

Part One

Personal & Public Involvement - the Definition



Margaret Grayson

Service User

HSC R&D PIER (Public Involvement Enhancing Research)

NI Cancer Research Consumer Forum



Defining Personal and Public Involvement (PPI) in Research

It is not:

Participation - where people are recruited to take part in research studies as the subjects of the research

It is not:

Engagement - where knowledge about research is shared to give information and to raise awareness

It is:

Involvement - where patients, carers and the public are actively involved in research decisions

Involvement! Engagement! Participation!

The following statements have been made in applications to Research Ethics Committees to show how researchers have involved patients and the public in the development of their research proposal or how they will involve them in the research. Thinking back to our definitions on the previous slide, decide whether it really is involvement or not.

1. Researchers have worked with a service user group and have service users as co – applicants who have influenced the design.
2. Patients will be invited to participate by completing questionnaires.
3. Researchers will disseminate findings to the public.
4. Patient information sheets were written or assessed by a patient advisory group.



Quiz- Involvement! Engagement! Participation!

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1. Researchers have worked with a service user group and have service users as co – applicants who have influenced the design.(I)
2. Patients will be invited to participate by completing questionnaires.(P)
3. Researchers will disseminate findings to the public.(E)
4. Patient information sheets were written or assessed by a patient advisory group.(I)

Involvement:

work is undertaken 'with' or 'by' patients and the public rather than 'to,' 'for' or 'about' them

or in other words

the research team is working collaboratively with patients and the public



Part Two

Why PPI?



Dr Janet Diffin
Programme Manager
HSC R&D Division
Public Health Agency
Northern Ireland



Personal and Public
Involvement (PPI)



Involving you,
improving care



Strategic drivers

Personal and Public Involvement (PPI) - DoH Guidance to HSC

Date published: 03 December 2015

Topics: Safety and quality standards, Personal and Public Involvement (PPI)

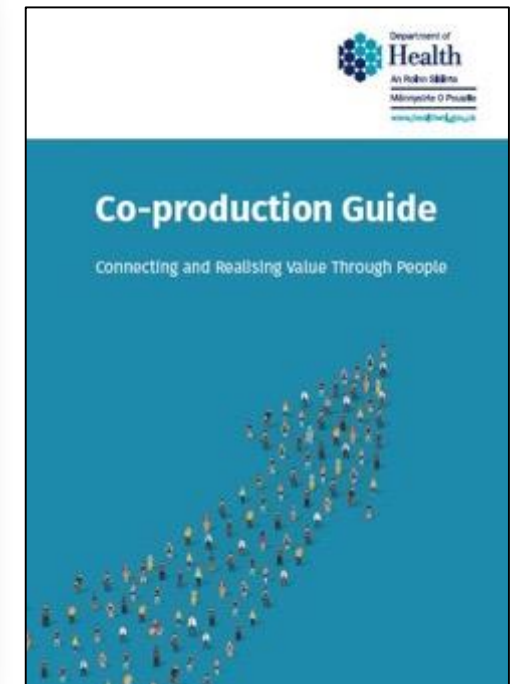
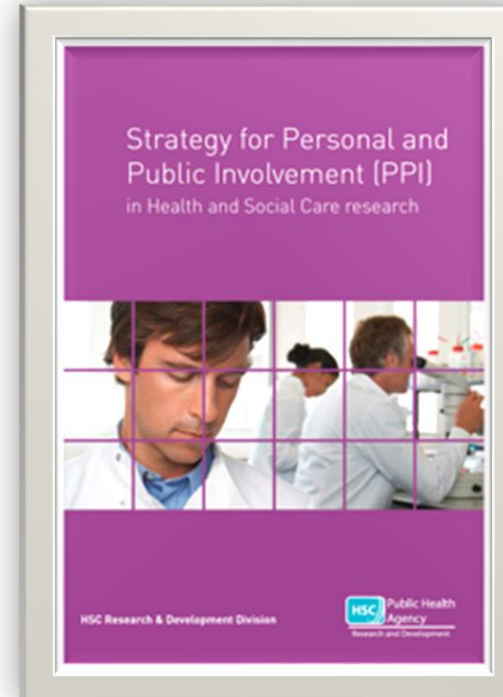
DoH Guidance issued to Health and Social Care Organisation in relation to Personal and Public Involvement (PPI)

Documents

-  HSC (SQSD) 03-12 - Guidance for HSC Organisations on Arrangements for Implementing effective Personal and Public Involvement Policy in the HSC
PDF (308 KB)
-  HSC (SQSD) 01-12 - Personal and Public Involvement – Regional Protocol on Exceptional Circumstances for Consultation Schemes
PDF (133 KB)
-  HSC (SQSD) 29-07 - Guidance on Strengthening Personal and Public Involvement in Health and Social Care
PDF (449 KB)



Health and Social Care (Reform) Act (Northern Ireland) 2009



HRA Shared Commitment to Public Involvement

‘Public involvement is **important, expected** and **possible** in all types of health and social care research.

Together our organisations and members fund, support and regulate health and social care research. This statement is our joint commitment to improve the extent and quality of public involvement across the sector so that it is consistently excellent’



UK Standards for Public Involvement



- Developed over three years by a UK-wide partnership, the standards are a **description of what good public involvement looks like.**



Why Use PPI in Research?

