HSC Public Health Agency

Research and Development

James Lind Alliance

In association with

Involvement Matters – Partnership & Collaboration for Health and Social Care

ALAN MCMICHAEL, PPI LEAD, HSC R&D DIVISION

MARGARET GRAYSON, PIER MEMBER, CO-CHAIR OF PUBLIC INVOLVEMENT & PRIORITY SETTING SUB-GROUP

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Thank you for being here & Agenda

☐ Introduce Personal and Public Involvement

☐ About the James Lind Alliance (JLA) and its role in this project

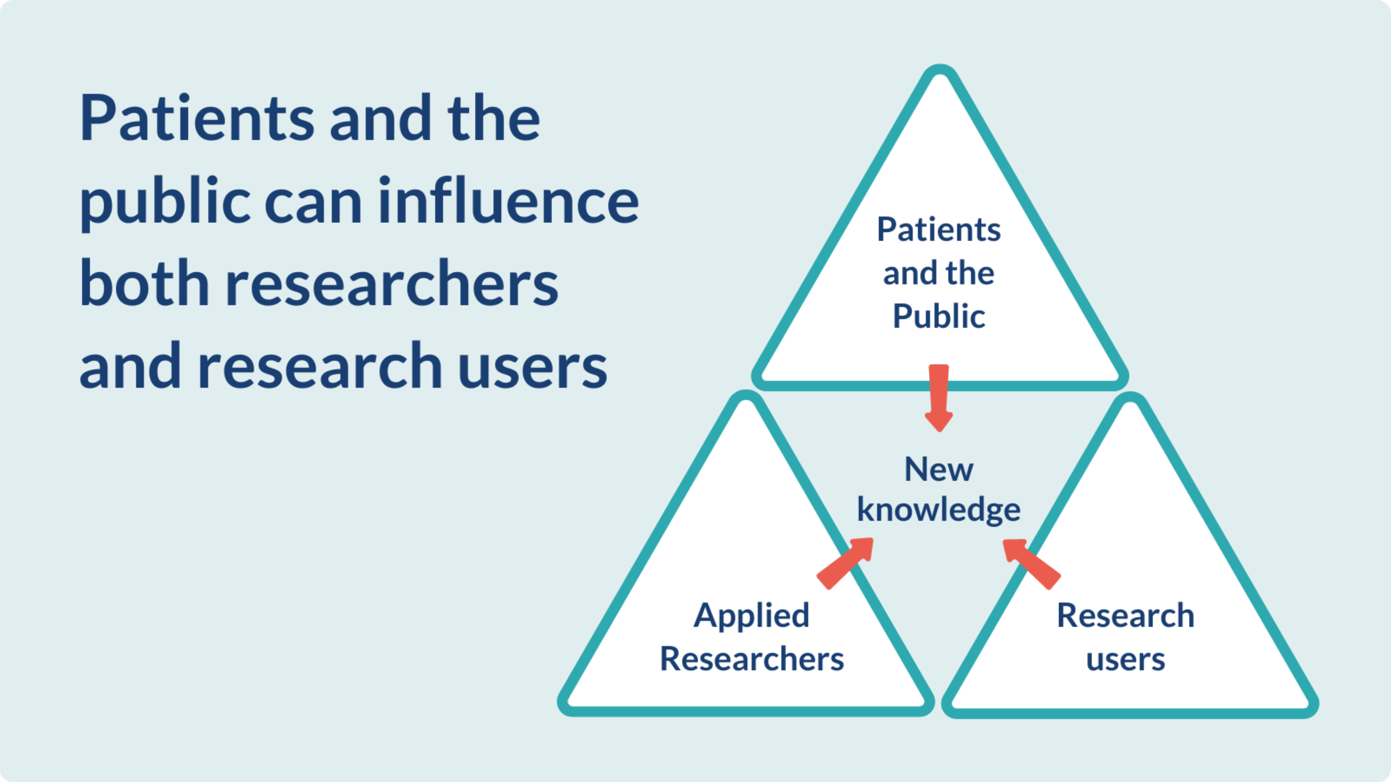
☐ Why do we need priorities for PPI?

☐ How will the results be used?

☐ Q & A

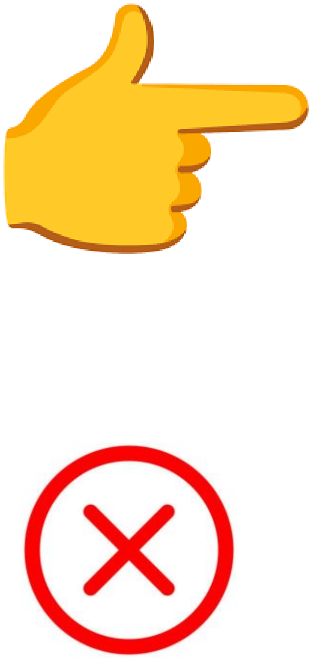
PPI in research- what does it mean?

