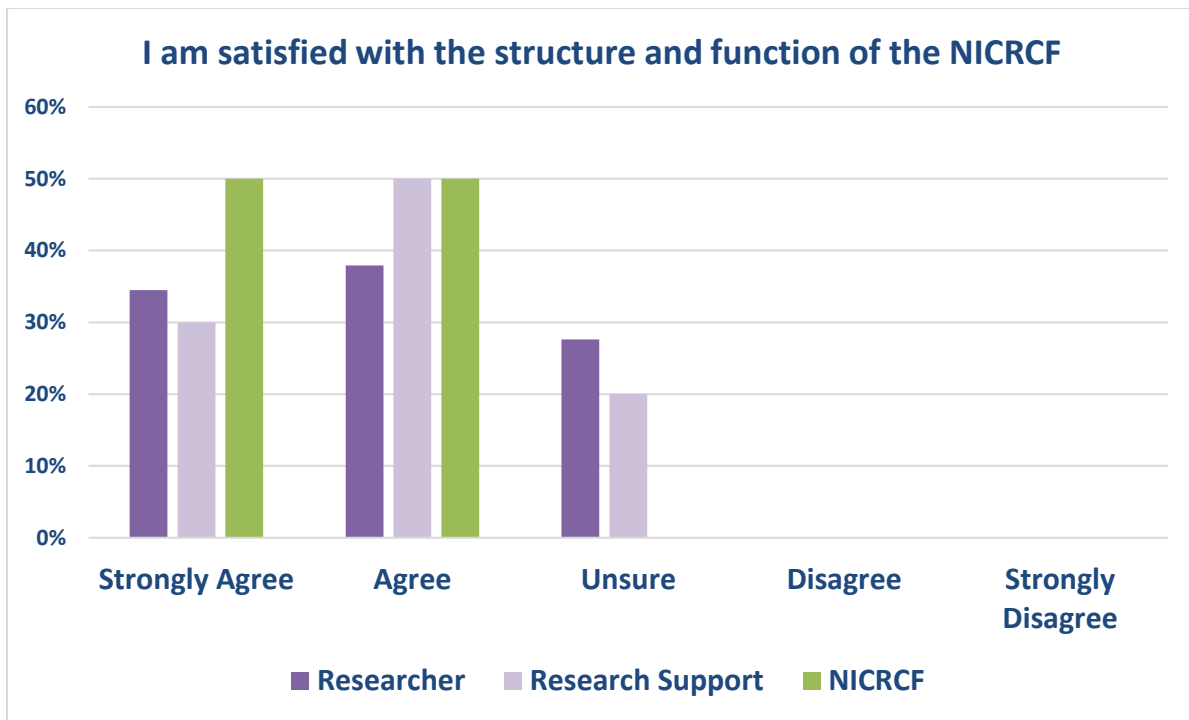
**Researchers** – *‘More funding is clearly needed!’*

*‘I think it is a combination of funding and mentorship support for researchers that is required to ensure that PPI is effective and not just a tick box exercise.’*

*‘I am not sure of how PPI is funded.’*

*‘Wasn’t aware of funding.’*

## Satisfaction with NICRCF Structure and Function?

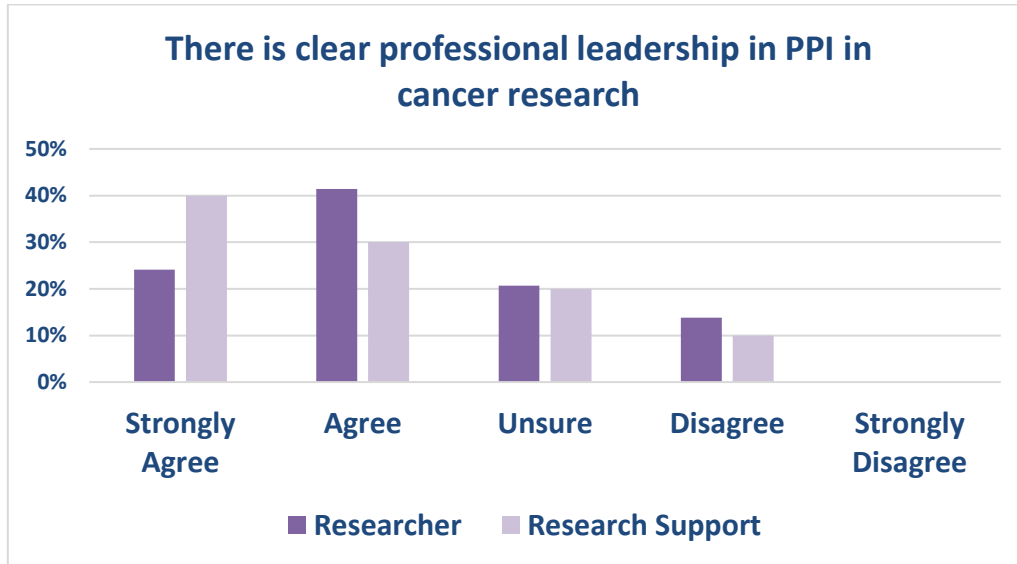


**Summary: Average Agree 84%, Unsure 16%, Disagree 0%**

**Comments:** **NICRCF member** - *'Would love to get collaboration with the WHSCT.'*

**Research Support** – *'But as with all services this should be kept under review to maintain standards.'*

## Leadership



**Summary: Average Agree 68%, Unsure 20%, Disagree 12%**

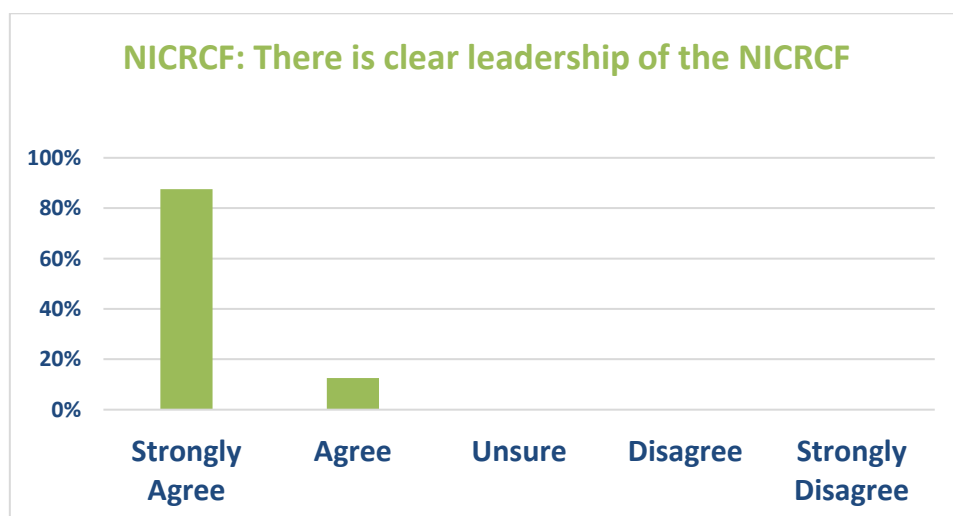
**Comments: Researchers** – ‘I know of the leadership in NI specifically, but not across the wider PPI leadership.’

‘Maybe too much professional PPI input.’

‘I think this again depends on which research group you are referring to.’

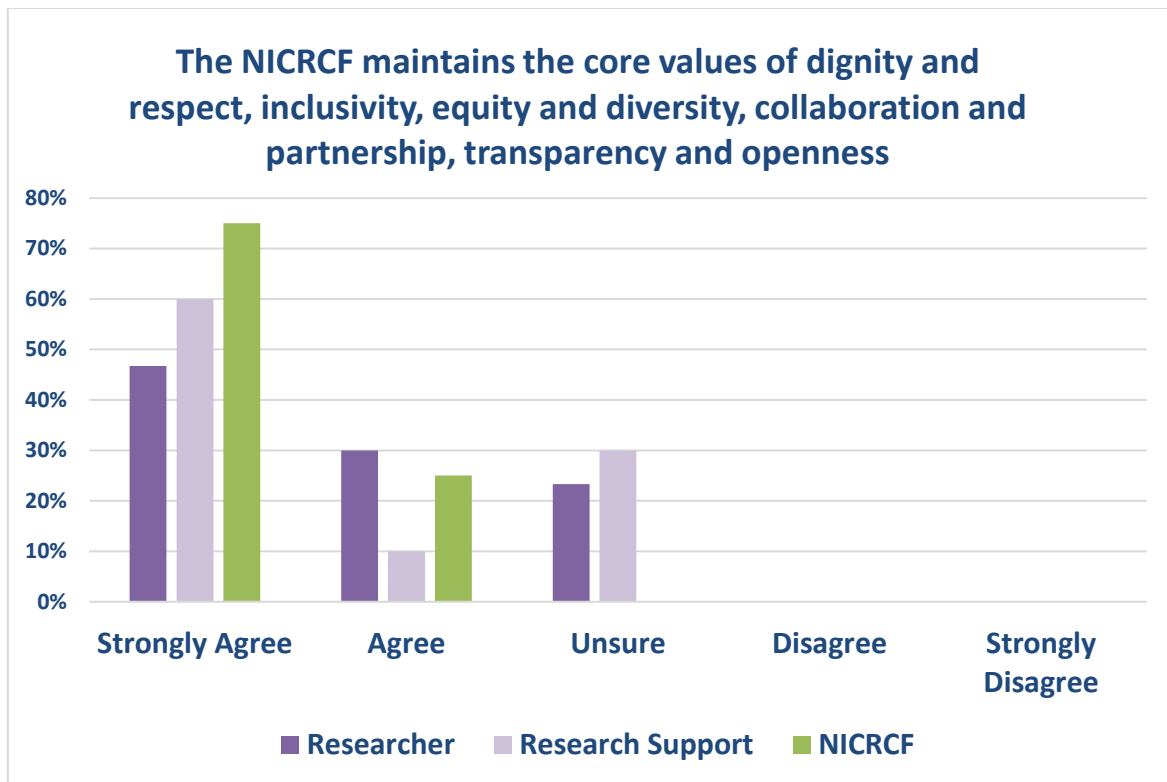
‘Margaret Grayson and Ruth Boyd!’

‘Ruth was a key advocate for including young people in research.’



