



AIHPC

All Ireland Institute of
Hospice and Palliative Care

How AIHPC can support you with Public and Patient Involvement in research through our Voices4Care group.

Clodagh O'Donovan, PCRN Project Manager, AIHPC
and Monica Burns, Voices4Care member



AIHPC Palliative Care Research Network (PCRN)

53 Palliative Care Research Network members across 9 disciplines



UCC
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland



**QUEEN'S
UNIVERSITY
BELFAST**



Respite
Rehabilitation Harold's Cross
Reassurance & Blackrock



St. Francis Hospice
Raheny | Blanchardstown



OLLSCOIL NA GAILLIMHE
UNIVERSITY OF GALWAY



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

AIHPC Early Career Researcher Forum (ECRF)

- For early and mid-career researchers in palliative care research
- Opportunities to access peer and mentor support, develop links with senior researchers, participate in capacity building workshops and events, and share knowledge
- Currently 219 members from academic, clinical, charity, service provider and regulatory organisations across the island of Ireland





Include public and patient voices to improve your research





V4C members: people with life-limiting conditions, family carers, and interested citizens who guide the work of AllHPC, our partners, and wider stakeholders





“

‘The opportunity to contribute and for my experiences as a former carer to be heard and hopefully help make improvements for others and myself in the future health care systems.’

”

“

‘This was a golden opportunity and to use your voice to make palliative care better for the next person – someday it could be you or one of your loved ones.’

”



‘I have really enjoyed being part of the Voices4Care work and am very impressed at the degree of engagement of members. It really isn't like any other group I've been on. It really has been an honour to be involved.’



16 members
NI

36 members
ROI

52 members

13%
Interested
citizen

8%
Service user

85%
females

68%
carer/former

15%
males

51
average age



When would you get Voices4Care members involved in research?

**EARLY &
OFTEN**





How to involve Voices4Care members in your research?

Voices4Care involvement request process and form

tinyurl.com/V4CinvolvementRequest

Email completed form to:
mrabbitte@aiahpc.org, and
codonovan@aiahpc.org



AIIHPC
All Ireland Institute of
Hospice and Palliative Care

Voices4Care Involvement Request Form

Please complete this form to enable us to provide more information on your request to our Voices4Care members. **When completed please send to mrabbitte@aiahpc.org.**

Name	
Organisation	
Phone Number	
Email address	

Please provide a **description of your request** in easy to understand language (avoiding the use of acronyms or



Final Thoughts

- Think about the value Voices4Care members can contribute to your project
- Respect that Voices4Care members are volunteering their time
- Provide ample time before a project and throughout the process – don't rush
- Consider any particular needs Voices4Care members may have, and make appropriate accommodations
- Important to feedback to Voices4Care members on your research and their impact on it

Other helpful resources on PPI in research:

- New **web resource** on public involvement in palliative care research on ProfessionalPalliative Hub.com: tinyurl.com/AIIHPCppi
- Recording from **PPI within context of palliative care research workshop**: tinyurl.com/PPIinResearch
- **Writing to be understood: plain English**: tinyurl.com/DigitalCommunicationSkills (43 minutes in)
- **Making a start** – how to build a PPI relationship: hrci.ie/a-new-ppi-toolkit

Patients, their Families and Carers, and Interested Citizens Involvement in Palliative Care Research

1. [What is PPI?](#)
2. [What is PPI in palliative care research?](#)
3. [Why is PPI important?](#)
4. [How do AIIHPC support PPI?](#)
5. [Helpful resources](#)

Online Workshop
March 2022, 9:10am-13:15pm

PPI Within the Context of Palliative Care Research

Host:  AIIHPC
All Ireland Institute of Hospice and Palliative Care

Proudly supported by:

 HSC Public Health Agency
Research and Development

 KING'S COLLEGE LONDON

 NATIONAL OFFICE FOR RESEARCH ETHICS COMMITTEES

 HRB
Health Research Board

 PPI NETWORK

 UCC
University College Cork, Ireland
Coláiste na hOileáine Corcaigh

 NUI Galway
OÉ Gaillimh

PPI within the context of palliative care research
35 views • 3 May 2022

 Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

 HRCI
Health Research Charities Ireland

MAKING A START:
A toolkit for research charities
to begin a PPI relationship

Thank you

Further information:

ProfessionalPalliativeHub.com/Research

thepalliativehub.com (*links to adult, children & young people, carers, learning, and professional palliative hubs*)

Contact:

codonovan@aiihpc.org



PPI in Palliative
Care Research