- ❑ Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.
- ❑ There is active involvement of patients, carers, service users and/or the public in research decisions.



Patients and the public can influence both researchers and research users

What PPI in research is not



- Creating a one way dialogue with the public about research.
- Recruitment of patients or members of the public taking part as participants (‘subjects’) of research studies.
- Using clinical interactions with patients
- Telling the public about research findings
- Ticking a box

Benefits of PPI for researchers & funders

☐ Greater knowledge and understanding of service users, patients and carers

☐ Greater satisfaction and enjoyment with research

☐ Increased credibility

☐ Greater public trust

☐ Improved relationships with communities

☐ Partnerships to effect change

Benefits for PPI contributors

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

PPI animation

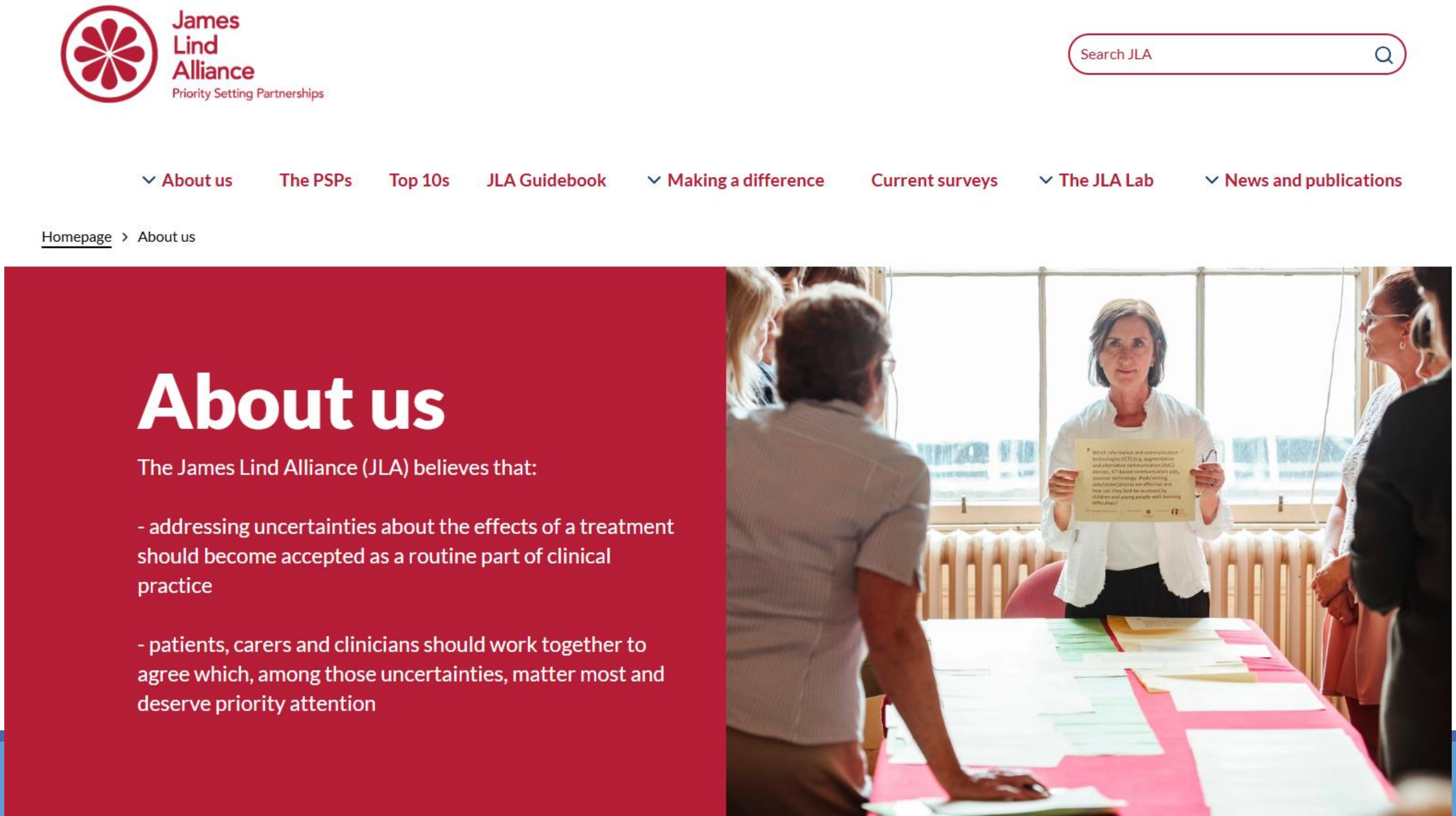
Animation link: https://vimeo.com/1105399072/7ffc637f81