**Comment:** ‘I take this opportunity to say what a wonderful job Ruth Boyd does. Her work is far above and beyond the call of duty, and if she were in the Services she would be given a Medal by HM the Queen.’

## NICRCF Values

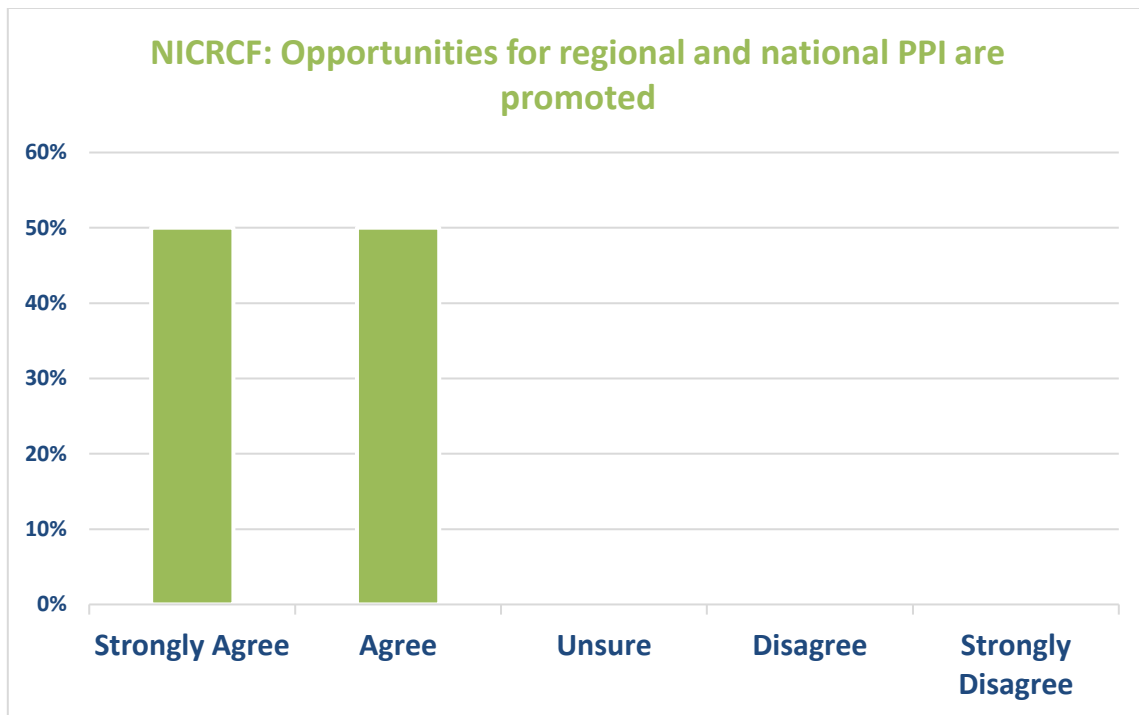


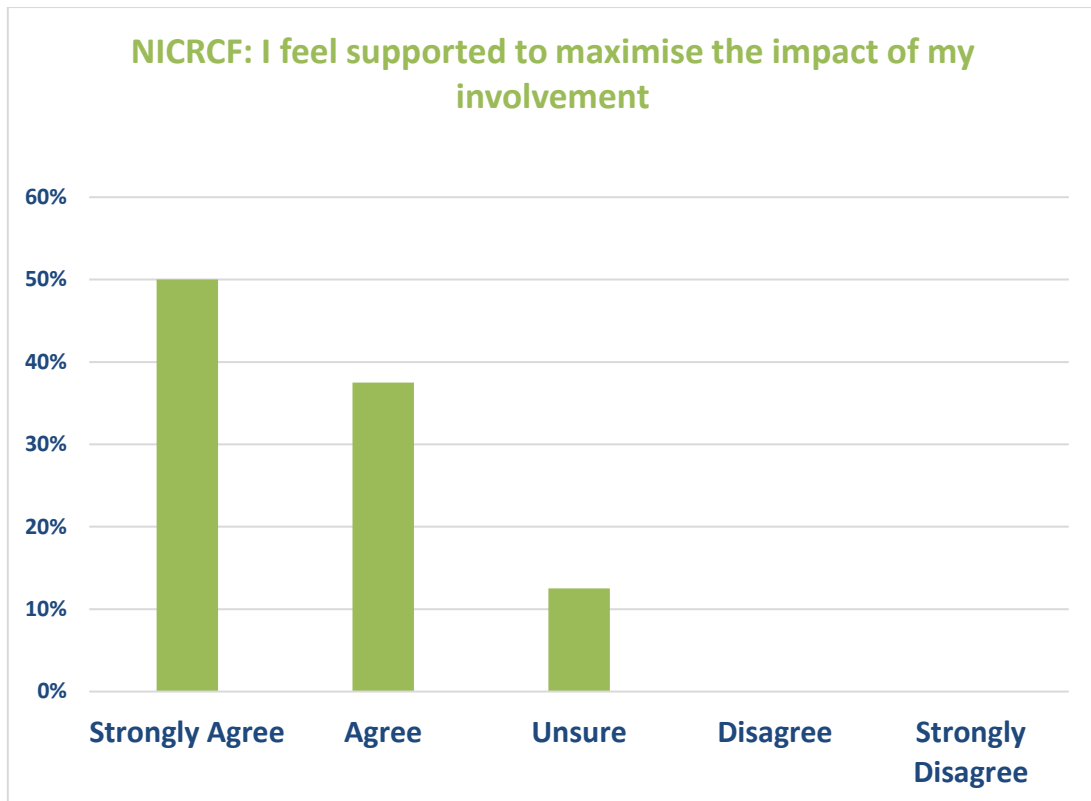
**Summary: Average Agree 82%, Unsure 18%, Disagree 0%**

**Comments: NICRCF member** – *‘This goes without saying.’*

**Researcher** – *‘Feel more collaboration is needed, I cannot speak to how diverse the group is.’*

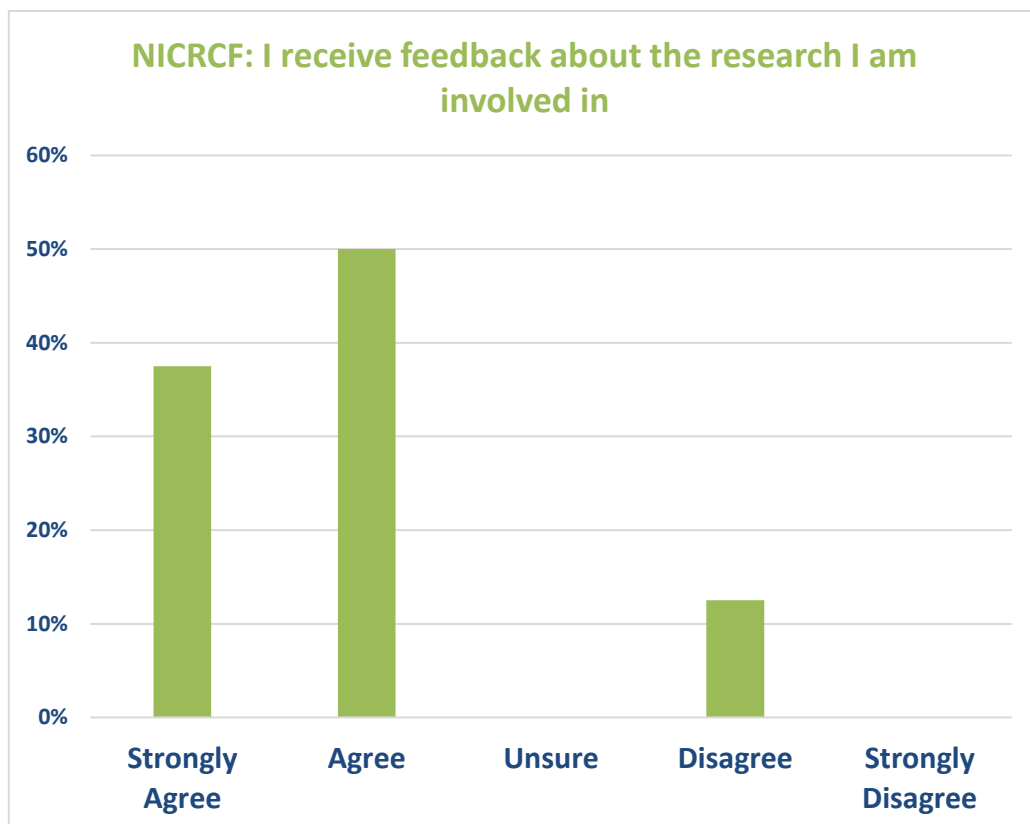
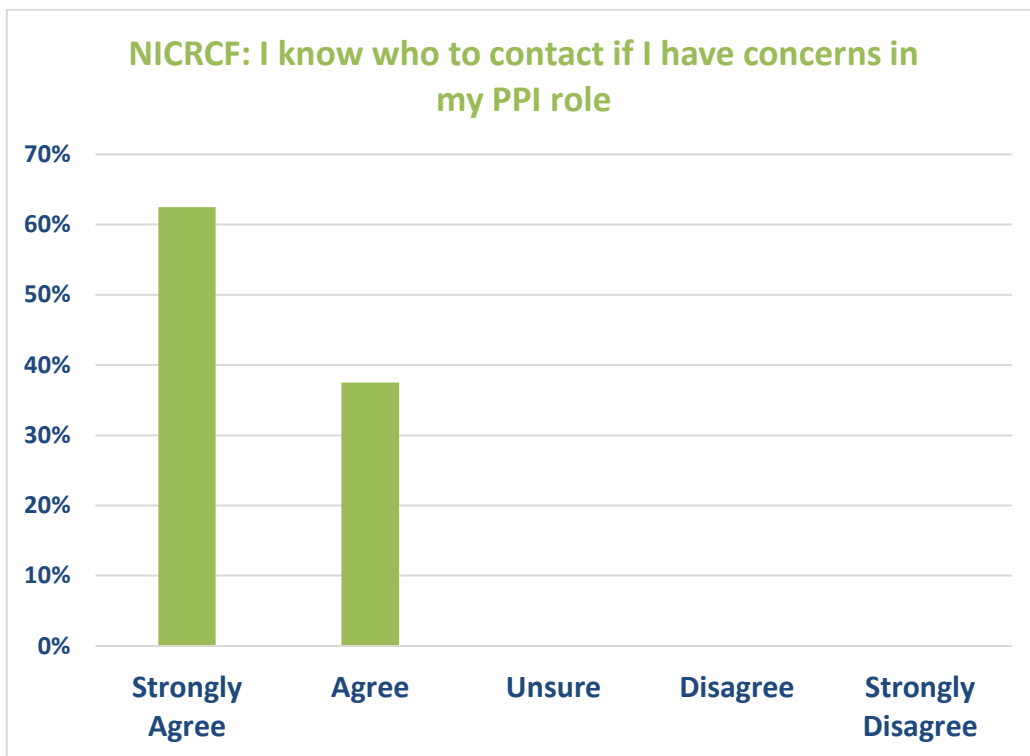
## NICRCF Member Opportunities