- Different Perspectives
- Identification of meaningful topics
- Funding areas prioritised
- Better information
- More practical methods
- Higher recruitment
- Richer Data
- Findings more relevant
- Dissemination targeted
- More timely interventions



Benefits of Building Research Partnerships

For Researchers

- Greater knowledge and understanding of service users and carers
- Greater satisfaction and enjoyment
- Increased credibility
- Greater public trust
- Improved relationships with communities
- Partnerships to effect change

For PPI Representatives

- New skills and knowledge
- Sense of empowerment
- Support and friendships
- Enjoyment and satisfaction
- Career benefits



Part Three

The Research Cycle



Margaret Grayson

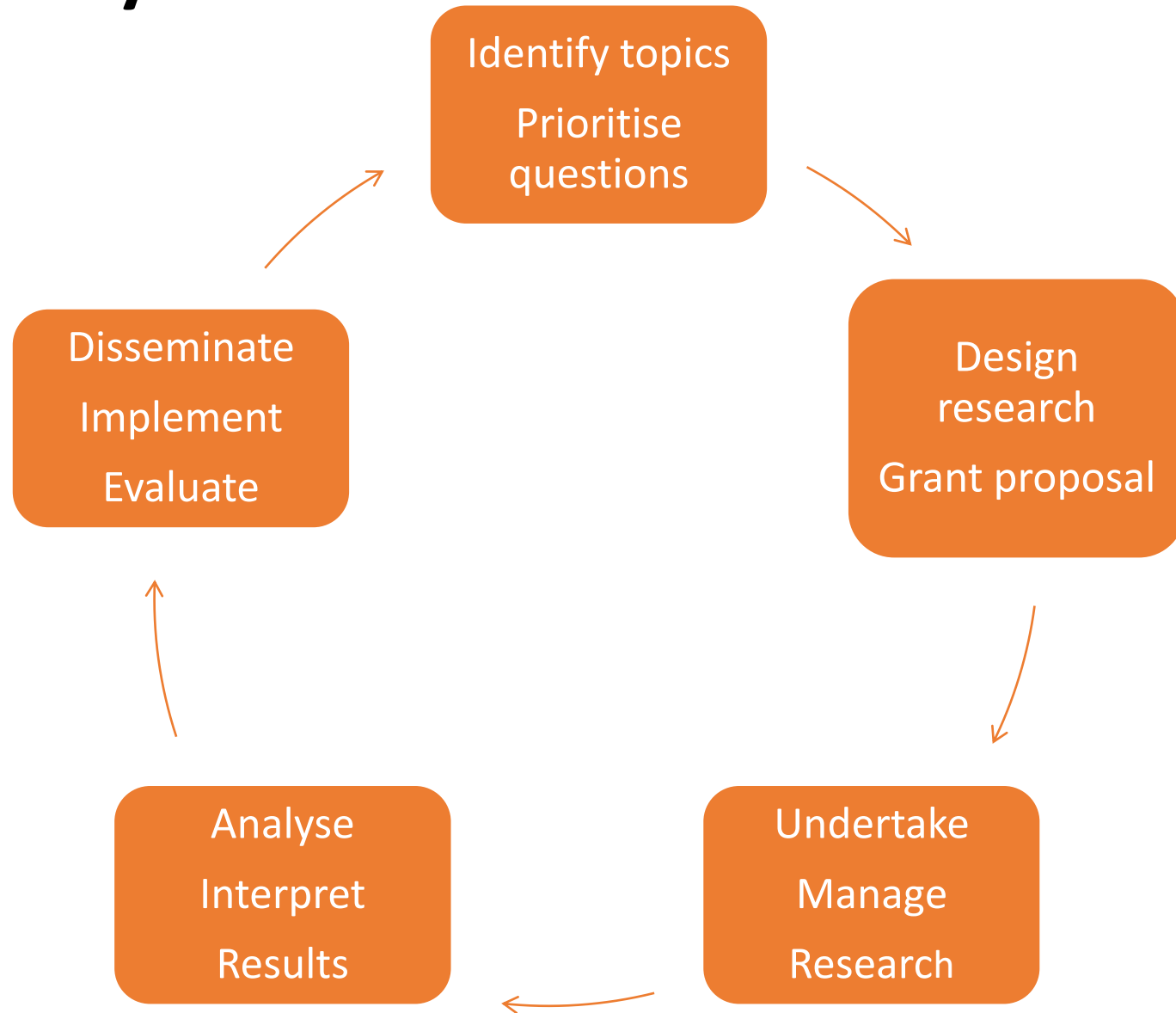
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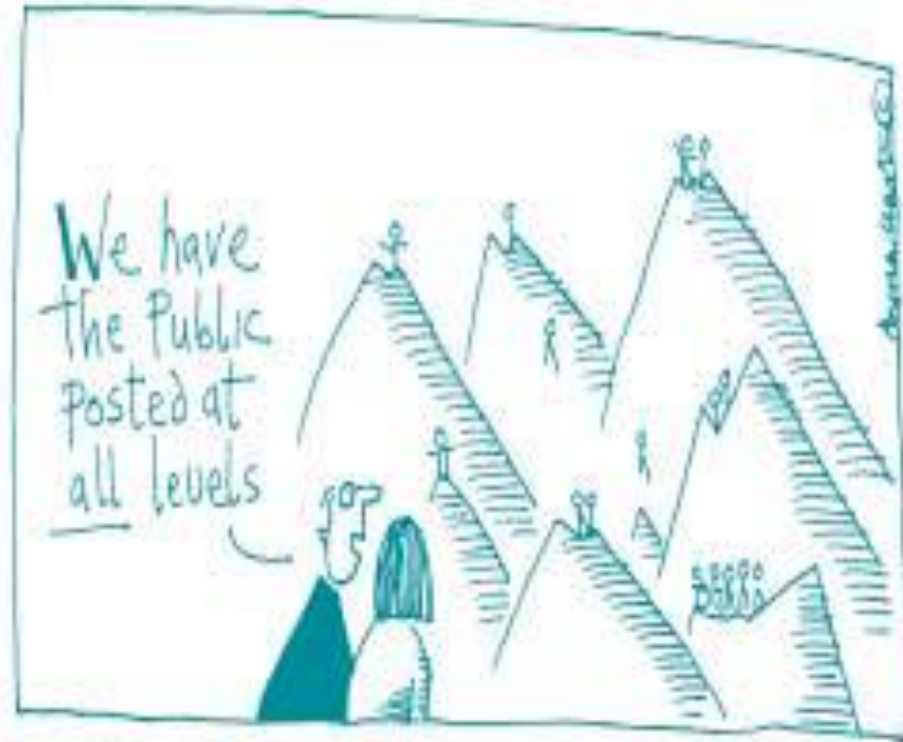


