

From Survey to Strategy:

The experience of the NI Cancer Research Consumer Forum and the NI Cancer Trials Network in evaluating PPI



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Our Journey Evaluating PPI

- *Background*

The first 6 years!

- *Survey (and Focus Group)*

Our PPI evaluation process and results

- *Strategy*

Evaluation-guided strategy and action plan



CANCER RESEARCH UK



Health and Social Care



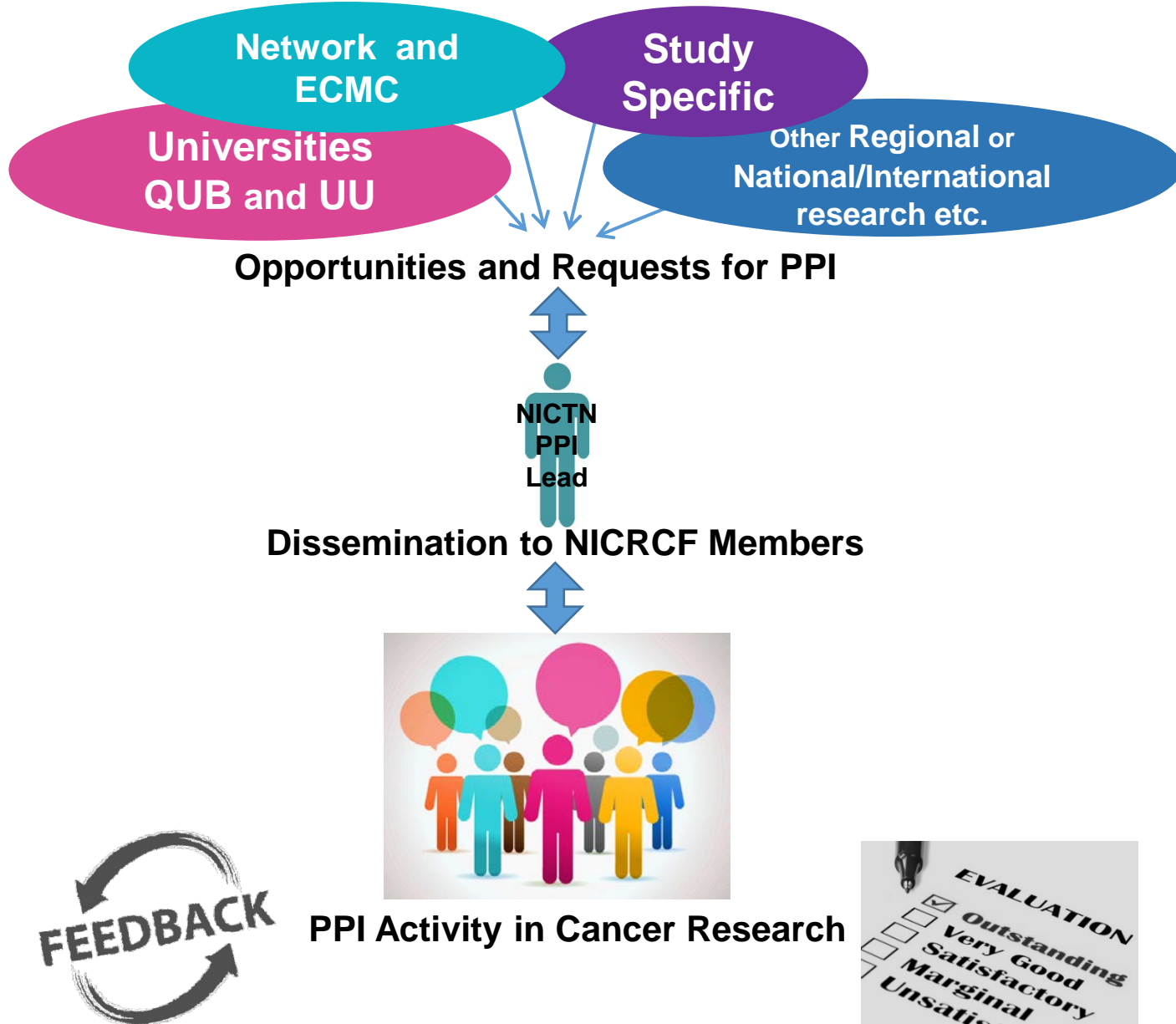
NI Cancer Trials Network (NICTN)