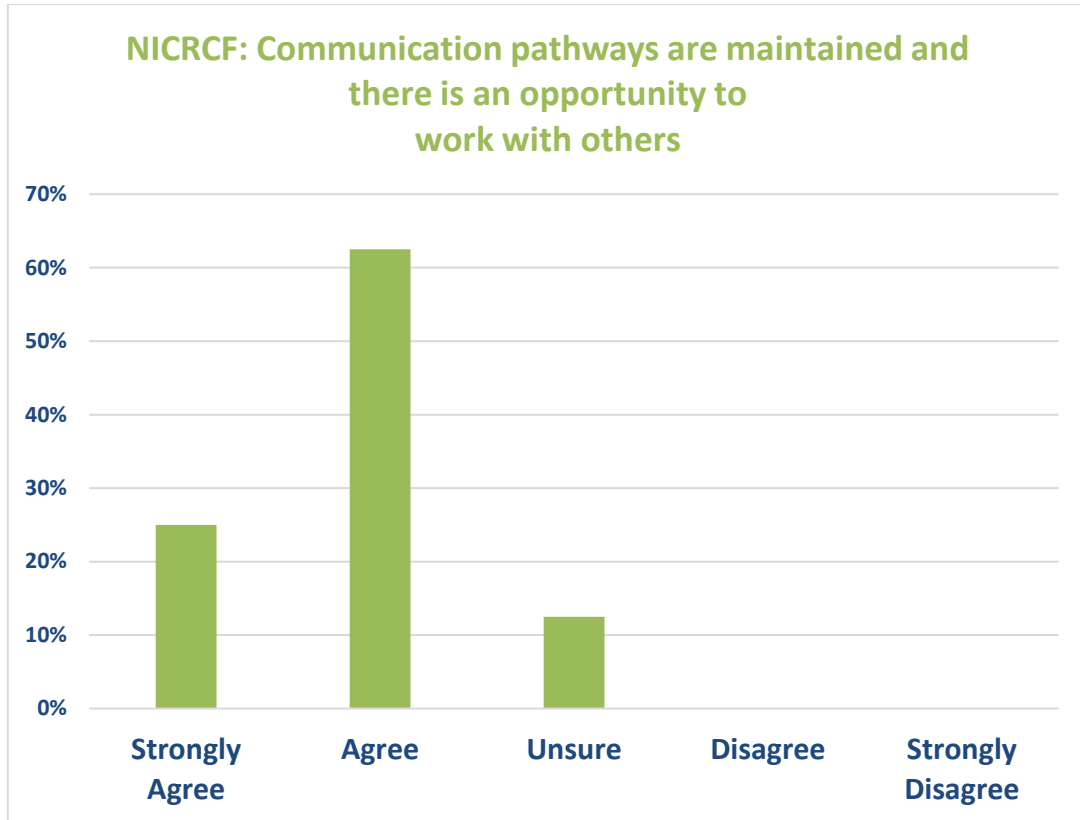


**Comments:** *'The Forum is so encouraging.'*  
*'You just get on with it.'*

## NICRCF Communication

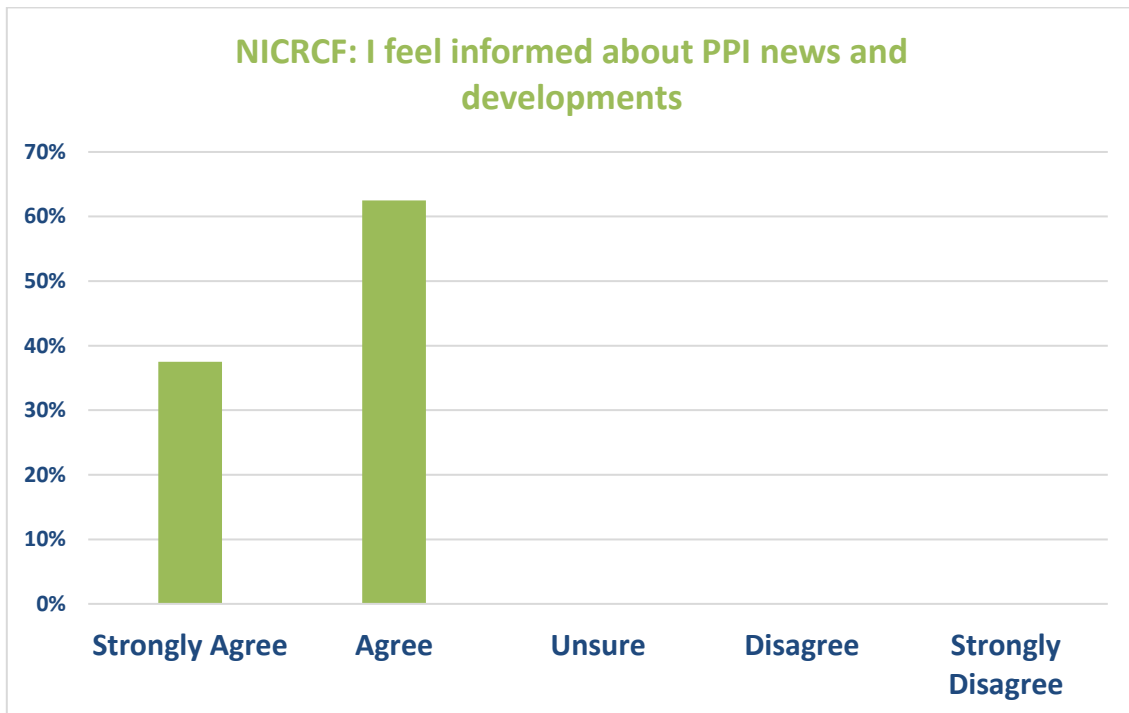


**Comment:** *'Sometimes!'*



**Comments:** *'Good communication within the forum but little contact with PPI in non-cancer fields.'*

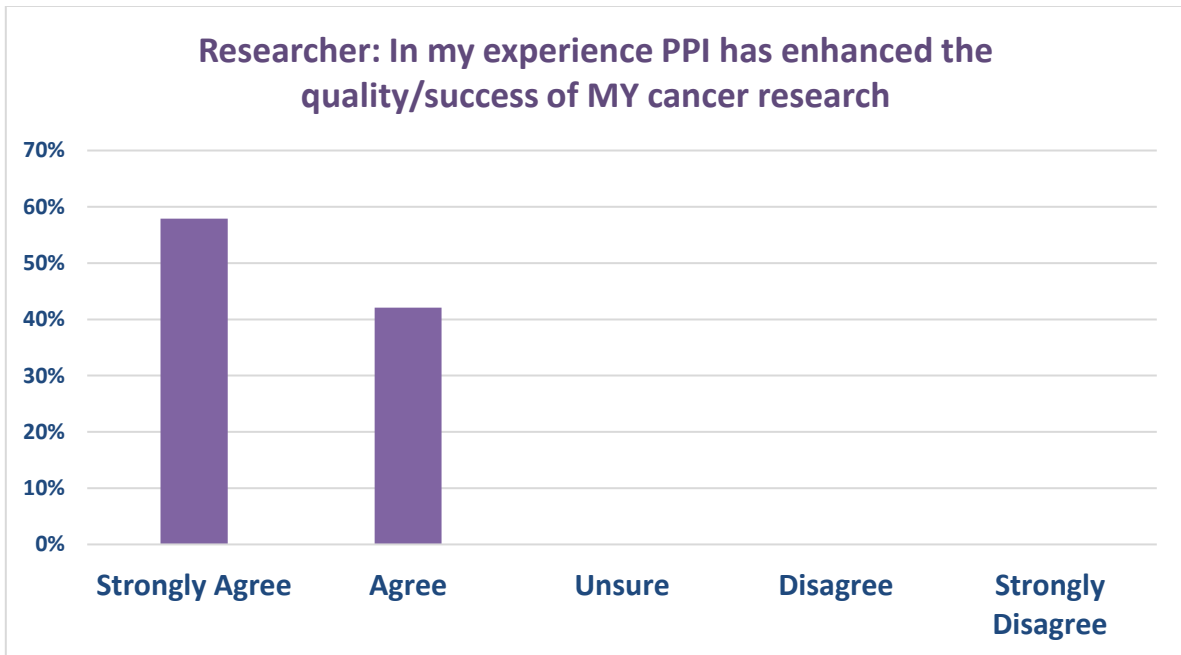
*'This is so important.'*



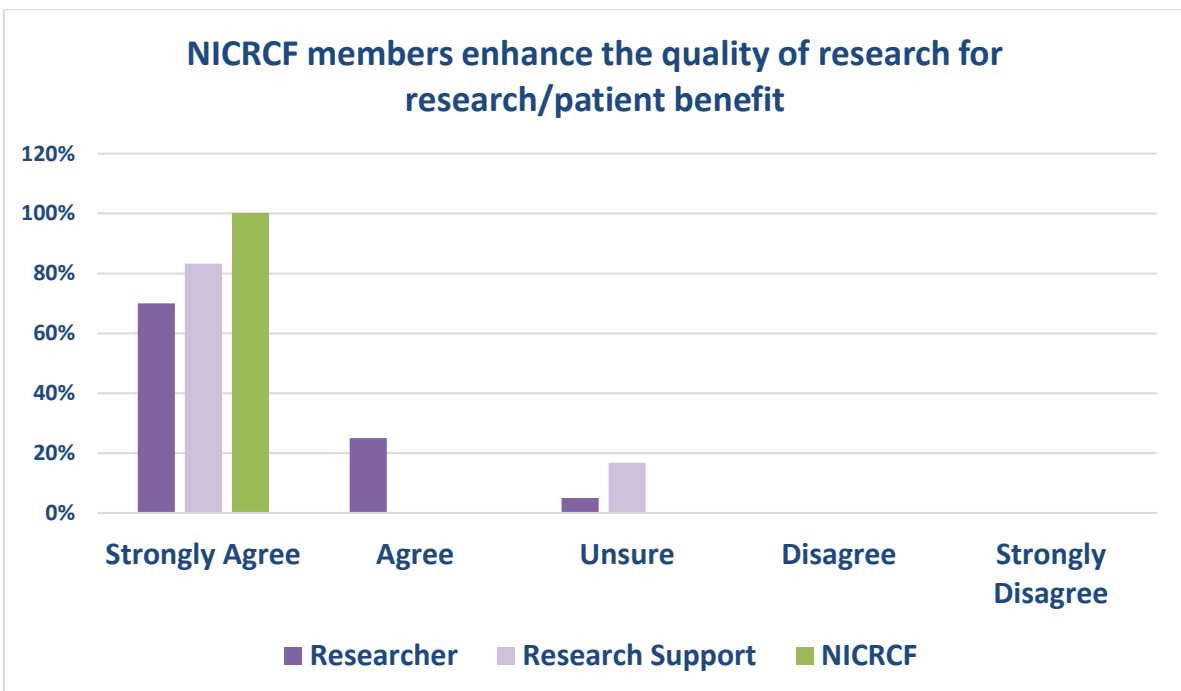
**Comment:** *'I would be happy to hear more.'*



## PPI Impact: Research Quality and Success

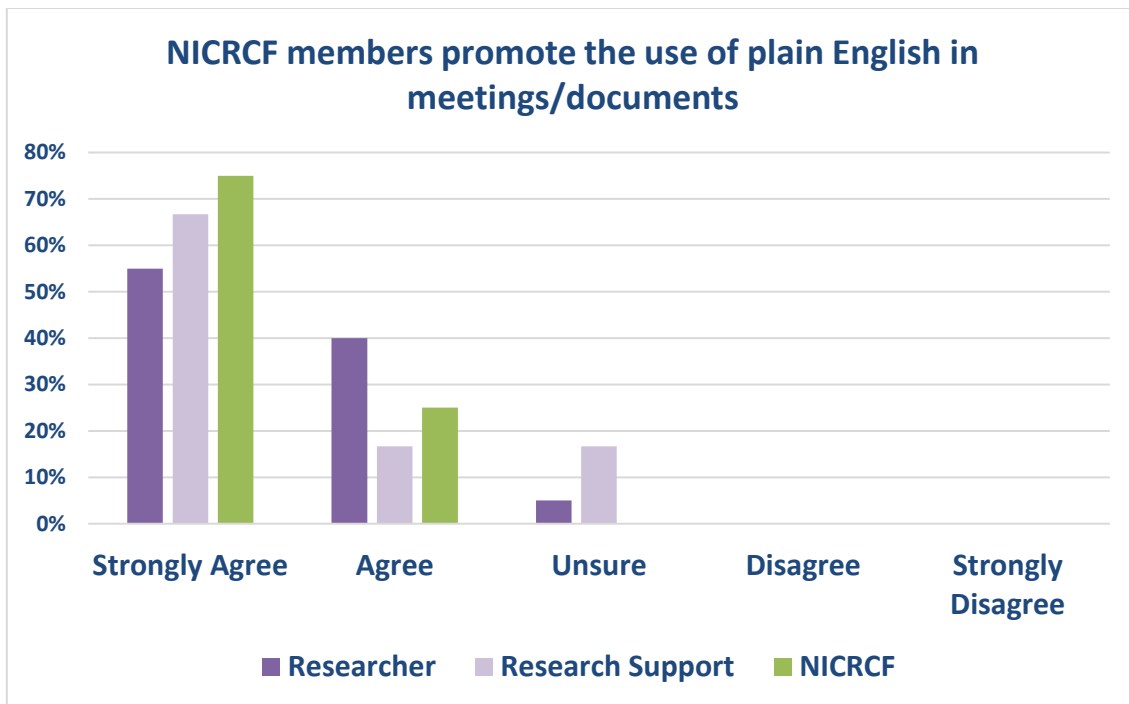


**Comment:** *'Having PPI at all stages of a research project ensures that research is both fit for purpose and more likely to succeed in attracting participants.'*



**Summary:** Average Agree 93%, Unsure 7%, Disagree 0%

**Comment:** **NICRCF Member** – *'I have seen this in action where things have been tweaked or changed.'*

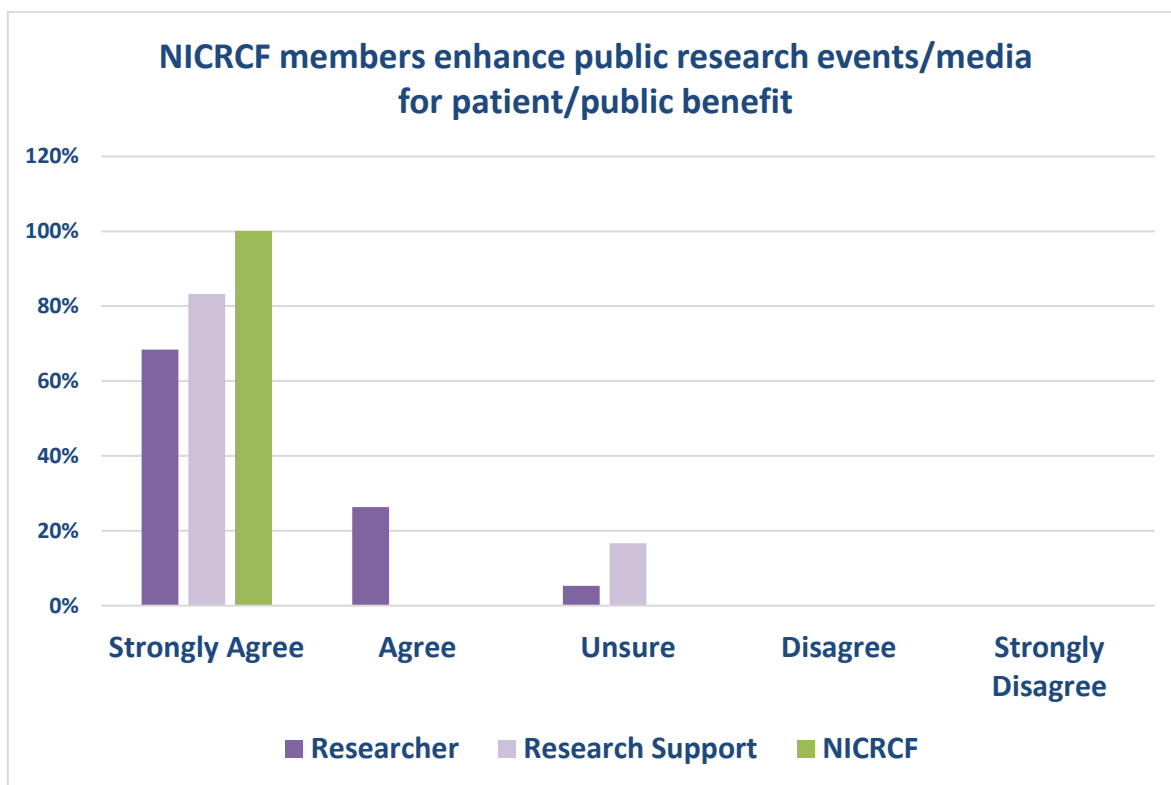


**Summary: Average Agree 93%, Unsure 7%, Disagree 0%**

**Comments: NICRCF Member** – *‘But I feel that this could go further.’*

**Researchers** – *‘Absolutely, which is a key skill that is given little attention for a lot of basic/translational researchers.’*

*‘I am aware that it can be difficult to be a lay member at a professorial meeting where technical jargon and acronyms are commonly used. NICRCF were very helpful in ensuring that my information leaflets were intelligible and jargon free.’*



**Summary: Average Agree 93%, Unsure 7%, Disagree 0%**

**Comments: NICRCF Members** – ‘A chance meeting at these public events can result in us getting another member interested in the NICRCF and perhaps in joining it! It can result in another person also being more pro medical research.’

‘Even the Poster Boys.’

