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

PPI IGNITE NETWORK

KING'S College LONDON

UCC
University College Cork, Ireland
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NATIONAL OFFICE FOR RESEARCH ETHICS COMMITTEES

HRB Health Research Board

NUI Galway
OÉ Gaillimh

Workshop background & objectives

PPI is a term used in health and social care research. On the island of Ireland PPI refers to Personal and Public Involvement or Public and Patient Involvement in research.

AIIHPC developed and delivered an online workshop 'PPI within the context of palliative care research' to support its Palliative Care Research Network and Early Career Researcher Forum members, and partner organisations to build capacity within PPI.

Attendees at this event expanded their knowledge on how to:

- Prepare for, and manage, PPI challenges and sensitivities which are unique to palliative care research
- Widen PPI activities to facilitate meaningful involvement of PPI contributors
- Develop PPI recruitment approaches and strategies that foster inclusivity and support diversity

Please note: *Not all presentation slides are available from the workshop and group work activities and group discussions are not included within the contents provided in the playback recording.*

1st Presentation

AIIHPC Voices4Care Involvement in Research

Dr Mary Rabbitte,
Research Programme Manager,
All Ireland Institute of Hospice and Palliative Care

AIIHPC
All Ireland Institute of Hospice and Palliative Care

VOICES 4 CARE

Improving the Palliative Care Experience

Research to Improve Quality of Life for People with Palliative Care Needs and Families

AIIHPC

Palliative Care Research Network

51 Palliative Care Research Network members across 9 disciplines

AIIHPC Early Career Researcher Forum

- 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 share knowledge
- Currently 209 members from academic, clinical, charity, service provider and regulatory organisations on the island of Ireland

AIIHPC
Early Career Researcher Forum

Join the ECRF apply online

VOICES 4 CARE

Improving the Palliative Care Experience

36 members people with life-limiting conditions, family carers and interested citizens who guide the work of AIIHPC, partners and wider stakeholders

When would you get Voices4Care members involved in research?

Which stage do you think was most popular with researchers to involve Voices4Care members ?

In 2021 Voices4Care members were involved in 17 research activities/projects

Think and Plan

- Feedback on proposal for research on people with heart failure preferences for care and treatment
- Feedback on funding proposal to National Institute of Health Research (NIHR) for Palliative and end-of-life care research partnership in Northern Ireland

Discover

- Members of advisory group on project examining the experience of people in the Republic of Ireland living in nursing homes, their families and staff during COVID-19

Gather and Analyse

- Attending a workshop to support the development of an e-health service on advance care planning
- Sharing perspectives for research study commissioned by the Department of Health to inform update of national palliative care policy in the Republic of Ireland

Write and Publish

- Attending an event to discuss perspectives on end-of-life care data collected by government bodies
- Reviewing and inputting content for PPI in Palliative Care webpage on The Palliative Hub – Professional

Share/Impact

- Informing AIIHPC's 10th Annual Palliative Care Research Network Symposium on 'Equality and Equity in Palliative Care' and taking part in panel discussion

Final Thoughts

- Do you know what you don't know?
- Just because it could be difficult doesn't mean it isn't achievable
- Think about what you would like Voices4Care members to contribute to
- Think about what recommendations they make and what action is taken. Important to feedback to Voices4Care members.

For further information on Voices4Care contact Mary Rabbitte mrabbitte@aiihpc.org or
Email: info@aiihp.org | **Visit:** www.thepalliativehub.com | **Follow**: @aiihpc

2nd Presentation

Public involvement in palliative care: principles and practicalities

Dr Lisa Brighton, Research Associate at Cicely Saunders Institute, King's College London and Margaret Ogden, Patient and Public Contributor at the Cicely Saunders Institute, King's College London

Public involvement in research: Principles and Practicalities

Lisa Brighton & Margaret Ogden

Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London

Lisa.brighton@kcl.ac.uk / margaretogden@hotmail.com

Acknowledgements:

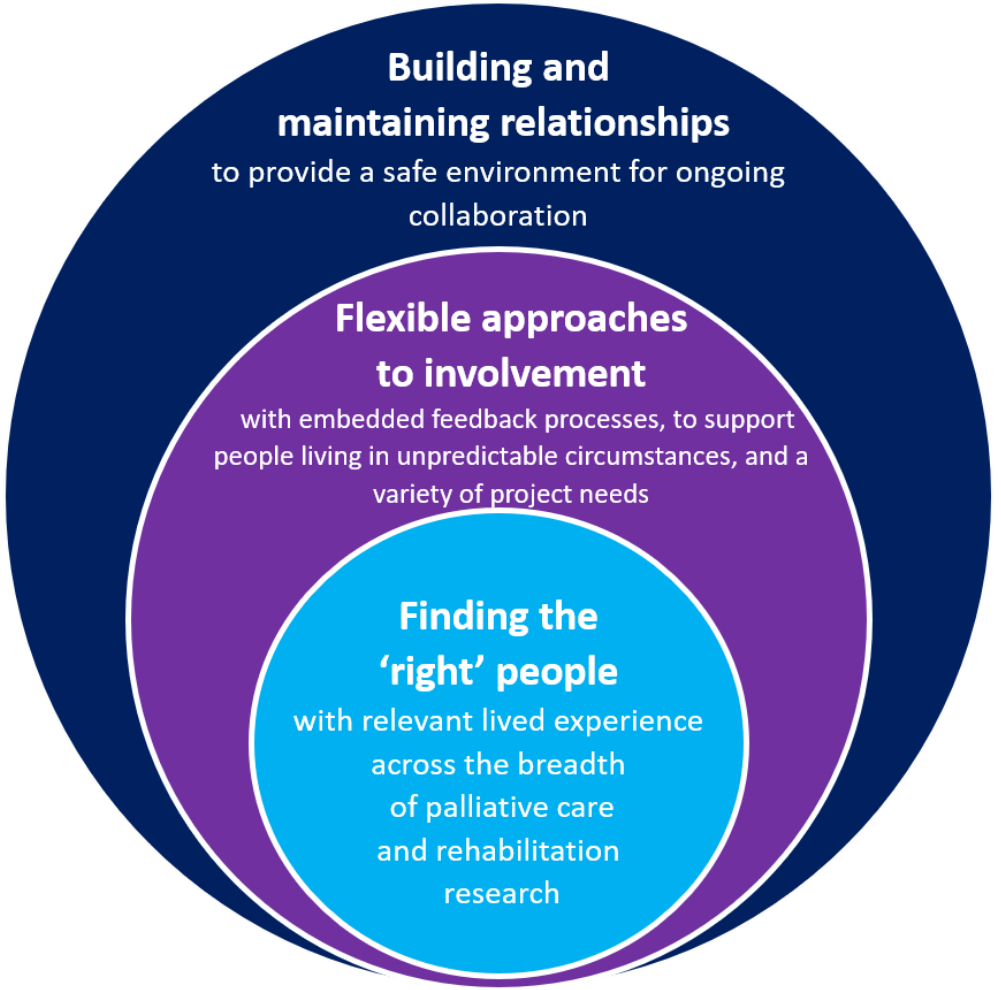
Thank you to professional and public colleagues for their contributions to previous versions of these slides

Plan for presentation

- Introducing our key principles and where they came from

- Putting these principles into practice:
  - Finding the right people
  - Flexible approaches to involvement
  - Building and maintaining relationships