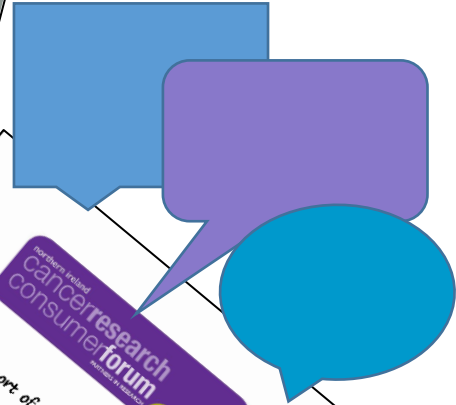
NI Cancer Research Consumer Forum (NICRCF)



Model of PPI in Cancer Research in NI



Evidence.....



Issue: 2015 Spring/Summer 7: 2014

Consumer Impact!

Newsletter of the Northern Ireland Cancer Research Consumer Forum

Forum Hosts a Celebration of Research on World Cancer Day

On February 4th 2014, Forum members hosted a public event to celebrate the global fight against cancer and discuss how NI researchers are making an international impact. The event, held in the McCauley Library Auditorium, Queen's University Belfast (QUB), was attended by representatives from a range of stakeholders in cancer care and research – the Department of Health, charity leaders with the support of Friends of the Cancer Centre, public. Following lunch, Wendy Laidlaw, Chair of the Forum, opened proceedings with an outline of the role of the Margaree Group, Chair of the Forum, Dr Edna Potts welcomed an invitation to address the audience, describing the value of early cancer diagnosis and the important role of research in addressing practice, advocating that all opportunities to improve cancer survival should be embraced.

Richard Kennedy, OBE, Professor of HSC, QUB, and Director of the HSC Cancer Research Centre, opened the proceedings by highlighting the importance of research in cancer care and research. He stated that research is the key to developing new treatments and that research is the key to understanding the underlying causes of cancer and how to prevent it. He also highlighted the importance of research in understanding the underlying causes of cancer and how to prevent it.

Professor Kennedy emphasised how integrated scientific and clinical research programmes, about ethically relevant issues, were a vital approach to improve patient outcomes.

Dr Edna Potts, Chair of the Forum, welcomed an invitation to address the audience, describing the value of early cancer diagnosis and the important role of research in addressing practice, advocating that all opportunities to improve cancer survival should be embraced.

4th Year Report of the Northern Ireland Cancer Research Consumer Forum

Partners in Research

September 2014 – August 2015



Evaluation Survey Plus Focus Group Process during Nov-Dec 2017

- Survey purpose:
 - (i) Evaluate PPI experience of PPI from a stakeholder perspective
 - (ii) Identify areas for further development
 - (iii) Gather recommendations for a new NI cancer research PPI strategy
- Questions devised from various sources/standards
- Anonymous on-line 'smartsurvey' ~ 6 minutes to complete additional text options (5 sections ~ 31 questions)
- Sent to 169 Researchers, 71 Research support staff, 22 Forum members (total **262**)
- Focus Group with Forum members - themed discussion: what works well / doesn't work so well / going forward

Evaluation Survey Plus Focus Group Results

Survey

- 48 (18%) responded
- 30 (18%) researchers responded
- 65% of responding researchers had experience of PPI

Focus Group

- 10 Forum members participated

NICTN northern ireland cancer research consumer forum **ecmc** Belfast

**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**

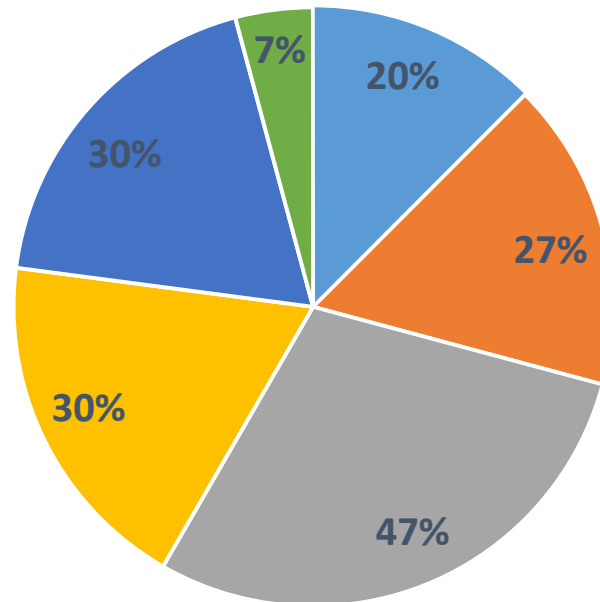
'I cannot describe the input of the Forum more highly. They are a dedicated bunch who give depth and clinical relevance to research. What they have taught me about research....no book or lecture ever could.'
Researcher