**Researcher** – ‘PPI talks at public events often have the greatest impact.’

## What would be Helpful to Develop the PPI Role in the Future?

### NICRCF Members -

*'I'd love to see a working/training day where the NICRCF members come together and collectively review PPI documentation to assure understanding of role what is expected. Sometimes I wonder if I have the full grasp or are there areas that I need to hone in on.'*

*'More training.'*

*'Additional training in how to respond effectively to researcher's information.'*

*'Access to training courses both generic and more online.'*

## From your (Researcher) Perspective, what would make PPI Easier to Implement?

*'A formal commitment from CCRCB to integrate PPI with all new proposals and research themes, alongside (financial) support to enable this from QUB.'*

*'More information and education needed for dissemination and ensure continuity of flow.'*

*'More cancer specific PPI (e.g. representation from Lung Cancer).'*

*'More information - a lot of people are still unaware of NICRCF.'*

*'More champions from within cancer research - bench to bedside and greater awareness of stories of success.'*

*'Better integration between researchers, clinicians and PPI representatives.'*

*'Employee role with the university? Half day a week when they meet with researchers?'*

*'More investment.'*

*'Change in culture in academia to appreciate the value of PPI and what it can add.'*

*'Setting up meetings/presentations from PPI member and researchers.'*

*'Online registration of research activities. PPI contacts for specific disease group.'*

*'A pool of available people who have completed training and areas of interest and expertise identified.'*

*'Maybe a 'heads up' email stating when the NICRCF is meeting to encourage more presentations.'*

## Examples of the Positive Impact of PPI in Research:

### **NICRCF Members -**

*'Working directly with researchers in IRAS applications for PhD Proposal was very rewarding. Having access to and forming great relationships with researchers at CCRCB and CTRad.'*