The Research Cycle

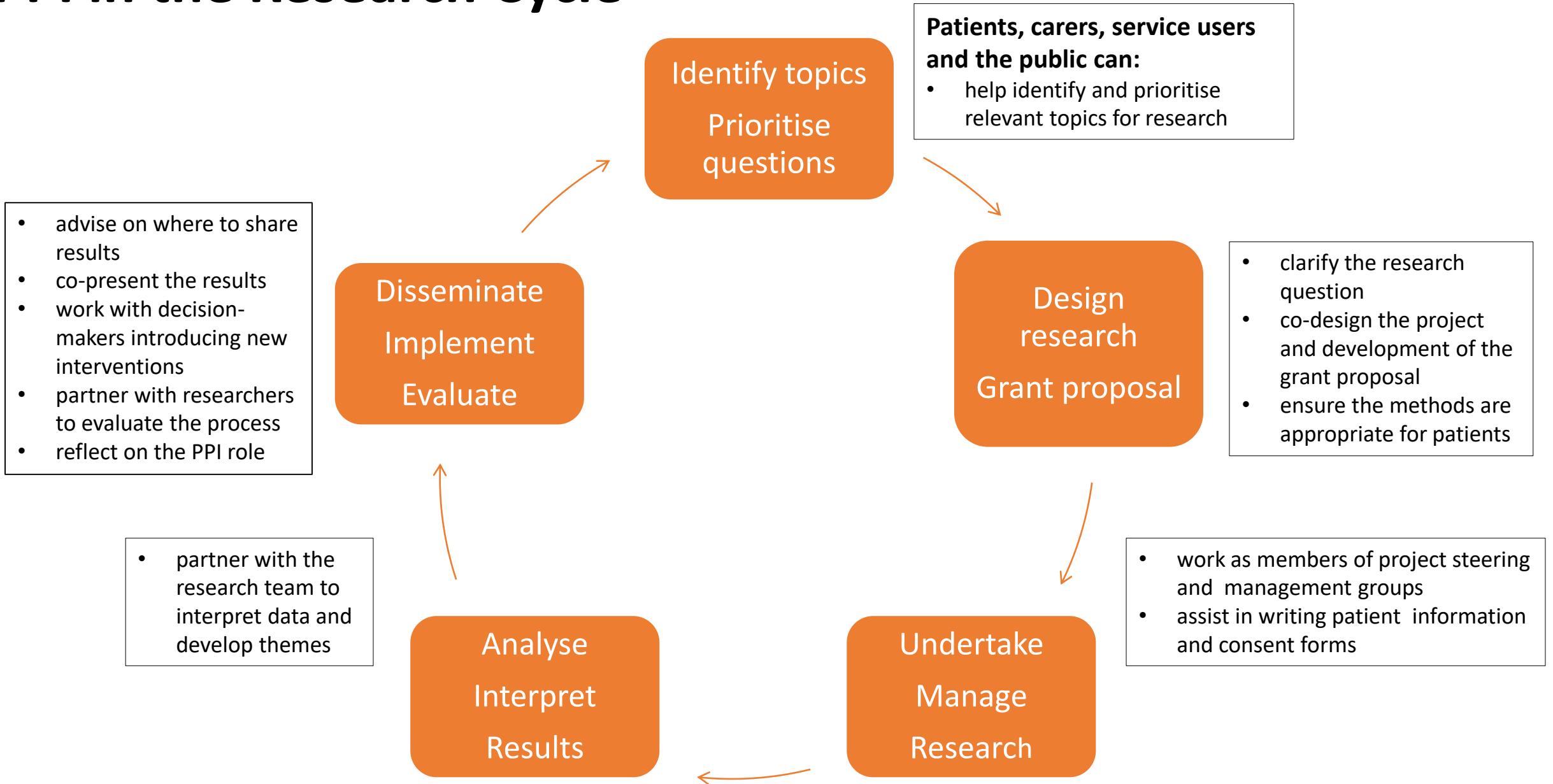


You are a researcher, thinking about involving people on a project on?