Final v 26.03.18

HSC Public Health Agency Research and Development Friends of the Cancer Centre CORC Centre for Cancer Research & Care Strategy HSC Health and Social Care Belfast Health and Social Care Trust *working supporting improving together*

Evaluation Survey Results – type of research

Researcher: Research Type (all that apply)

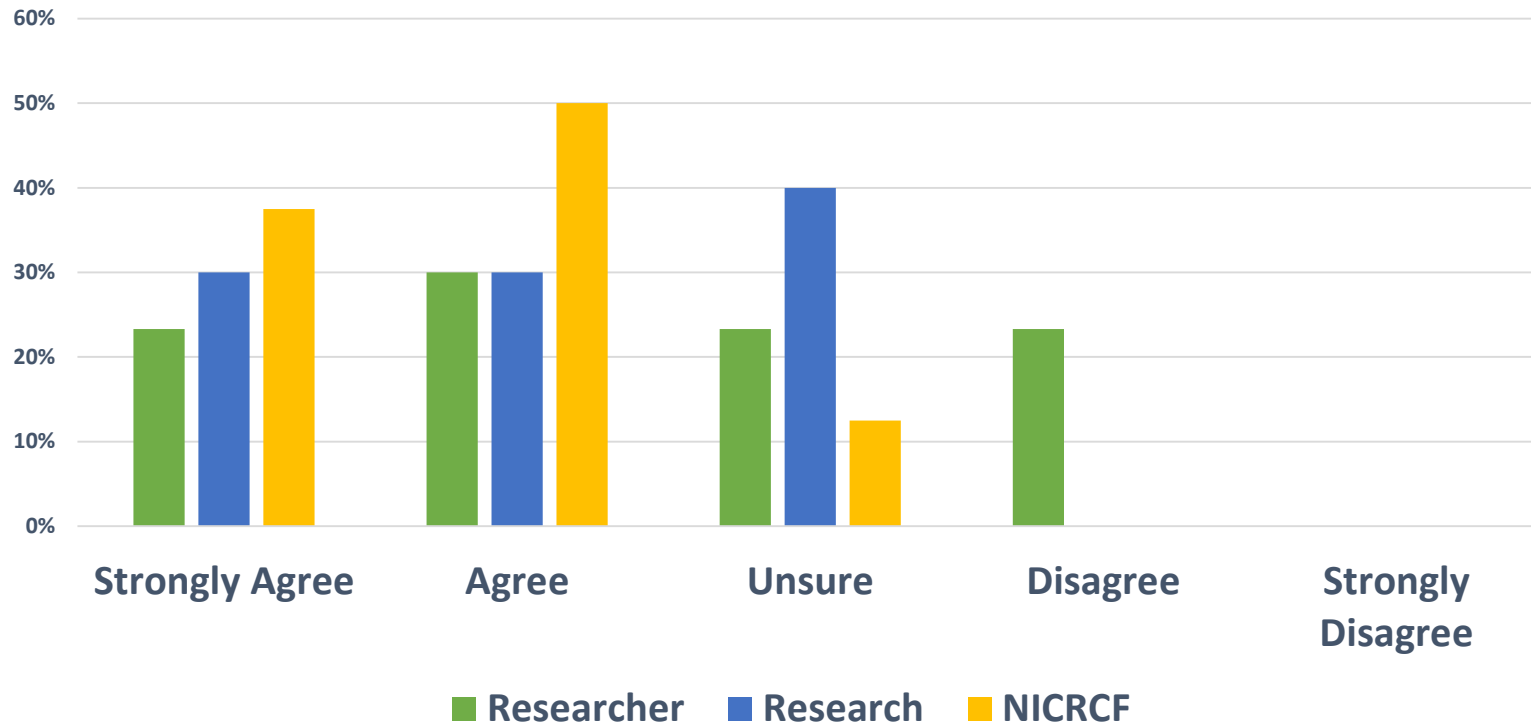


- Basic Research
- Clinical Trials
- Qualitative

- Translational research
- Population / Epidemiological
- Other

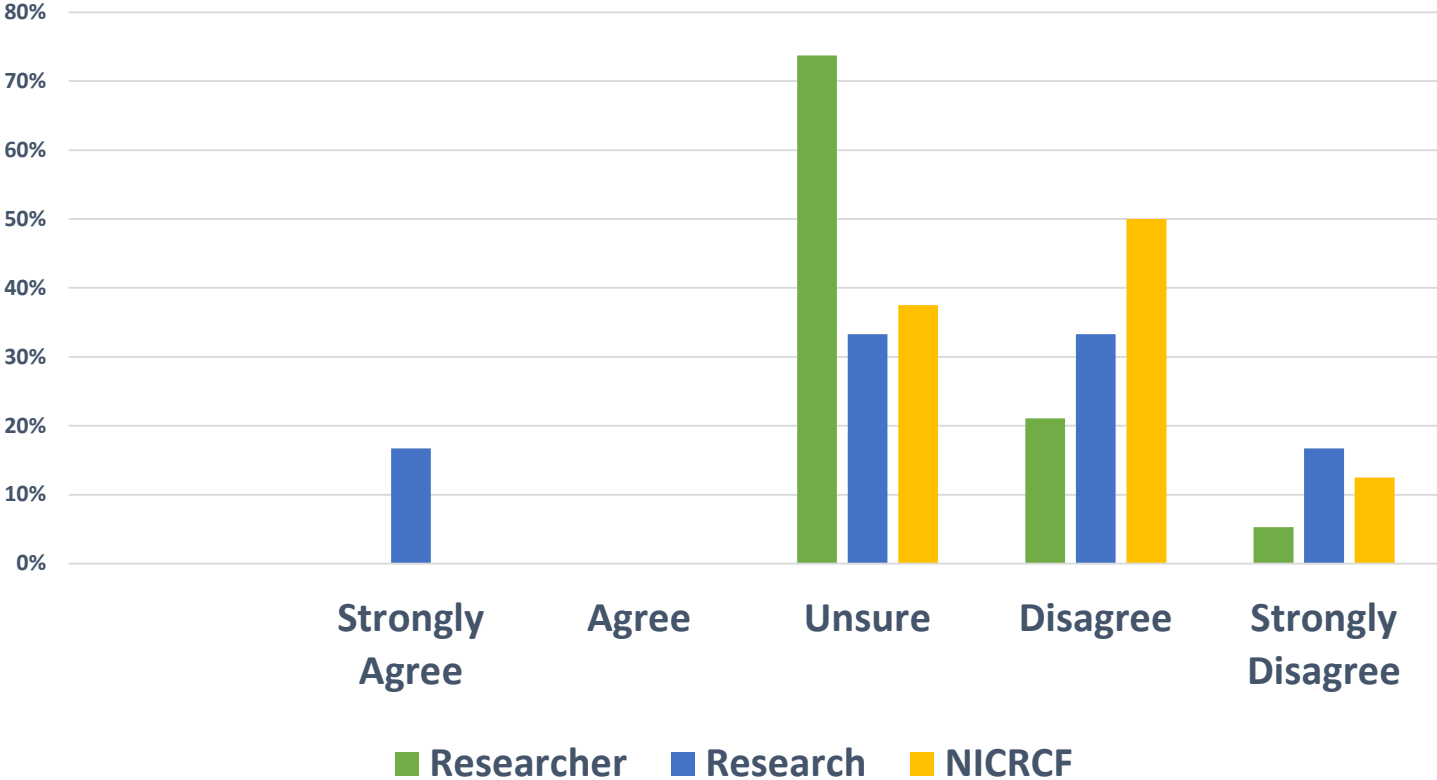
Evaluation Survey Results - training