*'The group have been involved in listening to, and supporting, various researchers and as a result of PPI support they have secured the funding required to undertake their research projects.'*

### **Research Support -**

*'NICRF members have contributed to higher quality patient information sheets for patients. In one incident, following NICRCF input, the quality of the PIS was commented on by an ethics committee as an example of an excellent PIS.'*

*'Too numerous to share - but the influence and impact of their advice has contributed to the success of many projects.'*

*'PPI in research is a valuable link between researchers and participants. PPI representatives provide valuable advice on recruitment and contact with patients.'*

*'Sharing their experiences from being a patient or a carer for a family member with cancer.'*

### **Researchers -**

*'Support in designing the ..... and ..... studies. Personal support to me to keep motivated in spite of the inordinate challenge involved in conducting clinical trials in oncology.'*

*'Very useful in ensuring the information sheets were appropriate for the target audience and provided very good ideas for implementing the research.'*

*Patient and public involvement was a key component of the research:*

- Influencing development of the research proposal*
- Supporting application to funders for research fellowship*
- Reviewing patient educational materials for ease of use and acceptability*
- Commenting on practical aspects of the (study) for the benefit of potential participants*
- Advising on the wording of patient information leaflets*

- *Supporting research processes*

- *Publically raising the profile of rehabilitation research and sharing research findings*

*Most importantly of all the PPI champions on my study provided a viewpoint from someone who saw the value of what we were doing beyond the purely academic. Through their engagement we were able to justify decisions queried by the ethics committee in relation to terminology used based on PPI support.*

*Ability to check in with PPI members from time to time in relation to how the project was doing also renewed my enthusiasm for the topic when things were tough.'*

*'It has given me even greater motivation to pursue the areas of work I presented to them (NICRCF). Although my grants didn't get funded I would not hesitate to get in touch with them to set up a meeting or to forward an outline of what I want to do.'*

*'Engagement with researchers at the NICTN breast cancer research showcase.'*

*'PPI particularly from the cancer consumer forum has greatly shaped our approach and agenda to research. We worked with the Forum to develop an online support system for cancer carers. The forum developed the idea from reading my research findings and worked in partnership with us to develop a strategy that would work. As an academic we develop answers based on books, papers and numbers, this group develop ideas that will work in real life and make an impact.'*

*'I have had invaluable insights on proposed projects and also patient materials and also writing of lay summaries. It is always valued to get the unique insights into the cancer or carer experience which are necessary to be captured for research.'*

*'Two young women and one young man provided feedback on patient information documents, particularly how the wording and language should be.'*

*'I received help from PPI in the form of allowing me to present my ideas in a meeting and giving me feedback. PPI members showed genuine interest in the proposed project and asked questions that helped me formulate the research question/endpoints and setting priorities. PPI also helped me to improve my project proposal and helped with the lay summary.'*

*'Intervention planning and delivery.'*

*'Their ability to communicate the patient perspective.'*

## Barriers to Effective PPI in Research:

### NICRCF Members -

*'These are being broke down. Continue to spread the word that early involvement is key to advancing cancer research.'*

*'We give feedback on projects, usually about using plain English, yet the same issues crop up over and over again. The researchers should be given some general training in this area.'*

### Research Support -

*'Researchers, sometimes, regard PPI as a tick box exercise. The realized value of PPI is not apparent to some researchers.'*

*'Historically the perception that using PPI was just another thing to be seen to do for little gain may have inhibited researchers utilizing PPI - but thankfully the support for PPI has escalated. A little work within the wider research (non-cancer) community to highlight the real benefits of PPI may help encourage early engagement in study design rather than leaving it to the last minute.'*

*'It can be difficult to allocate time specifically to PPI.'*

*'Availability of PPI team members to cover all of the trusts in NI.'*

### Researchers -

*'The most important thing that PPI do for me is to remind that clinical trials is about benefiting people who have cancer. They are about the person involved, which to me is the key element. On my many dark days when trials seem impossible to do, it is this direct contact with those persons involved with cancer which inspires to keep going!'*

*'I would say that two of the biggest barriers to better PPI engagement in research are*

*1) mentoring for researchers to ensure that they understand what opportunities for PPI exist and fully engage with PPI at the right times in their project*

*2) Having sufficient people with experience of a range of different cancer diagnoses to ensure the sustainability and growth of the NICRCF.'*

*'Financial; no funding to pay for basic supplies for PPI participants in most cases. There needs to be a provision for this in the university.'*

*'Beyond specific grant applications, most cancer researchers do not really have the opportunity to present their work to audiences where PPI representatives/members are present.'*

*'Lack of time - lack of face-to-face contact. I appreciate evening meetings suit many members of the group but as a parent to young children they don't suit me. Would like the opportunity to go through all my research with PPI and what they feel is important.'*

*'Please see above comment on 'data' research and PPI'*

*'Often, time constraints involved in applying for funding affects the level of PPI involvement that can be made. If PPI involvement is pre-emptive in generating ideas, an appropriate funding call may not arise therefore, research is often dictated by the research funders.'*

*'I would have loved a young person to attend the ORECNI meeting but this process is far too daunting for me as a practitioner that I wouldn't want to subject a young person to this experience. I also wanted to include participants of the study in the dissemination of the results which would enhance the PPI process, but ORECNI's views on confidentiality meant they couldn't be included in this.'*

*'Barriers are for funding of PPI time and research expenses especially of they are of working age and returned to employment following treatment.'*

*'None.'*



## What's the Best Thing about PPI currently?

### **NICRCF Members -**

*'I can say that in NI there is a much better collaborative approach in PPI and an appreciation of its value by the research community.'*

*'Feeling your opinions can make a difference.'*

*'As NI is a small place and the cancer research community very centralised we get to know each other and the research scientists, oncologists, nurses etc. which is undoubtedly one of the main reasons for our success.'*

*'Having a voice as a lay person to support on-going research and development. Using my own experiences to inform future development of services and support for patients and their carers.'*

*'The people. When it works it's great.'*

### **Research Support -**

*'Cancer patients and families are improving research for cancer patients as they are helping to influence the research.'*

*'Patients and carers are given the opportunity to give their input into studies and may recognize issues which the researcher has overlooked.'*

*'PPI in Cancer Research in NI is a well-established group that are recognized nationally as leading the way.'*

*'Getting a lay person's perspective on issues that can so often be missed by the professional!'*

*'There is a growing awareness of the benefits of PPI in research. This will hopefully lead to better communication with participants and in turn better recruitment and retention rates.'*

*'It is giving public a voice.'*

*'Promoting awareness of clinical trials and Research. Helping to embed clinical trials participation into routine patient care.'*

## **Researchers -**

*'The people involved in it and their passion for the work.'*

*'The people involved!'*

*'Enthusiasm and dedication of a few leaders in this area such as Ruth and Margaret.'*

*'Accessibility. I know who to contact and having been through the process I've found it straightforward.'*

*'Enthusiastic and motivated group, good leadership.'*

*'To hear the patient and public voice.'*

*'Ruth Boyd and Margaret do an amazing job in their roles with the NI Cancer Consumer Forum. I have always felt welcome and support when I have attended their meetings. It is the people that really allow the Forum to function in the way that it does.'*

*'Dedicated PPI members. My experience is extremely good.'*

*'The overall engagement of PPI with the cancer research community'*

*'Network group and passionate leadership.'*

*'The people involved in promoting PPI are very accommodating even when you've left PPI to the last minute (as a novice to research).'*

## Recommendations for the Future PPI Cancer Strategy in NI

### NICRCF Members -

*'Keep doing what we are doing and involve early. Is there anything that we can do to help secure more funding for cancer research?'*

*'Continue to value the Forum. Suggest the appointment of a Vice chair to help carry the load.'*

*'That PPI should be brought into research at base level & should be recognised as extremely important to research both in general practice and as a whole.'*

*'Get the message out there to encourage others to become involved and support this very important work. Everyone has something to offer.'*

*'We need to be told more about the big picture and see where we fit in. It would be good if we had an event once in the year when people who have presented their research could give us an update on what they are doing. Perhaps the head of the clinical trials unit could also give an overview at this - we never know how things are progressing.'*

### Research Support -

*'More funding to develop further.'*

*'To continue in its current format.'*

*'The current strategy is very good. The PPI have become the experts in development and design of understandable, user friendly patient information sheets. Would there be any value in running workshops for Investigators? Is there room for engagement between RECs and NICRCF?'*

*'Keep doing what you are doing but push for funding to sustain and expand the good work delivered to date.'*

*'More awareness and participation needed.'*

*'More study adoption meetings being held. More PPI members available.'*

### Researchers -

*'To introduce/incorporate PPI into mainstream cancer research training/education. Potential subjects incorporated into ongoing BSc, MSc and PhD training programmes.'*

*'Online access for support.'*

*'Opportunities for PPI to shape more research in cancer care - e.g. through sandpit events with researchers across a breadth of different research (lab to end of life clinical care) with backing from PHA R&D office.'*

*'Same as ..above, more crosstalk between dedicated research centres, cancer clinicians and PPI.'*

*'As above - formalise the appointment, have members rotate through a formal role meeting researchers.'*

*'I think to have more young people included in PPI cancer research strategy we need to incentivize them through their CV's- offer translational training, encourage them to be involved in accessing clinical trials for other patients. Pay for transport costs (this might already be the case).'*

*'I was privileged to have a chance to speak to some of PPI members. I think every cancer researcher (clinical, pre-clinical and translational research) will benefit from such communications.'*

*'PPI contact presence in cancer research environments. More engagement with all cancer disease types. More engagement with local charities.'*

*'It might be good (forgive me if this is already done) but to cultivate more carers whose patients had poor prognosis, and these patients may be under represented in your panel?'*

## **Other Comments**

### **NICRCF members -**

*'The FORUM does great work.'*

*'I would like to thank all those involved for the time they give and the positive contribution they make.'*

### **Researchers –**

*'Thank-you for all your work - it so very much appreciated!'*

*'PPI is great! But could be better...'*

*'I have very little knowledge of PPI but work with a lot of clinical trials.'*

## **FOCUS GROUP METHODS**


To provide an opportunity for more detailed feedback a Focus Group was undertaken among NICRCF members. For convenience, the Focus Group was arranged to coincide with one of the NICRCF's quarterly meeting. The group was facilitated by Janet Morrison, Macmillan Information and Support Centre (MISC) Manager / PPI Lead for Cancer Services, BHSCT and Margaret McManus, MISC Information Manager. The PPI Professional Lead was not present during the Focus Group to promote open and honest discussion. Themes explored incorporated areas similar to the survey. Feedback to support the evaluation of PPI was captured via 'post-it' notes completed by the Focus Group participants. The participants' 'post-it' statements were themed and are reported below.