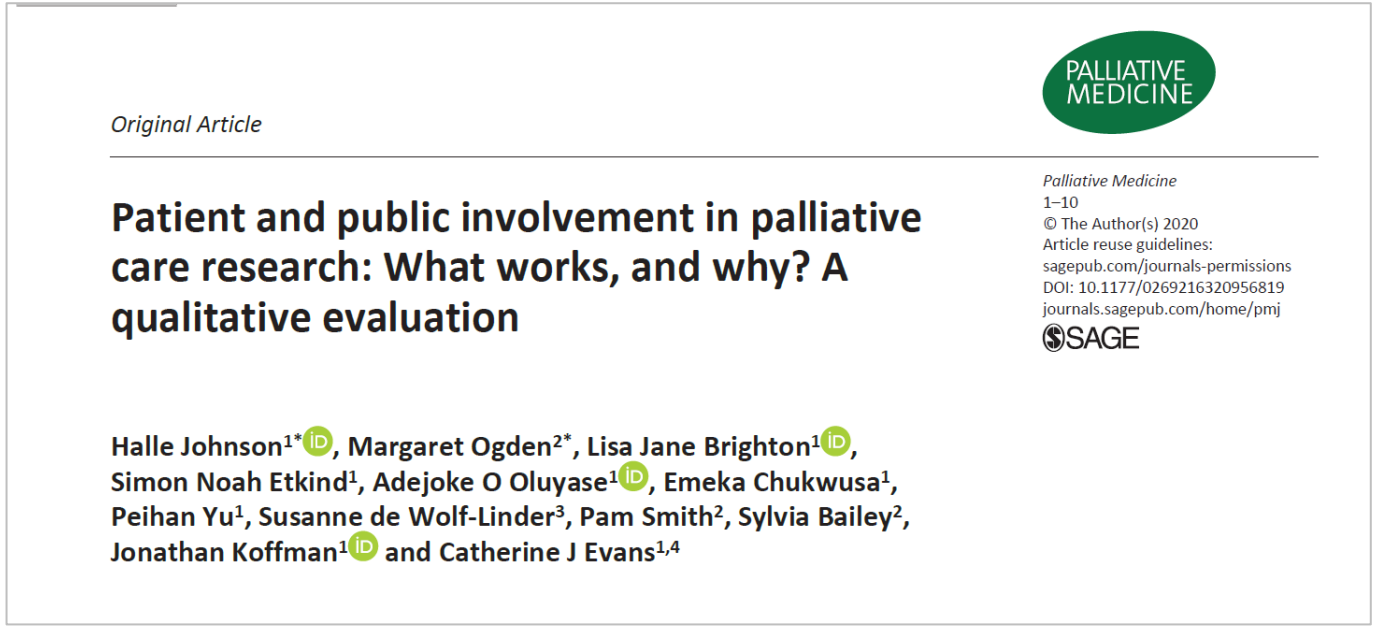
Note - common abbreviations:
PPI: Patient and Public Involvement
CSI: Cicely Saunders Institute



Background to our principles

- **Aim:** To evaluate our public involvement strategy, & identify successful approaches

- **Design:** Coproduced qualitative evaluation, including focus groups & interviews with public members & researchers at our Institute