I have adequate access to relevant PPI training and information



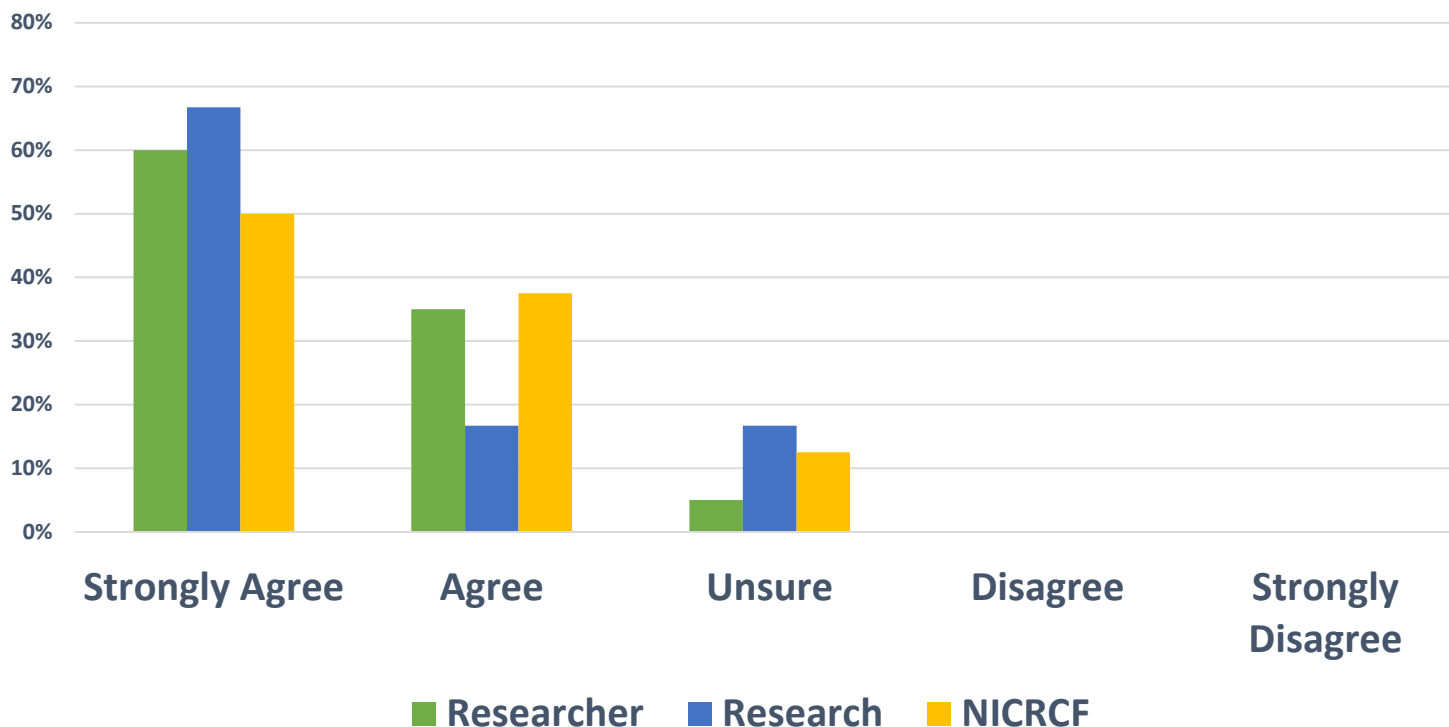
Evaluation Survey Results- funding

There is enough funding for PPI in cancer research in NI to be effective



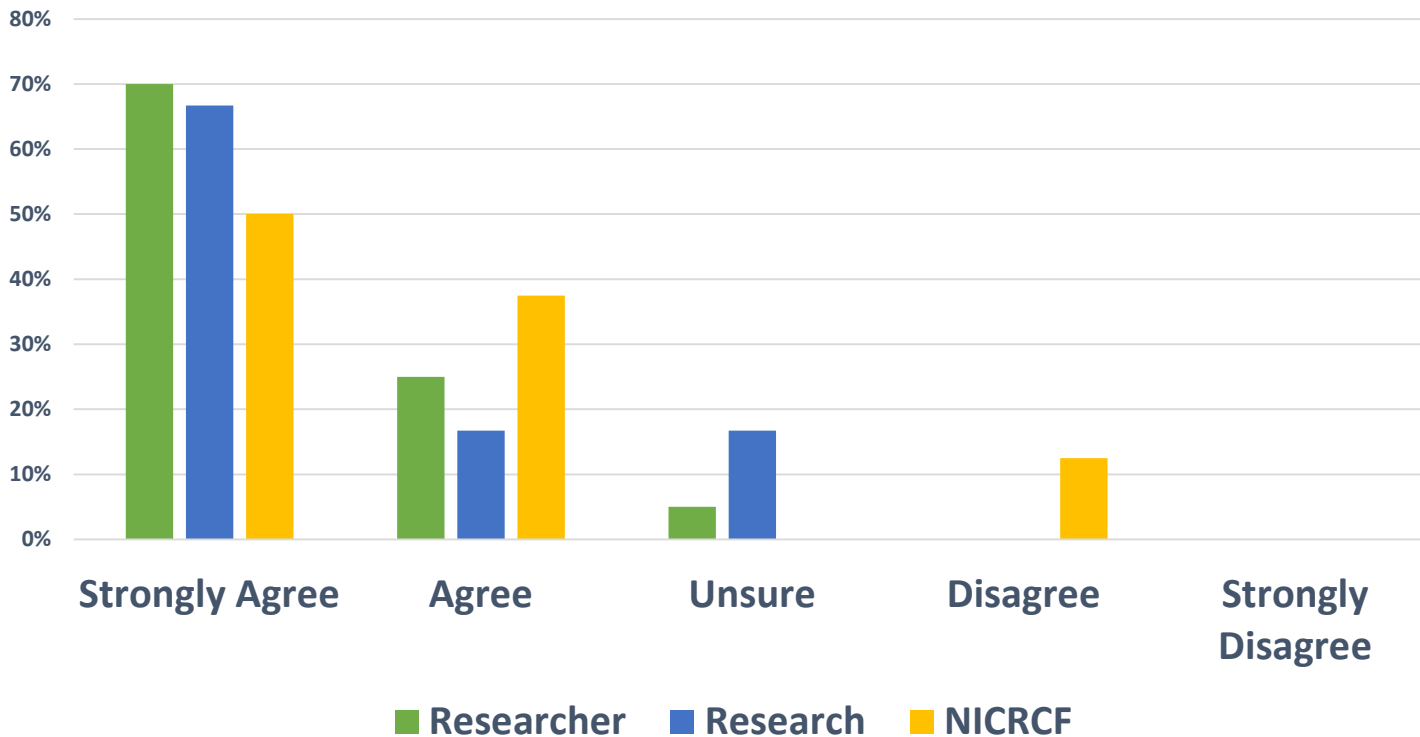