- When
- Who
- How Many
- Where
- What



PPI in the Research Cycle



How to incorporate patient and public involvement in the research process¹

Monitoring and Evaluation

Patients and public can have continued involvement with the study to maintain focus and address issues as they arise.
Collaborate with researchers to evaluate the research process
Reflect on their role and what they have learned

Implementation

Patients and public can increase the likelihood of results being implemented by adding validity to the findings
Develop patient information for new services/interventions within hospitals/GP surgeries etc

Dissemination

Patients and public can

1. Advise on different avenues for disseminating results
2. Jointly present the research findings with the researchers
3. Write information for local patient groups/hospitals
4. Assist in getting results/findings published on charities'/local voluntary organisations' websites
5. Help distribute results within their informal networks
5. Produce summaries of findings

Analysing and interpreting

Patients and Public can

1. Assist the research team in developing themes from data
2. Be consulted to see if they understand and interpret data in the same way as the research team

Identifying and Prioritising

Patients and public can

1. Help inform research priorities through local user groups
2. Be consulted about research topics and priorities important to them as service users
3. Collaborate with researchers to identify topics for research
4. Identify topics themselves

Design

Patients and public can

1. Inform the design of the research study
2. Clarify the research question and affirm its importance
3. Ensure the methods selected are appropriate for patients
4. Assist in creating a recruitment strategy
5. Review and comment on proposed questionnaires and data collection tools

Development of the Grant Proposal

Patients and public can

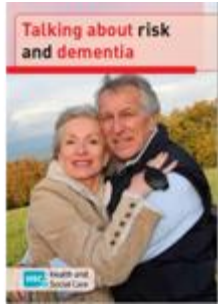
1. Help to ensure that the research proposed and chosen methods are ethical
2. Inform areas where patients and public could be involved
3. Provide ongoing advice on where patients and public could be involved
4. Define outcome measures
5. Advise on appropriateness of lay summary
6. Raise awareness of costs of involvement and expenses and prompt researchers to cost for involvement
7. Be named as co-applicants

Undertaking and Managing

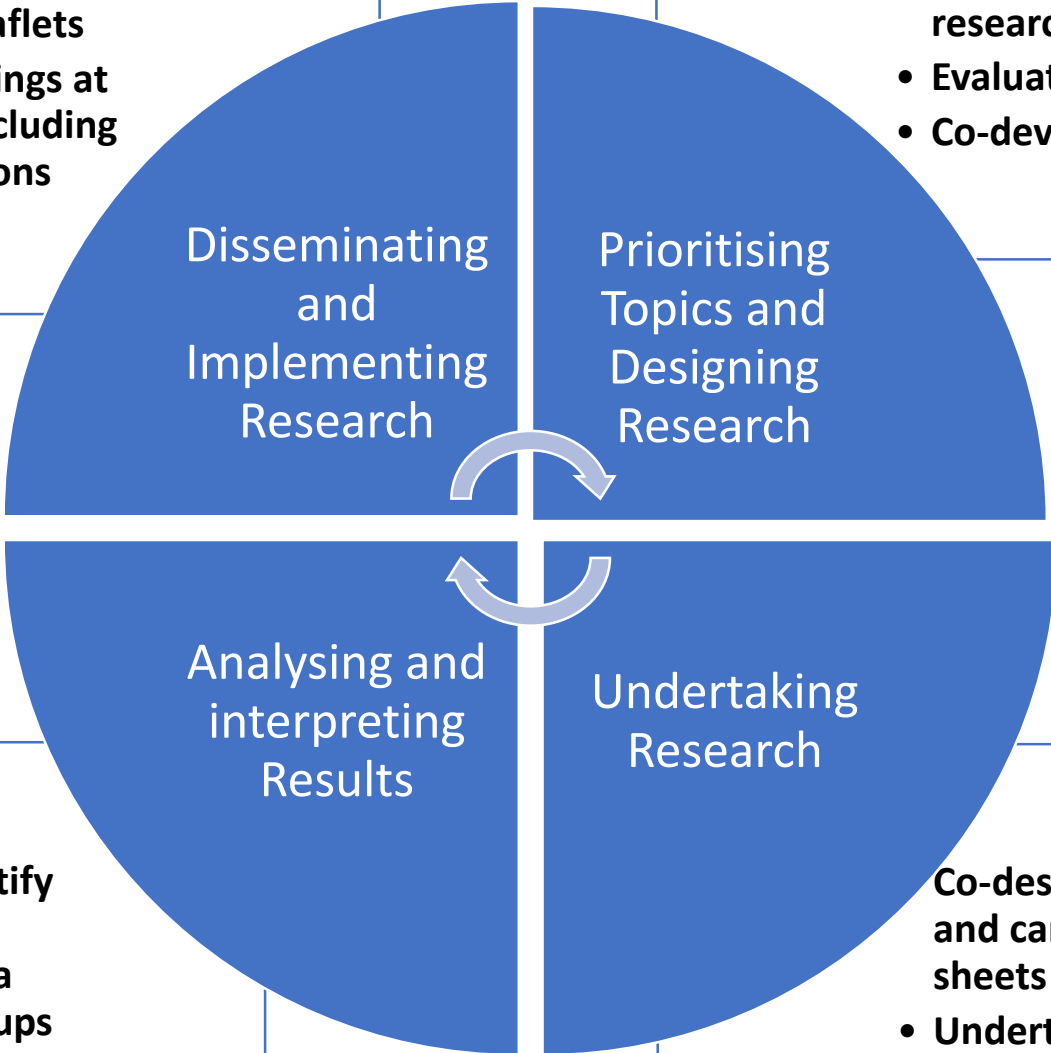
Setting up a steering group to manage and monitor the research, Patients and public can