Original Article

PALLIATIVE MEDICINE

Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation

Palliative Medicine
1–10
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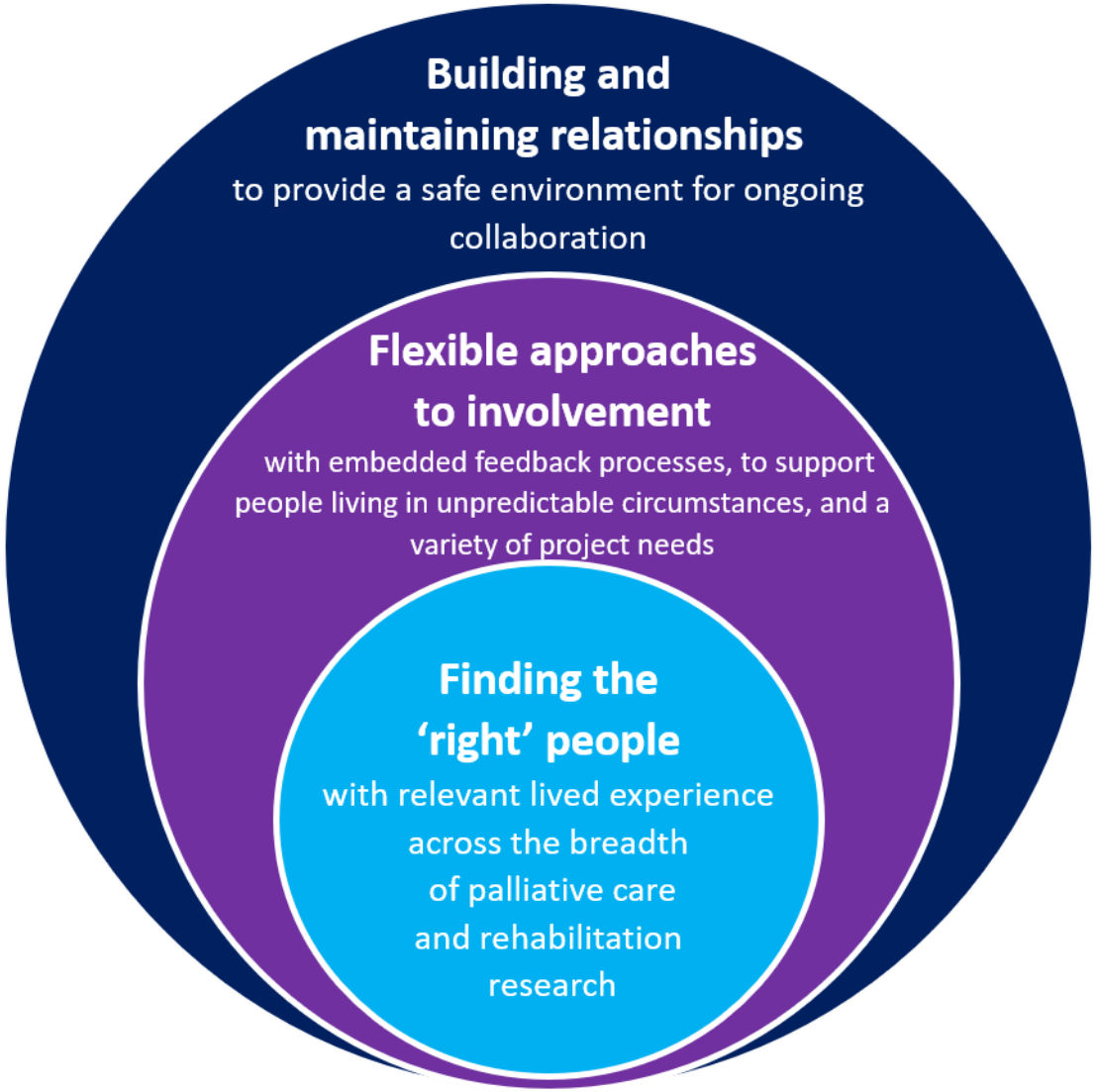
Halle Johnson[1*], Margaret Ogden[2*], Lisa Jane Brighton[1], Simon Noah Etkind[1], Adejoke O Oluyase[1], Emeka Chukwusa[1], Peihan Yu[1], Susanne de Wolf-Linder[3], Pam Smith[2], Sylvia Bailey[2], Jonathan Koffman[1] and Catherine J Evans[1,4]

https://doi.org/10.1177/0269216320956819

Key principles for public involvement in palliative care



Putting these principles into practice…

A helpful starting point

What is the aim of public involvement for your study?

Finding the right people

Who are the ‘right people’ to involve in my project?

People with relevant lived experience

Finding the right people – level of experience

Should I involve brand new public members, or more experienced public members?

Often depends on the task, but can be beneficial to hear from both.

Finding the right people – diversity & inclusion

How can I attend to diversity and inclusion within my public involvement activities?

- **reach out to seldom-heard groups**
- **be flexible**
- **check accessibility requirements**
- **reimburse people**

Lots of resources to help

- Available resources…
  - Improving diversity in health research and trials
  - Principles of Engagement
  - Survey guidance
  - INCLUDE ethnicity framework
  - Being Inclusive in Public Involvement in Health Research
  - Toolkit for increasing participation of Black Asian and Minority Ethnic Groups in Health and Social Care Research
  - Positive image library

egality
diversity in research
equality in health

edis
Equality, Diversity and Inclusion in Science and Health

NIHR | National Institute for Health Research

Centre for Ageing Better
Action today for all our tomorrows

Thank you to Cat Harvey for highlighting these resources

Flexible opportunities for involvement

How can I be more flexible with involvement opportunities?