Evaluation Survey Results - PPI Expectations

My experience of PPI in cancer research met my expectations



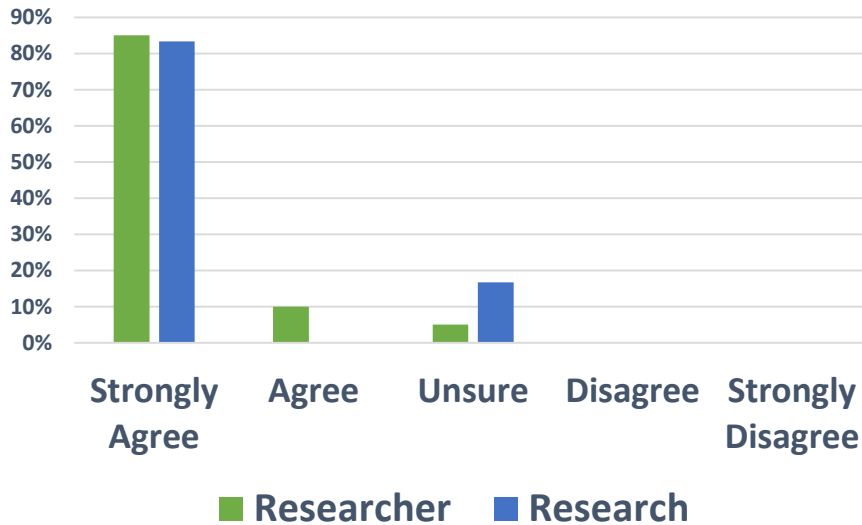
Evaluation Survey Results - PPI members valued

NICRCF members are valued research partners/
NICRCF feel a valued research partner