1. Steer the project throughout the research process
2. Assist in writing the patient information and consent forms
3. Aid in designing the research protocol
4. Produce research updates that are patient friendly
5. Can assist in conducting patient interviews and surveys

PPI in Dementia Care Research²



- Co-wrote reports and information leaflets
- Presented findings at conferences including via art exhibitions



- Prioritised Topics for research
- Evaluated proposals
- Co-developed an app

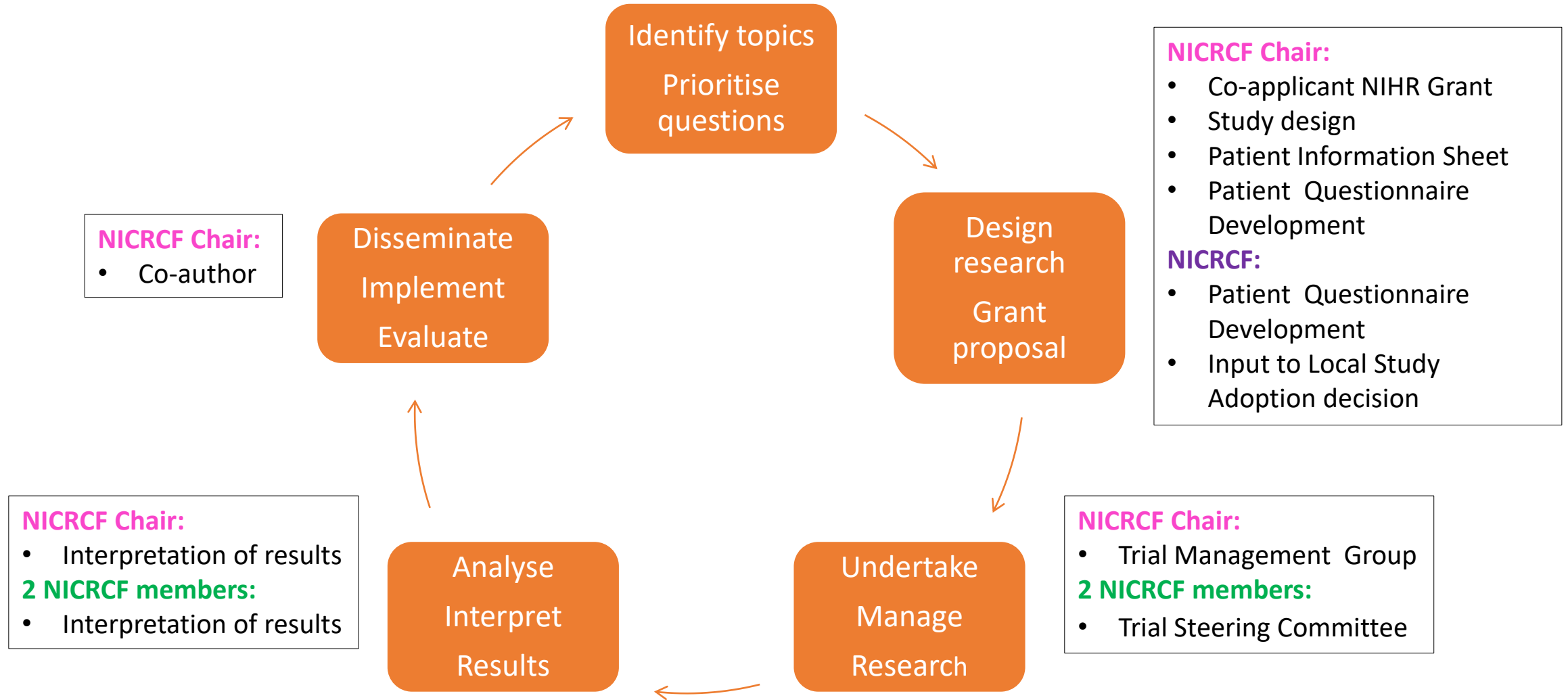


- Helped to identify themes in qualitative data from focus groups

- Co-designed patient and carer information sheets
- Undertook interviews



NI Cancer Research Consumer Forum (NICRCF) Involvement in the EASI-SWITCH trial - Early switch to oral antibiotic therapy in patients with low risk neutropenic sepsis³