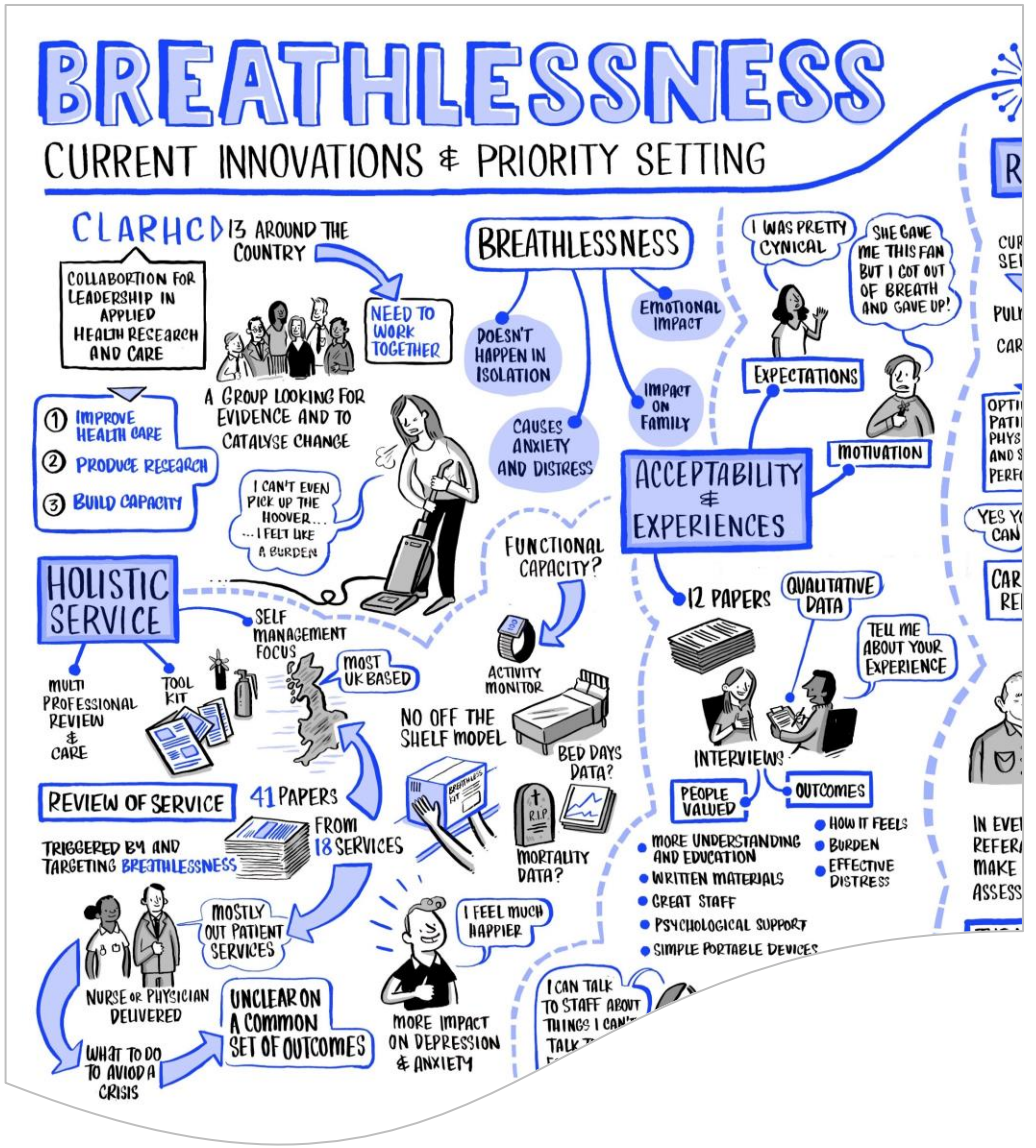
- **Allow plenty of time (where possible!)**
- **Use multiple methods of communication**
- **Use varied involvement activities**
- **Provide opportunities throughout the research cycle**
- **Consider out-of-ours activities**