## FOCUS GROUP RESULTS

### Focus Group Participation

The Focus Group was conducted on 23 November 2017. Ten members of the NICRCF took part in the Focus Group.

### Focus Group Responses

| <b>What works well?</b>                    |   |  |
|--|---|---|
| <b>Theme</b>                               | <b>Comment</b>  |   |
| <b>Awareness</b>                           | <ul style="list-style-type: none"> <li>• There is no recruitment drive as such. A friend may suggest it knowing their circumstances</li> <li>• Word of mouth – suggested that someone may like to join in</li> <li>• Members not recruited – word of mouth</li> <li>• Informal interview with Margaret and Ruth</li> </ul>  |   |
| <b>Involvement Methods / Opportunities</b> | <ul style="list-style-type: none"> <li>• Working Group</li> <li>• Opportunities to join groups – non-medical backgrounds</li> <li>• Listening and commenting on presentations from researchers</li> <li>• Providing feedback / questions for researchers</li> <li>• Contributing to researchers</li> <li>• Different aspects of the various roles in the Forum. People who work fulltime can still contribute- reading and reviewing patient literature, attending open days and conferences</li> <li>• Researcher presentations</li> <li>• Presentations by researchers</li> </ul> |   |
| <b>Feeling Valued</b>                      | <ul style="list-style-type: none"> <li>• Medical staff haven't looked down their nose and listen to and value opinion</li> <li>• Compassion/Genuine</li> <li>• Information from researchers very good</li> <li>• Makes you aware that researchers really care</li> <li>• Genuine interest and commitment</li> </ul>   |   |
| <b>Support</b>                             | <ul style="list-style-type: none"> <li>• <u>Wonderful</u> support within the group</li> <li>• Members supportive to each other</li> <li>• My colleagues in the Forum so supportive and encouraging great to work with</li> <li>• Social aspect of the group. We have become friends and do things together outside the group</li> <li>• Social element of the group</li> </ul>  |   |
| <b>Role Clarity</b>                        | <ul style="list-style-type: none"> <li>• Involvement opportunities in groups – using your own experience</li> <li>• Members personal experience with cancer</li> <li>• Carers- personal experiences</li> <li>• Personal experience of cancer as either survivor or patient</li> </ul>   |   |

|                                  |  |
|----------------------------------|--|
|                                  | <ul style="list-style-type: none"> <li>• No oncologist knows what it's like to have a cancer diagnosis or go through chemo – we do, because we've been there!</li> <li>• Each member's experience of cancer patient/carer</li> <li>• Members who have 1<sup>st</sup> hand experience of chemo/radiotherapy</li> <li>• Members have knowledge of cancer that professionals may not have experience of</li> <li>• <u>Personal experience</u> is brought to the group</li> <li>• Members are committed to group</li> <li>• Members want to 'give something back'</li> <li>• People join to 'give something back' – to contribute</li> <li>• Members committed</li> <li>• Commitment to the group</li> </ul> |
| <b>Training/knowledge/skills</b> | <ul style="list-style-type: none"> <li>• Good training days – broadens your understanding</li> <li>• Good training days to learn about research</li> <li>• Good training opportunities</li> <li>• Very informative re: range of research and efforts made to cover all aspects</li> <li>• Tour of labs at Queens etc.</li> </ul>   |
| <b>Funding</b>                   | <ul style="list-style-type: none"> <li>• Having carpark paid is very useful</li> </ul>   |
| <b>Structure and Function</b>    | <ul style="list-style-type: none"> <li>• Time management is excellent. Margaret ensures the meetings start and end at the said time</li> <li>• Variety/consistency across the Trusts</li> <li>• Geographical coverage of members – cancer support across province</li> <li>• Size of group important</li> <li>• Intimate</li> <li>• Not under pressure to participate</li> <li>• You never feel under pressure to contribute or be involved</li> <li>• No pressure to 'do' just as you have time</li> </ul>  |
| <b>Leadership</b>                | <ul style="list-style-type: none"> <li>• Consistent, effective, leadership</li> <li>• Consistent leadership</li> <li>• Consistency of leadership</li> <li>• Margaret and Ruth – two exceptional leaders</li> <li>• Passion and genuine commitment of Margaret and Ruth</li> <li>• Group has a PPI professional lead who believes in involvement not just a tick box person</li> <li>• Good and consistent leadership</li> <li>• Passionate leadership</li> </ul>   |
| <b>Values</b>                    | <ul style="list-style-type: none"> <li>• Diversity of membership</li> </ul>  |
| <b>Communications</b>            | <ul style="list-style-type: none"> <li>• On-line communication allows group members to contribute</li> <li>• Ruth keeps everyone informed</li> </ul>   |

## What doesn't work so well?



| Theme                  | Comment  |
|------------------------|--|
| Feeling Valued         | <ul style="list-style-type: none"> <li>• Need to make sure the Trust understand the value of the work</li> </ul>   |
| Funding                | <ul style="list-style-type: none"> <li>• Long waiting process for expenses but may be better to have a payment up front -other disagree</li> <li>• Trust new process for car parking could be a problem</li> </ul>   |
| Structure and Function | <ul style="list-style-type: none"> <li>• Need 'Word' on computer</li> <li>• Require software (t10) Trusts</li> <li>• Work commitment unable to get involved daytime</li> <li>• Laptop to use when doing presentations</li> <li>• Resource laptop that group could use for their presentations</li> <li>• 'Word' resource</li> <li>• 'Office'</li> <li>• Computer limits</li> <li>• Software reduced cost open to group</li> <li>• PDF – licenses?</li> <li>• Template for going forward</li> </ul> |

## Going Forward.....

| Theme                               | Comment  |
|-------------------------------------|--|
| Awareness                           | <ul style="list-style-type: none"> <li>• PPI conference</li> <li>• Nights good source of new members</li> </ul>  |
| Involvement Methods / Opportunities | <ul style="list-style-type: none"> <li>• Seeing even more researchers</li> <li>• Meet with researchers more often, perhaps more Forum meetings</li> <li>• Communication about other PPI group in cancer services</li> </ul>          |
| Feeling Valued                      | <ul style="list-style-type: none"> <li>• Trust Xmas card to acknowledge the work?</li> </ul>   |
| Support                             | <ul style="list-style-type: none"> <li>• Annual get together</li> </ul>  |
| Training/knowledge/skills           | <ul style="list-style-type: none"> <li>• Work with other groups such as PIER</li> <li>• An annual joint conference with other PPI groups</li> <li>• Wider PPI conferences and social events</li> </ul>                               |
| Funding                             | <ul style="list-style-type: none"> <li>• Back to funding</li> </ul>  |
| Structure and Function              | <ul style="list-style-type: none"> <li>• Template so that you collate broad/general guidelines that apply to all researchers</li> <li>• Laptop</li> <li>• Are we coping with the demand that researchers want to present?</li> </ul> |
| Leadership                          | <ul style="list-style-type: none"> <li>• Succession training for future / Ruth / Margaret</li> </ul>   |
| Communications                      | <ul style="list-style-type: none"> <li>• Communication plan so that PPI is feedback up to the Trust hierarchy</li> <li>• Business cards</li> <li>• Business card- Forum / + aims of the Forum on it</li> </ul>                       |



## SURVEY AND FOCUS GROUP SUMMARY AND RECOMMENDATIONS

### Survey Response Rate

The overall research response rate was low. Alongside this, it must be noted that 33.3% of researcher respondents (n=10) and 40% (n=4) of research support respondents reported they had not worked with the NICRCF or did not have involvement in PPI to date. Hence the 26 respondents answering more specific questions about the experience of PPI/NICRCF and its evaluation from a Researcher or Research Support perspective equated to 12% and 8.5% of those asked, respectively. Researchers who responded represented a gamut of cancer research – from basic to epidemiological research, the most frequently reported being clinical trials.

### Positive Highlights from Survey Results

The survey has demonstrated that PPI in cancer research is active and there are a number of enthusiastic proponents of this. Over 90% of researcher respondents were **familiar with PPI** and nearly 75% were aware of the NICRCF. 60-70% of research respondents had **involved patient/carers representatives** in research. PPI involvement was most frequently reported as consultation, but a range of involvement levels were identified. There was also evidence of involvement **across the research cycle**, and adoption of a range of communication methods. The NICRCF was not the only source of PPI patient/carers representatives, recognising the wide community of patients/carers with relevant experience.

Overwhelmingly the survey responses have been positive about PPI experience and impact. For the majority of respondents in research and for PPI representatives, the experience of **PPI had met expectations**. In fact, researchers in particular took the opportunity to express how, in several cases, **expectations had been exceeded**. The majority in research reported that NICRCF members were **valued research partners**, and the majority of members themselves **felt valued**. Though felt less strongly by researchers and NICRCF members, there was also agreement that NICRCF members are **supported in their role**. When NICRCF members were asked about researchers the majority reported **researcher communication was supportive** and **researchers had the right reasons** for working with them. The majority of research respondents 'strongly agreed' **involvement was meaningful**.

The majority of respondents agreed there was **clarity of PPI roles and responsibilities**, although there was also some uncertainty and disagreement with this. The majority reported NICRCF members were **skilled in their role**. NICRCF members were confident in their **awareness of confidentiality and ethical and legal research issues**, and this was reflected by research respondents also. The majority of NICRCF members felt they had a clear **understanding of the purpose**

**of NICRCF.** The majority across all the groups surveyed felt they had **adequate access to PPI training**, though there was uncertainty about this across groups.