References

1. Building Research Partnerships, Macmillan Cancer Support - adapted with kind permission from Patient and Public Involvement in Health and Social Care Research: A Handbook for Researchers by Research Design Service, London.
2. <https://research.hscni.net/dementia-care-commissioned-call-2013-2014>
3. Forde, C., McMullan, R., Clarke, M. *et al.* Early switch from intravenous to oral antibiotic therapy in patients with cancer who have low-risk neutropenic sepsis (the EASI-SWITCH trial): study protocol for a randomised controlled trial. *Trials* **21**, 431 (2020). <https://doi.org/10.1186/s13063-020-04241-1>

Part Four

Researcher Roles and Responsibilities



Ruth Boyd

Cancer Research UK Senior Research Nurse

NI Cancer Trials Network

**Personal and Public Involvement Professional
Lead**



Personal and Public
Involvement (PPI)



Involving you,
improving care



Researchers /Clinicians Responsibilities (1)



- ☺ **Plan** PPI from outset throughout research life cycle (and think PPI **funding**)
- ☺ **How** - type of opportunity (focus group, co- applicant, steering group.....)
- ☺ **Who** - patients / carers / public. **What** skills or experience (needed or not)
- ☺ **When** - time commitment / how long / how often / time of day
- ☺ **Where** - venue / access / online
- ☺ Think equality, diversity, inclusion
- ☺ Develop **PPI Role Profile** - background to the project and role expectations
- ☺ Advertise with specific criteria – scope groups and clinics

Public Involvement Enhancing Research in Northern Ireland (PIER) NI.



Get involved in health and social care research

As a patient, carer or member of the public, would you like the opportunity to influence health and social care research in Northern Ireland in order to improve care?

Are you interested in research and have good communication skills?

Have you had experience of working on groups or committees?

If so, we would like to hear from you.

Please visit www.research.hscni.net for more information or email

Gail.Johnston@hscni.net.



Have you, or someone you care for,
had an experience
of cancer?



Want to influence cancer research in Northern Ireland?

The Northern Ireland Cancer Research Consumer Forum is looking for people like you to:

- Review clinical trials
- Raise awareness of clinical trials
- Work in partnership with cancer researchers
- Become a member on a research committee or group

About the Forum

The Northern Ireland Cancer Research Consumer Forum was set up to increase personal and public involvement in cancer research in Northern Ireland. The Forum meets 4 times a year and training and support is available for members.

We recognise the importance of diverse representation and would welcome applications from a broad range of people

For more information contact **Ruth Boyd** at

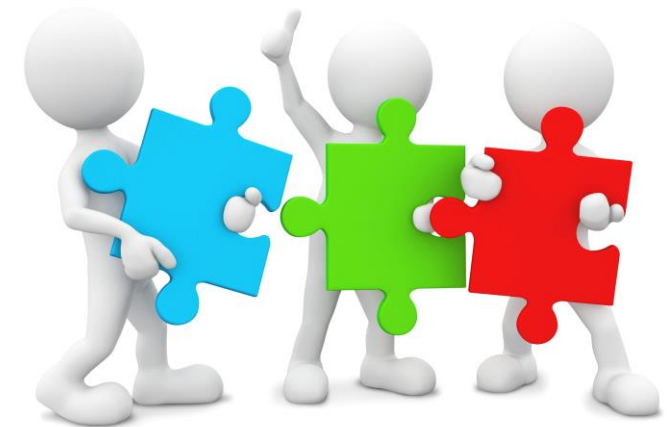
✉ nictn@belfasttrust.hscni.net

☎ 028 9615 2652



Researchers /Clinicians Responsibilities (2)

- ☺ Application / interview process?
- ☺ Think support - PPI role induction, resources, training, jargon busting
- ☺ Confidentiality - agreement
- ☺ Meetings - preparation / support / mentor
- ☺ Expenses and Payment – guidance or policy what’s covered / prompt easy claim process
- ☺ Feedback - impact
- ☺ Thank you - how? Events, publications ...
- ☺ Check alignment of expectations throughout – partnership development