Examples from individual projects

- Encourage contributions to areas that particularly suit peoples' interests and/or backgrounds
- Offering other ways to contribute when unable to attend a meeting or event
- Offering extra training or support for new/complex activities
- Having additional team members to account for likely absences

Examples of diverse activities

- Reviewing applications & being a co-applicant
- Study branding & promotion
- Supporting qualitative analysis
- Co-authoring papers & blog posts
- Involvement with teaching (e.g. masters students)
- Involvement with executive strategy groups



Part of an illustration by Joel Cooper - www.joelcooper.co.uk

Building and maintaining relationships

- Top 3 characteristics of a researcher in a public involvement relationship…

1. A researcher who is a good communicator, e.g. someone who keeps in touch

2. A researcher who can show respect, empathy and understanding

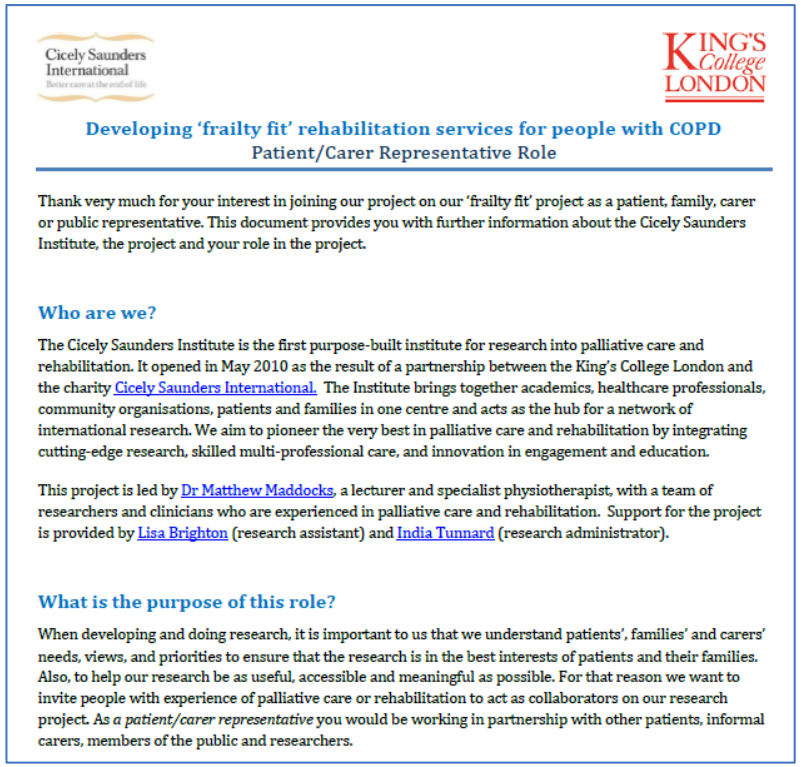
3. A researcher who has time for the public contributors

See here: Making a start toolkit

Thank you to Cat Harvey for highlighting this resource

Starting off:

- Plain English study description
- Aim/Purpose of involvement
- What help you'll be looking for
- Practical information on travel/reimbursement/timelines
- What they can expect from you



Cicely Saunders International
Better care at the end of life

KING'S College LONDON

Developing 'frailty fit' rehabilitation services for people with COPD
Patient/Carer Representative Role

Thank very much for your interest in joining our project on our 'frailty fit' project as a patient, family, carer or public representative. This document provides you with further information about the Cicely Saunders Institute, the project and your role in the project.

Who are we?

The Cicely Saunders Institute is the first purpose-built institute for research into palliative care and rehabilitation. It opened in May 2010 as the result of a partnership between the King's College London and the charity Cicely Saunders International. The Institute brings together academics, healthcare professionals, community organisations, patients and families in one centre and acts as the hub for a network of international research. We aim to pioneer the very best in palliative care and rehabilitation by integrating cutting-edge research, skilled multi-professional care, and innovation in engagement and education.