The majority expressed **satisfaction with the NICRCF structure and function** although there was some uncertainty within research respondents. There was also **agreement that NICRCF values were maintained.** NICRCF members generally strongly agreed there was **clear leadership.** Respondents in research, while the majority felt there was clear professional leadership in PPI in cancer research there was also uncertainty and disagreement this was the case.

All NICRCF members reported they felt regional and national **opportunities for PPI were promoted,** as were **opportunities for leadership, partnership and collaboration.** The majority of NICRCF members surveyed felt **supported to maximise the impact** of their involvement. The majority also reported **communication pathways** were maintained and there were **opportunities to work with others.** All NICRCF members **felt informed** about PPI news and developments and the majority agreed they **received feedback about the research** they were involved in. All members reported they knew who to contact if they had concerns.

**All researchers responded that PPI had enhanced the quality/success of their research** and the majority agreed NICRCF members **enhance research for patient benefit.** Across the groups surveyed the majority agreed **NICRCF members promoted the use of plain English in documents and meetings,** and they **enhanced public events and media,** for patient/public benefit.

When respondents were asked to provide examples of the positive impact of PPI in research, the comments span 2 pages of this document. **PPI impact** related to the following areas:

#### **Research impact:**

- Shaping the research agenda
- Proposal development
- Securing funding
- Recruitment advice
- Study design / intervention planning
- Good / practical implementation ideas
- Higher quality patient information sheets / patient materials / lay summaries
- Justification of terminology to ethics
- Raising awareness and research dissemination
- Project success

#### **Researcher / Research Support / PPI Representative Impact:**

- Rewarding

- Great relationships
- Research motivation / enthusiasm

Asking about **the ‘best thing’ about PPI** in cancer research in NI generated several comments. **A clear strength was ‘the people involved.’** Themes reported were:

- The people involved and their passion
- The patient / public voice
- PPI influencing/impacting research – recognising things the researcher/professional doesn’t
- Established PPI group, the members and leadership
- PPI accessible and accommodating
- PPI valued / growing awareness
- Collaborative approach
- Feeling you are making a difference
- Embedding clinical trial participation as the norm

**Given the positive survey results it is clear that what is currently in place and what has already been achieved in PPI at present needs to be sustained and nurtured,** alongside those areas more clearly identified as needing development.

### **Areas for Future Development Indicated by the Survey**

The most negative responses from the survey related to the topic of **funding**. The majority of NICRCF members and research support disagreed that there was enough funding for effective PPI. The majority of researchers were unsure. Expanding on this, comments related to funding included the following suggestions:

- **Support** for NICRCF leadership
- Automatic **payment** of PPI expenses
- **Funding** / direct funding for PPI
- **Clerical** support
- Researcher **mentorship**

Funding was an issue that was referenced again when researchers proposed how **PPI could be easier**. The suggestion they made fell into the following categories:

- More **financial/role investment/support** for PPI
- Organisation/culture **integration of PPI**
- Increased **information/awareness** and **education/training**
- More frequent **collaborative meetings** and on-line registration
- More researcher **champions**
- **Wider cancer-type PPI representation**

**Training** was an area noted by both researchers and PPI representatives. Some researchers themselves felt unsure or disagree they have adequate access to PPI training. The most significant level of uncertainty about training was reported by the research support group. There are still some gaps in researchers' knowledge of the NICRCF, the PPI strategy, and the pathway for accessing PPI. The topic of **training** was the single issue raised by NICRCF members when asked what would help them develop their role. There is also a need for NICRCF members to be familiar with the strategic context within which they work.

Researchers in particular expressed uncertainty in whether PPI was adopted as routine by the cancer research community in NI. There was also some uncertainty about PPI integration into practice, management and strategy, although the majority of research support respondents 'strongly agreed' with this. However, **embedding PPI** into various dimensions of research practice would appear to be an area where work should continue. **Early involvement of PPI** in a project is a recurring theme emphasised by researchers themselves and by PPI representatives. When asked if there was **clear professional leadership** in PPI in cancer research, the majority agreed, however a number of research respondents were unsure or disagreed, so greater clarity in this area is also required.

When directly asked about **barriers to effective PPI**, a range of issues were described across the groups:

- Researchers **not recognising** the **value** of PPI
- **Lack of time** for PPI/face-to-face contact
- **Research processes**
- **Time constraints in funding applications** inhibits involvement/research ideas at that stage
- **Last minute** engagement
- **Lack of opportunity** to work with a PPI audience
- **Difficult** to create collaborative **opportunities** in the setting of secondary analysis of existing datasets
- General researcher **training needed** (e.g. Plain English)
- **No researcher mentoring**
- **No funding** for PPI supplies/expenses
- **More PPI/NICRCF members needed** to cover all Trusts / range of cancer
- **None**

**Strategy recommendations** made by respondents also gave support to sustaining existing work and the topics of funding and training were highlighted again. Wider opportunities for cross working, feedback to NICRCF members and increased PPI awareness were also endorsed:

- **Keep doing what you are doing**

- **Secure more funding**
- **Value the NICRCF**
- **Share the load of the NICRF Chair**
- **Annual research event to present feedback**
- **More PPI / more representatives / more carers**
- **More incentives for PPI reps and young people – training, expenses**
- **More PPI awareness**
- **NICRCF/REC engagement**
- **More engagement with charities**
- **More cross-talk / more PPI presence in research**
- **More opportunities to shape research e.g. sand-pit events**
- **PPI in mainstream cancer research education**
- **On-line (researcher) support**
- **Investigator workshops**

## **NICRCF Focus Group Positive Highlights**

Many of the comments of the Focus Group are reflected in the positive survey results. However, the Focus Group feedback provides more context to the **positive experience of involvement and working with researchers**. NICRCF **valued themselves and felt valued**. They felt clear about what they could contribute and evaluated the NICRCF well. **Training and leadership** were also evaluated very positively. A dimension not evidenced so significantly through the survey **was the support NICRCF members received from the other members of the group**, which was clearly valued.

## **Areas for Future Development Indicated by the Focus Group**

Compared to positive evaluation there was substantially less negative evaluation. This fell into 3 categories:

- **Feeling the Trust did not understand the value of their work**
- **The expenses process**
- **Difficulties reading/working with e-mailed documents when home / hospital computer software not compatible**

The last issue raised most concerns.

Again some future suggestions mentioned at the Focus Group are similar to the survey findings, such as increased **awareness, funding** and **increased opportunities** for working with researchers and an **annual event**. NICRCF members want to see **wider PPI networking, leadership succession planning, a communication strategy** and promotion of **Trust recognition**. They also requested a **laptop** for the NICRCF and NICRCF awareness '**business cards**'.

## Concluding Recommendations

The survey and focus group evaluation provide **overwhelming endorsement for the NICRCF to continue functioning**. The members of the NICRCF have made a significant positive impact on both researchers and research for which they should be commended. The enthusiasm, skill and impact of NICRCF members has brought a new, valuable and dynamic asset to the cancer research community over the past six years.

The array of researchers who have had involvement with the NICRCF suggests that the original NICTN strategy to facilitate open access to the NICRCF beyond the operations of the network has proved to be a very beneficial approach. Since the NICRCF was originally established, the PPI landscape has changed, making PPI increasingly main-stream. Expectations have increased, however the approach to funding and infrastructure to support PPI in cancer research have not transformed. Recommendations must address the gap between the mandate for PPI in cancer research and the reality of what's required to deliver PPI into the future, including a necessary expansion in both numbers of PPI representatives and research involvement opportunities. PPI in research has multiple stakeholders and hence, while some of the following recommendations apply solely to the NICTN/NICRCF, others are beyond their remit. It is noted that recommendations such as funding and awareness were also recommendations in the reported research 'Personal and Public Involvement and its Impact'<sup>4</sup>. **Future recommendations** are summarised in the table below:

|   |   |  |
|---|---|--|
| 1 | <b>Provide dedicated PPI funding and expenses processes</b> | <ul style="list-style-type: none"> <li>• <i>Provide ring-fenced funding for PPI</i></li> <li>• <i>Review processes for payment of expenses to maximise respect for PPI representatives</i></li> </ul>  |
| 2 | <b>Enhance support structures</b>                           | <ul style="list-style-type: none"> <li>• <i>Research institutions integrate PPI into research / proposals and provide PPI roles</i></li> <li>• <i>Provide clerical support for PPI</i></li> <li>• <i>Provide support for NICRCF leadership</i></li> <li>• <i>Provide relevant IT support/guidance to PPI Representatives to facilitate electronic PPI activities/input</i></li> <li>• <i>Corporate recognition for PPI volunteers</i></li> </ul> |
| 3 | <b>Expand PPI Representative numbers and networking</b>     | <ul style="list-style-type: none"> <li>• <i>Expand the number of patients and carers involved in PPI - increasing Trust and cancer type representation</i></li> <li>• <i>Provide experiences that incentivize young people to get involved</i></li> <li>• <i>Increase engagement with local charities</i></li> <li>• <i>Increase opportunities for PPI representatives to network and collaborate with other groups</i></li> </ul>               |

|   |  |  |
|---|--|--|
| 4 | <b>Enhance training</b>                          | <ul style="list-style-type: none"> <li>• <i>Integrate PPI training into graduate, post-grad and cancer researcher education</i></li> <li>• <i>Provide researcher mentorship support</i></li> <li>• <i>Provide researcher training/workshops about developing patient / lay information in plain English</i></li> <li>• <i>Utilise group training approaches in NICRCF to build confidence and clarify expectations</i></li> <li>• <i>Provide on-going NICRCF training and mentorship and assure role clarity</i></li> <li>• <i>Provide on-line PPI training for PPI representatives</i></li> </ul> |
| 5 | <b>Raise researcher and public PPI awareness</b> | <ul style="list-style-type: none"> <li>• <i>Increase awareness/culture of PPI benefits to research</i></li> <li>• <i>Provide on-going researcher awareness</i></li> <li>• <i>Develop and utilise researcher PPI champions</i></li> <li>• <i>Increase PPI access awareness.</i></li> <li>• <i>Devise PPI on-line register / resource / experience register</i></li> <li>• <i>Promote awareness of PPI role opportunity</i></li> </ul>   |
| 6 | <b>Increase PPI opportunities</b>                | <ul style="list-style-type: none"> <li>• <i>Promote wider adoption of PPI in research</i></li> <li>• <i>Promote early PPI in research projects</i></li> <li>• <i>Facilitate face-to-face researcher / PPI opportunities</i></li> <li>• <i>Increase opportunities for more researcher / clinician / PPI meaningful collaboration. Sandpit events.</i></li> </ul>  |
| 7 | <b>Share PPI impact</b>                          | <ul style="list-style-type: none"> <li>• <i>Provide feedback about PPI impact</i></li> <li>• <i>Annual public PPI events</i></li> <li>• <i>Share success stories</i></li> </ul>  |

## Next Steps

The results of the survey and focus group will be published via the NICTN website and circulated to survey participants and other relevant stakeholders. The results will be a key resource to inform a new PPI strategy for cancer research in NI, due to be developed by the NICTN and NICRCF in consultation with all relevant stakeholders. The invaluable input of all the Survey and Focus Group respondents in providing evaluation and informing the recommendations and strategy is greatly appreciated.

