



# AIIHPC

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All Ireland Institute of  
Hospice and Palliative Care

Monica Burns, Voices4Care



# Experience of Palliative Care in Partnership Research



## ‘Cradle to grave’ care

Health care “from the cradle to the grave” is the founding promise of the NHS.

‘The care that gets us to the cradle is proactive, research-based and commissioned based on population needs. But ..... how carefully is care for those in the process of dying, a process that will affect every citizen, being commissioned, planned and delivered?’

... And that’s where all of you – and we – come in



## Who are we in Voices 4 Care?

- Voices4Care is the patient and carer voice within the All Ireland Institute for Palliative and Hospice Care
- All members are either recipients of care for a life limiting condition or are carers for friends or family who are receiving end of life care or who have already died
- Every one of the members has real life experience of what dying is like – and every one of them is happy to share their experience if it will help to make end of life care better for more people



# The role of Voices 4 Care members in research

We contribute to the work of the Strategic Scientific Committee by

- Advising on research topics
- Commenting on research proposals
- Reviewing and commenting on research papers



# How to make it easier to use lay people in your research

Keep the research real. The more esoteric the less likelihood volunteers will want to be involved!

Make the language accessible - we don't all speak the same professional jargon

Accept that volunteers are fitting their involvement in with their own jobs and everything else they're doing



# How to request involvement from Voices4Care

Voices4Care involvement request form:

[tinyurl.com/V4CinvolvementRequest](https://tinyurl.com/V4CinvolvementRequest)

Email completed form to:

[mrabbitte@aiahpc.org](mailto:mrabbitte@aiahpc.org) and [codonovan@aiahpc.org](mailto:codonovan@aiahpc.org)