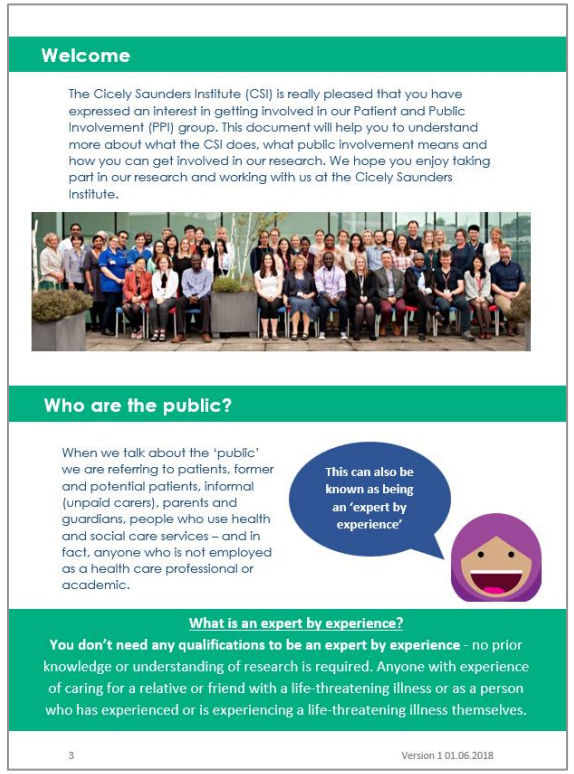
This project is led by Dr Matthew Maddocks, a lecturer and specialist physiotherapist, with a team of researchers and clinicians who are experienced in palliative care and rehabilitation. Support for the project is provided by Lisa Brighton (research assistant) and India Tunnard (research administrator).

What is the purpose of this role?

When developing and doing research, it is important to us that we understand patients', families' and carers' needs, views, and priorities to ensure that the research is in the best interests of patients and their families. Also, to help our research be as useful, accessible and meaningful as possible. For that reason we want to invite people with experience of palliative care or rehabilitation to act as collaborators on our research project. As *a patient/carer representative* you would be working in partnership with other patients, informal carers, members of the public and researchers.

Training needs

- In-person public involvement training e.g.
  - Biomedical Research Centre
  - Funders (e.g. Marie Curie, NIHR)
  - Imperial College London online resources
- PPI Research Handbook
- INVOLVE jargon buster
- Informal one-to-one / project group training



Welcome

The Cicely Saunders Institute (CSI) is really pleased that you have expressed an interest in getting involved in our Patient and Public Involvement (PPI) group. This document will help you to understand more about what the CSI does, what public involvement means and how you can get involved in our research. We hope you enjoy taking part in our research and working with us at the Cicely Saunders Institute.

Who are the public?

When we talk about the 'public' we are referring to patients, former and potential patients, informal (unpaid carers), parents and guardians, people who use health and social care services – and in fact, anyone who is not employed as a health care professional or academic.

This can also be known as being an 'expert by experience'

What is an expert by experience?

You don't need any qualifications to be an expert by experience – no prior knowledge or understanding of research is required. Anyone with experience of caring for a relative or friend with a life-threatening illness or as a person who has experienced or is experiencing a life-threatening illness themselves.

3 Version 1 01.06.2018

Providing feedback

Guidance from Elspeth Mathie's team at the University of Hertfordshire

Reflections and reporting

GRIPP2 Reporting checklists for public involvement in research
Staniszewska et al. BMJ 2017
https://doi.org/10.1136/bmj.j3453

Table 2 GRIPP2 short form

Section and topic	Item
1: Aim	Report the aim of PPI in the study
2: Methods	Provide a clear description of the methods used for PPI in the study
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience

PPI patient and public involvement

UK National Standards for public involvement
https://sites.google.com/nihr.ac.uk/pi-standards/home

Final messages

- Lots of tools/resources to help with, patient and public involvement
- Important to think through early on to ensure enough time and resources
- No ‘right way’ - different projects, different involvement
- Important to share feedback, learning and impact

Thank you for listening

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