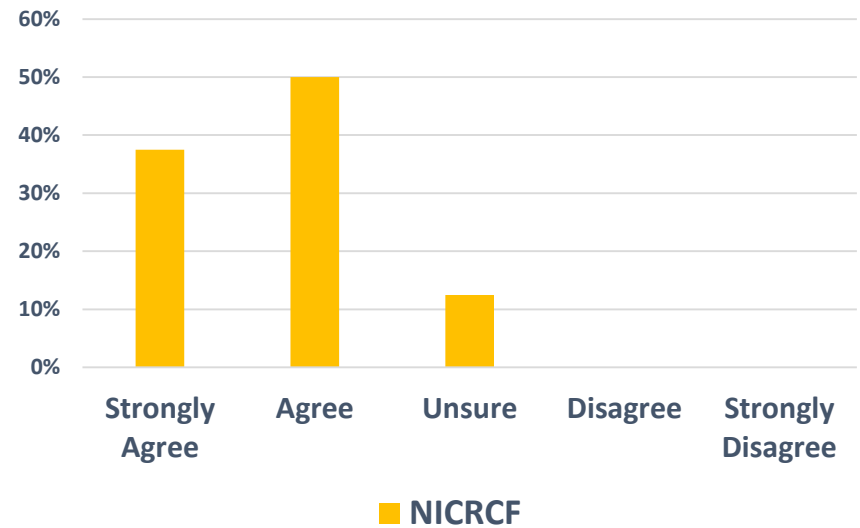


Evaluation Survey Results – meaningful PPI

I support NICRCF / NICRCF members to have meaningful involvement in research

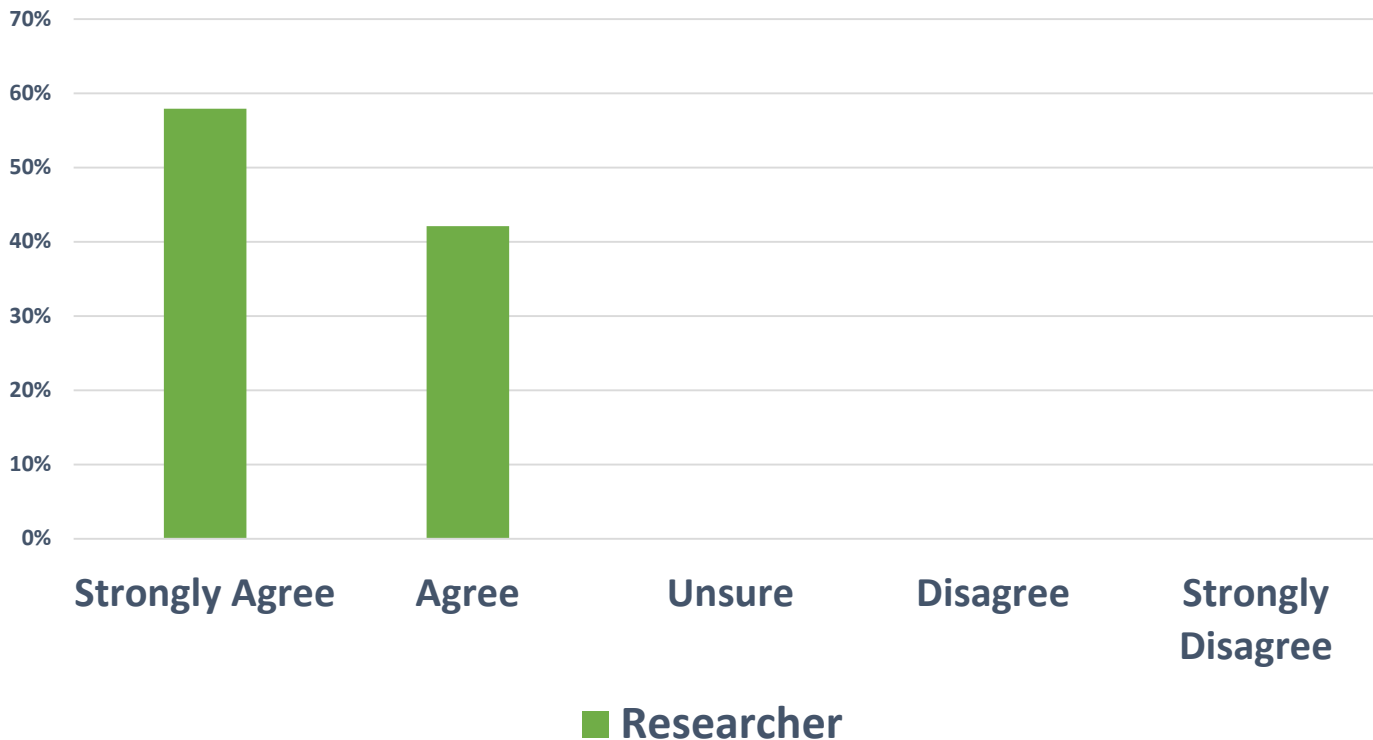


NICRCF: Researchers have the right reasons for wanting to work with me/us



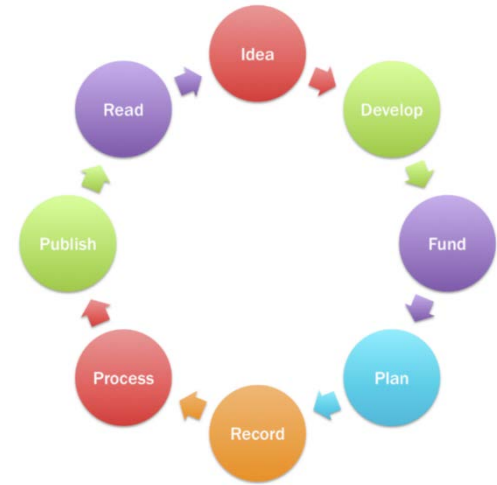
Evaluation Survey Results – quality research

Researcher: In my experience PPI has enhanced the quality/success of MY cancer research



Evaluation Survey Results – 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



Evaluation Survey Results – other impact

‘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*



Evaluation Survey Results – other impact

‘The most important thing that PPI do for me is to remind that clinical trials are 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!’

Researcher



Evaluation Focus Group Results

- **Many positives:** e.g. researchers and their compassion, support within the members of the Forum, experience and commitment of members, flexible level of involvement, consistent leadership etc.
- **Not so good:** Concern Forum PPI work not valued by Trust, expenses process, lots of IT issues etc.