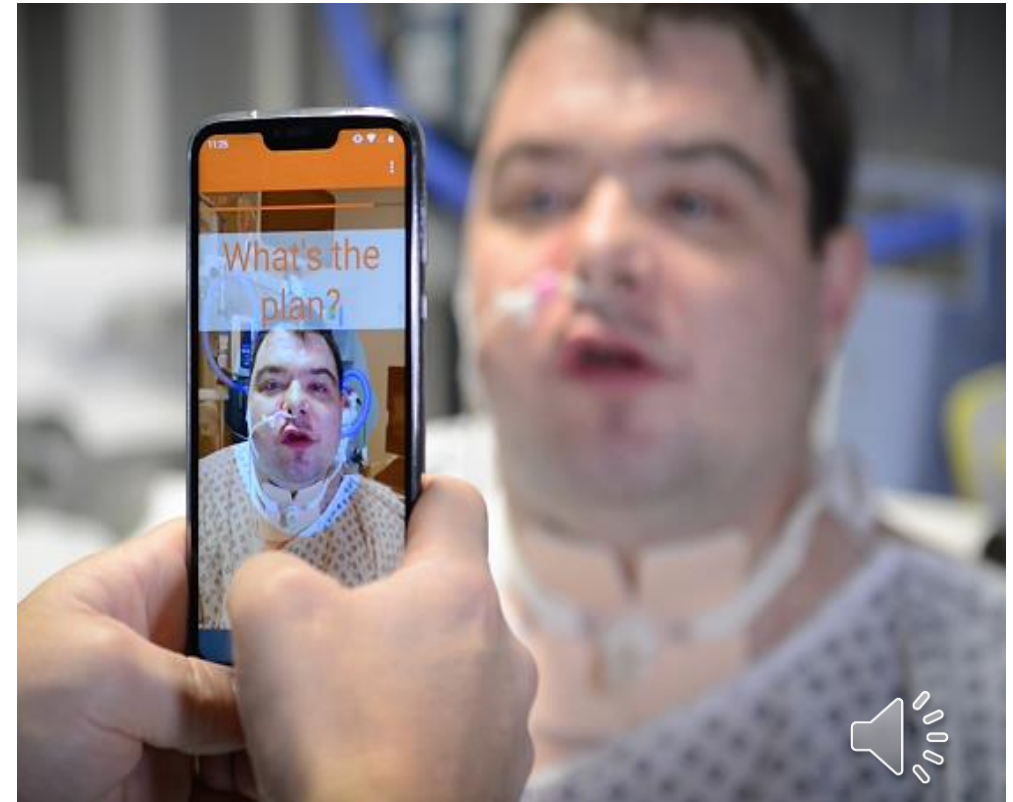
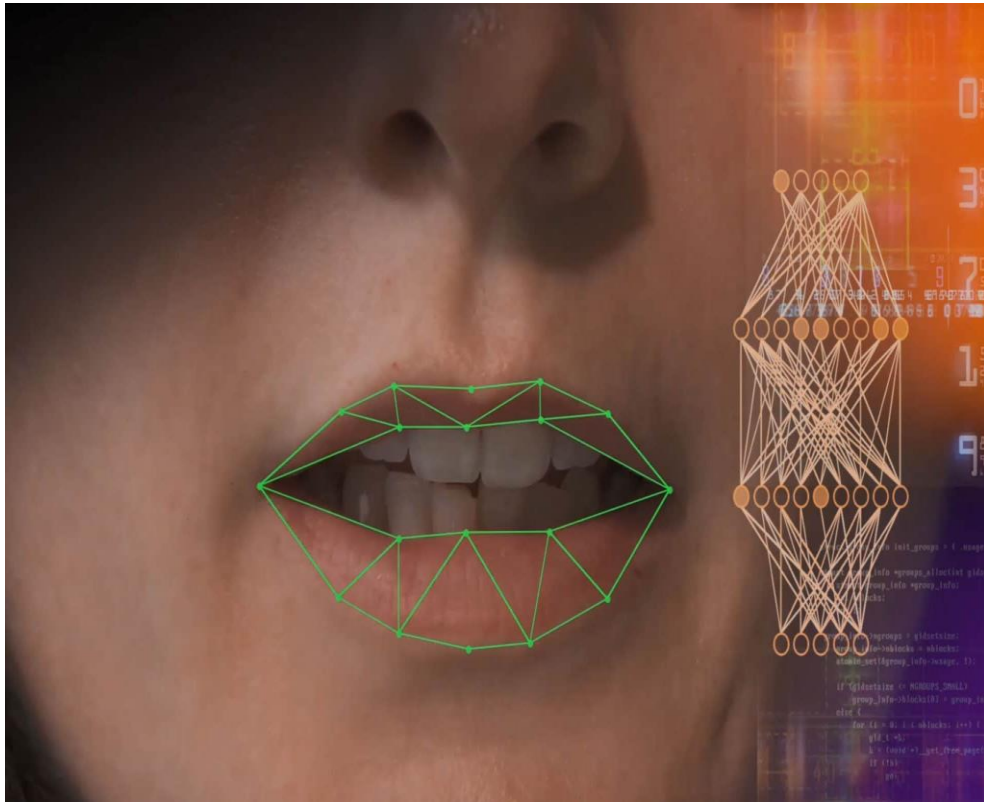
Part 6: A Case Study

CARLA MCCLINTOCK

2ND YEAR PHA R & D FELLOW



SRAVI: Speech Recognition Application for the Voice Impaired



Why is this study needed?

- ▶ ~ 14,000 UK patients receive tracheostomy annually.
- ▶ Presence of inflated tracheostomy cuff 'seals off' patient's upper airway.
- ▶ Oral communication not possible.