## Thanks and Acknowledgements

The NICTN wishes to thank all who participated in the Surveys and Focus Group and all who have supported PPI in Cancer Research in NI since 2011.

Thanks to Gail Johnston (HSC R&D Division) and Sandra McCarry (BHSCT) for their input into the Survey development.

Special thanks to Cillian McGinn, BHSCT Digital Communications Officer, for setting up the SmartSurvey™ and providing survey data.

Massive thanks to the members of the NICRCF through the years, for their sustained enthusiasm and commitment to both their role and to research to benefit the care and treatment of cancer patients now and in the future.

## Contact Us

Your comments and feedback about this evaluation and document are very welcome. Should you wish to contact us about this or any other matter related to the NICTN/NICRCF please contact Ruth Boyd, Cancer Research UK Senior Nurse, (NICTN/NICRCF PPI Lead) at [nictn@belfasttrust.hscni.net](mailto:nictn@belfasttrust.hscni.net) .

## References

<sup>1</sup> NICTN (2011) A Strategy for Personal and Public Involvement (PPI) in Cancer Research in Northern Ireland <http://www.nictn.hscni.net/download/reports/Post-Consultation-V1-A-Strategy-for-PPI-in-Cancer-Research-in-Northern-Ireland.pdf> (accessed 22.01.18)

<sup>2</sup> Public Health Agency (2015) Setting the Standards, PHA, Belfast [http://www.publichealth.hscni.net/sites/default/files/PPI\\_leaflet.pdf](http://www.publichealth.hscni.net/sites/default/files/PPI_leaflet.pdf) (accessed 22.02.18)

<sup>3</sup> Staniszewska, S. *et al.* (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research *BMJ* 2017;358:j3453

<sup>4</sup> Duffy, J. *et al.* (2017) Personal and Public Involvement (PPI) and its impact- Summary Report. Public Health Agency and Patient and Client Council [https://www.patientclientcouncil.hscni.net/uploads/research/PPI\\_Summary\\_Report\\_\[web\].pdf](https://www.patientclientcouncil.hscni.net/uploads/research/PPI_Summary_Report_[web].pdf) (accessed 25.03.18)



## Appendix 1

### Example (Researcher) Cover Message to Survey Participant

Dear Cancer Researcher,

The NI Cancer Trials Network (NICTN) and the NI Cancer Research Consumer Forum (NICRCF) is undertaking an **anonymous survey** of PPI in cancer research. Back in 2011 we published the first [strategy for PPI](#) in cancer research in NI and the NICRCF was established. It's now time to reflect on what was achieved and any areas for development in the future.

**Please help us by participating in this survey!** As an important stakeholder in cancer research in Northern Ireland, **your response to a brief on-line survey about PPI would be invaluable.**

The purpose of the survey is to:

1. Evaluate existing experience of PPI in cancer research in Northern Ireland from a stakeholder perspective
2. Identify areas for further development
3. Gather recommendations to help inform a new cancer research PPI strategy

Please take part in the Researcher Survey of Personal and Public Involvement (PPI) in Cancer Research in Northern Ireland at this link: <https://www.smartsurvey.co.uk/s/SO62UPPI/>

It is anticipated **the basic survey will take approximately 6 minutes to complete.** If you wish to provide additional information in the comments' sections, that will be much appreciated also.

The survey will close on Friday 22<sup>nd</sup> December 2017.

**Again, please note your responses are anonymous.**

Many thanks

Ruth Boyd

NI Cancer Trials Network/ NI Cancer Research Consumer Forum PPI Professional Lead

## Appendix 2

### Example (Researcher) Survey (Word Version which was transferred to SmartSurvey™)

#### Survey

Title: Cancer Researcher PPI Survey

| 1. Background Information   |  |   |   |  |             |          |                            |
|---|--|---|---|--|-------------|----------|----------------------------|
|   |  |   |   | Free Text box  |             |          |                            |
| a) Please select the type of organisation where you are a researcher (Select <b>all</b> that apply) | HSC organisation   | University  | Other   | If 'other' please describe   |             |          |                            |
| b) Please select the type of research you conduct (Select <b>all</b> that apply)                    | Basic research   | Translational research                                    | Clinical Trials   | Population/epidemiological   | qualitative | Other    | If 'other' please describe |
| c) <u>Before</u> this survey: (Select <b>all</b> that apply)  | I knew about Personal and Public Involvement (PPI) in research | I knew there was a PPI Strategy for Cancer Research in NI | I knew about the NI Cancer Research Consumer Forum (NICRCF) | I knew who to contact to request involvement of the NICRCF in research   |             | Comments |                            |
| d) I have worked with the NICRCF/NICRCF member before   | Yes  | No  | Unsure  |  |             |          |                            |
| e) I have involved patient and carer representatives (NICRCF or non-NICRCF) in my research          | Yes  | No  | Unsure  | If you have worked with <b>non-NICRCF</b> patient/carer representatives, please list the type of group etc. you have involved in your research (do not name individuals) |             |          |                            |
| <b>If you responded 'No' to 1e please go to section 4</b>   |  |   |   |  |             |          |                            |

**2. Working with PPI representatives/NI Cancer Research Consumer Forum (NICRCF)**

|   |  |  |   |  | Free Text Box |
|---|--|--|---|--|---------------|
| a) I have worked with PPI representatives/NICRCF in the following areas of the research process:<br>(select <b>all</b> that apply)            | Concept and design of a research proposal        | Research grant proposal / application              | Conduct and analysis of a research project e.g. a Trial Management/Steering Group | Study patient documents/lay summaries / publications | Comments      |
| b) I have worked with PPI representatives/NICRCF in the following areas of the research process:<br>(select <b>all</b> that apply)            | Identifying research priorities                  | Research funding / governance / strategy decisions | NICTN portfolio study adoption meetings   | Research awareness /research events                  | Comments      |
| c) In my experience working with PPI representatives/NICRCF in research has involved the following process:<br>(Select <b>all</b> that apply) | face-to-face feedback/discussion about a project | e-mailed feedback about a project                  | being influenced by their comments/perspectives at meetings/events attended       | other  | Comments      |
| d) In my experience the level of PPI in research has been:<br>(select <b>all</b> that apply)  | consultation                                     | collaboration                                      | PPI controlled/ directed/managed research   | unsure   |               |

| 3. Evaluation of PPI in research   |                |       |        |          |                   |         |
|--|----------------|-------|--------|----------|-------------------|---------|
| a) My experience of PPI in cancer research met my expectations                 | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| b) In my experience PPI in cancer research has been easy to implement          | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| c) In my experience PPI has enhanced the quality/success of my cancer research | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| d) NICRCF / NICRCF member(s):  |                |       |        |          |                   |         |
| • are valued research partners   | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| • are supported in their role  | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| • have clear roles and responsibilities  | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| • are skilled in their role  | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| • are aware of legal/ethical and confidentiality issues in research            | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| • promote the use of plain English in meetings/documents                       | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| • enhance the quality of research for research/patient benefit                 | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
| • enhance public research events / media etc. for patient/public benefit       | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |

|   |                |       |        |          |                   |         |
|---|----------------|-------|--------|----------|-------------------|---------|
|   |                |       |        |          |                   |         |
| e) I support NICRCF / NICRCF members to have meaningful involvement in research                 | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|   |                |       |        |          |                   |         |
| f) There is enough funding for PPI in cancer research in NI to be effective                     | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|   |                |       |        |          |                   |         |
| g) Please share your example(s) of the positive impact of PPI in research                       | Comment        |       |        |          |                   |         |
|   |                |       |        |          |                   |         |
| h) Please share your example(s) of barrier(s) to effective PPI in research from your experience | Comment        |       |        |          |                   |         |
|   |                |       |        |          |                   |         |

| <b>4. Meeting PPI Strategy Aims and Standards</b>  |                |       |        |          |                   |         |
|--|----------------|-------|--------|----------|-------------------|---------|
| <b>In your experience</b> , where cancer research involves people, their tissue or data: |                |       |        |          |                   |         |
| a) PPI is adopted as a routine/standard process by the cancer research community in NI   | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|  |                |       |        |          |                   |         |
| b) PPI is integrated into local and regional research practice, management and strategy  | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|  |                |       |        |          |                   |         |
| c) I have a clear pathway for accessing PPI in cancer research                           | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|  |                |       |        |          |                   |         |
| d) I have adequate access to relevant PPI training and information                       | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|  |                |       |        |          |                   |         |
| e) There is clear professional leadership in PPI in cancer research                      | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|  |                |       |        |          |                   |         |
| f) I am satisfied with the structure and function of the NICRCF                          | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |

|   |                |       |        |          |                   |         |
|---|----------------|-------|--------|----------|-------------------|---------|
|   |                |       |        |          |                   |         |
| g) The NICRCF maintains the core values of dignity and respect, inclusivity, equity and diversity, collaboration and partnership, transparency and openness | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Comment |
|   |                |       |        |          |                   |         |

| 5. Your recommendations for the future   |         |
|--|---------|
| a) From your perspective, what would make PPI in cancer research easier to implement?    | Comment |
| b) What's the best thing about PPI in cancer research in NI currently?                   | Comment |
| c) Please tell us your recommendations for the future PPI cancer research strategy in NI | Comment |
| Any other comments   | Comment |

**Thank you for your participation in this survey.**

**Your responses are really appreciated.**