- **Going forward:** More acknowledgement of contribution, wider networking, effective researcher guidance, outreach communications etc.

Evaluation Survey Plus Focus Group

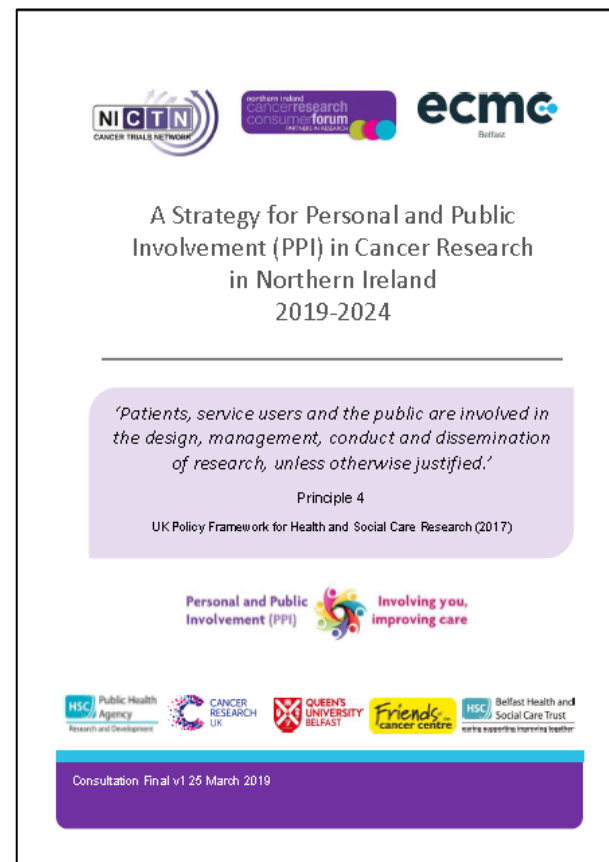
Summary of Recommendations:

1. Provide dedicated PPI **funding** and expenses processes
2. Enhance **support structures**
3. **Expand** PPI Representative numbers and wider networking
4. Enhance **training**
5. Raise researcher and public **PPI awareness**
6. Increase **PPI opportunities**
7. Share **PPI impact**

The NEW Strategy for PPI Cancer Research in NI – Consultation to end June 2019

GOALS

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



Early signs of Strategy Impact



- New Forum members
- New researcher PPI training in development
- New Forum member induction in development
- More systematic/comprehensive PPI data gathering

Special thanks to...

- Margaret Grayson and the Forum members
- The NI Cancer Trials Network
- All PPI researcher partners
- All cancer research stakeholders / survey participants
- Gail Johnston, HSC R&D
- Sandra McCarry, Belfast Trust PPI Senior Manager



Thank you so much.....



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