Powerlessness

Fear

Anger

Depersonalisation



Panic

Frustration



During ICU

Emotional
distress

Recovery

Negative
psychological
outcomes

-Anxiety

-Depression

-PTSD



Communication Strategies



No tech



Low tech



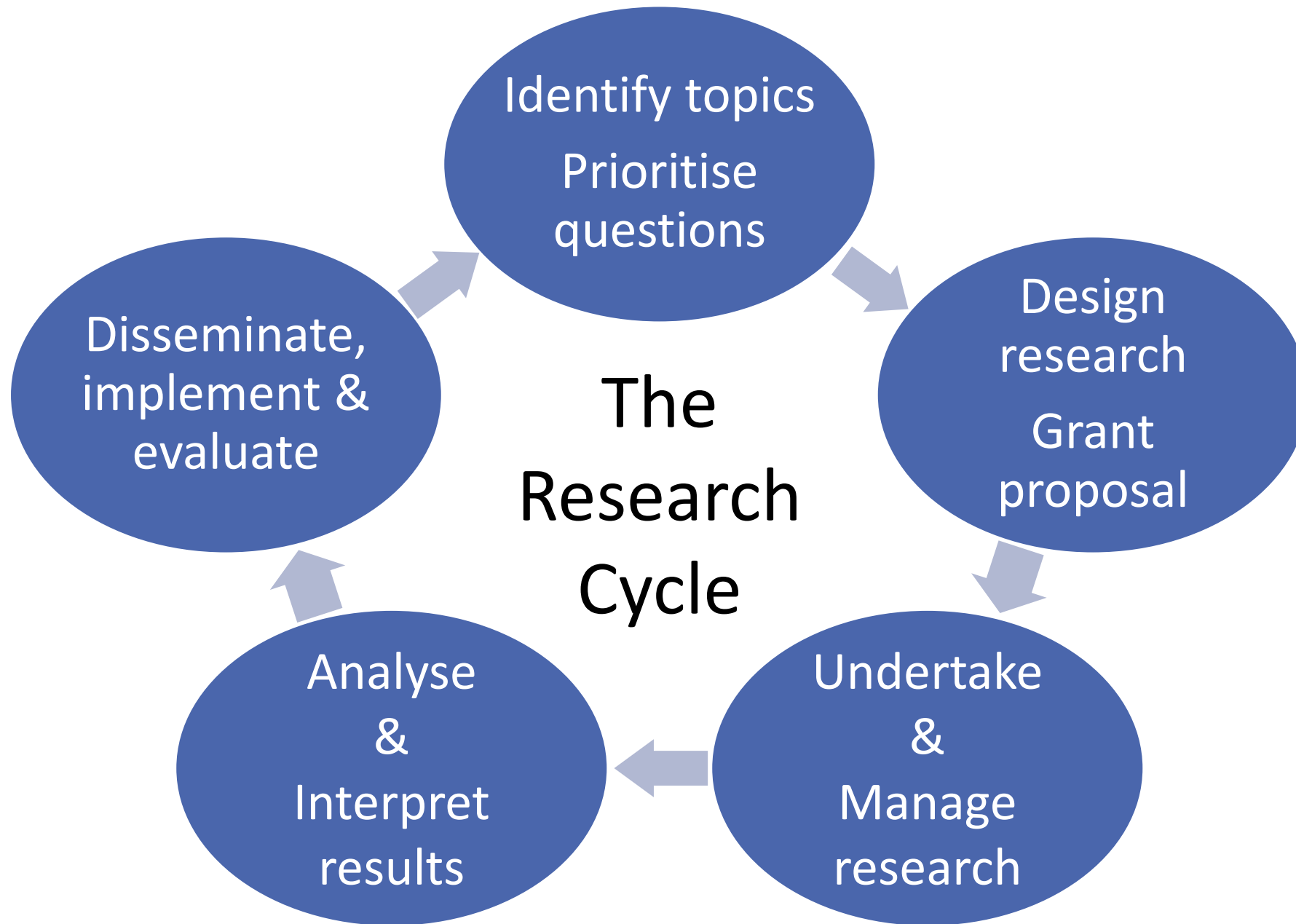
High tech



Study Overview

- ▶ Aim: To establish feasibility & acceptability of SRAVI for adult critical care patients with a tracheostomy who are unable to communicate using verbal speech.
- ▶ Design: Prospective Observational Cohort study with qualitative component
- ▶ Sample size: 55 patients
- ▶ Setting: 3 ICUs in N.I





Identify topics Prioritise questions



James Lind Alliance: www.jla.nihr.ac.uk



Design research Grant proposal

- ▶ PPI advisory panel formed
- ▶ Re-evaluation of design:
 - ▶ Change from RCT to cohort study



5 members



Monthly meetings



SRAVI 'voice'



Undertake & manage research

- ▶ Reading of lay summary, patient information sheets & consent forms.
- ▶ Tailoring to be more understandable to non-experts.
- ▶ Lead PPI- part of project governance (Steering Group Committee).
- ▶ Interview schedules- content & timing of interviews.
- ▶ Patient outcomes following discharge.



Analyse & interpret results

- ▶ Training & support requirements of PPI panel.
- ▶ Additional perspectives on literature & in analysing & interpretation of results.
- ▶ Strengthen validity of conclusions from a patient & public perspective.



Disseminate, implement & evaluate

- ▶ Review of final documentation before dissemination.
- ▶ Co-author on papers.
- ▶ Dissemination of findings at conferences & through ICU Steps.
- ▶ Involvement from outset enables ownership & knowledge of context of project.





WHAT I have LEARNED

- ▶ Be proactive – PPI involvement from outset.
- ▶ Active involvement in whole process.
- ▶ Recognise value of the lived experience.
- ▶ Not a case of ‘us’ versus ‘them’- collaborative working.