Margaret Grayson,

PPI contributor, Co-chair of Public Involvement & Priority Setting Sub-Group

PIER Member

Overview of James Lind Alliance



About us

The James Lind Alliance (JLA) believes that:

- addressing uncertainties about the effects of a treatment should become accepted as a routine part of clinical practice

- patients, carers and clinicians should work together to agree which, among those uncertainties, matter most and deserve priority attention

About the James Lind Alliance

Established in 2004 to set up priority setting partnerships for:

- Patients, carers and healthcare professionals to work together
- Focusing on a single conditions or area of health/social care
- Identifying unanswered questions (‘unknowns’ /evidence uncertainties) for research
- Prioritising the ones they think are most important for research to address
- Promoting the priorities to researchers and funders

James
Lind
Alliance
Priority Setting Partnerships

James Lind Alliance’s involvement in this project

This project draws on elements of the JLA’s method of priority setting to:

- Highlight the actions **already known** to support public involvement in research in Northern Ireland; and
- Identify what is **not yet known** about how to extend and strengthen public involvement for future research to address

Support from the JLA includes:

- **Chairing** the steering group that has oversight of the project
- **Advising** on the workplan, the consultation exercise and agreeing the priorities for action as well as research

Why set priorities for PPI

Aligning Research with Real-World Needs

- Priority setting ensures that research focuses on the questions that matter most to patients, carers, and the public — not just researchers or funders

- To support best practice in line with the UK Standards for Public Involvement, including inclusive opportunities, working together, and impact.

Supporting Better Health and Social Care Outcomes

- When research reflects public priorities, it’s more likely to lead to meaningful improvements in services, policies, and outcomes — creating a healthier, fairer society.

Why set priorities for PPI

❑PPI is valued, but not consistent – we know involvement improves research, but practices vary widely.

❑Unclear what matters most – we don’t yet have a shared view of the biggest barriers, enablers, and next steps.

❑Setting priorities ensures time, funding, and energy are focused on actions that will make the biggest difference.

❑Creates a roadmap – gives researchers, funders, and organisations clear guidance to strengthen PPI in a systematic, sustainable way.

What we are doing?

Who can complete the survey?

<u>We want to hear from everyone!!</u>

- ☐ Researchers, health and social care professionals
- ☐ PPI contributors
- ☐ Community & voluntary sector
- ☐ People who are interested in being involved in research.

INVOLVEMENT MATTERS – PARTNERSHIP & COLLABORATION FOR HEALTH AND SOCIAL CARE RESEARCH

When you submit this form, it will not automatically collect your details like name and email address unless you provide it yourself.

This survey aims to improve how members of the public are involved in health and social care research. We would like people across **Northern Ireland** to share their views on how the public is involved in health and social care research. This includes patients, carers, service users, charities, voluntary and community groups, and anyone with an interest — even if you've never been involved in research before. You don't need to have any special experience — just your own thoughts and ideas.

By "research", we mean work that explores questions to improve health, care, and services — across hospitals, communities, and wider populations.

By Personal and Public Involvement (PPI) in research, we mean research carried out *with* or *by* members of the public — including patients, service users, carers, and community and voluntary sector groups — rather than research done *to*, *about* or *for* them. This could mean helping to design a research project, advising on how research is carried out, or helping to share or explain the findings.

An animation explaining PPI can be viewed here: https://vimeo.com/1105399072/7ffc637f81

We are keen to hear from

- People (16+) who have been actively involved in the design or delivery of health and social care research (in roles other that study participation, such as contributing insights or guiding project development).
- People (16+) who are interested in being involved in research, even if they have not done so before
- PPI Leads and practitioners (people who advise/lead PPI within their organisations)
- Health and social care professionals who lead on or help to deliver research projects
- Funders of health and social care research, and academic researchers
- Community or voluntary organisations

This is your chance to share what's working well, what's getting in the way, and what could be improved. Your experiences and ideas will help us to identify a list of priorities for action to help improve Personal and Public Involvement (PPI) practices in health and social research within Northern Ireland in the future.

All responses are anonymous. Your details (e.g., name, email address) will not automatically be collected, unless you provide them. If you choose to provide your contact details (e.g. to stay involved or hear updates), your information will be kept safe and used only for this project.

This project, conducted in partnership with the James Lind Alliance, is funded by the Northern Ireland Clinical Research Recovery, Resilience and Growth.

If you have any questions or would like this consultation in an alternative format, please contact Dr Alan McMichael by email (Alan.McMichael@hscni.net) or phone (07591448603).

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How will the priorities will be used?

- Health and social care research initiatives, funding calls, and the overall design of different research studies and projects

- Support training and resources – identify gaps where researchers and PPI contributors need more support

- Priorities will help shape the direction of future research, ensuring that public involvement is deeply integrated into research processes and decision-making

- Universities, Research & Development offices and health and social care trusts will be encouraged to consider the priorities relevant to them

How can you help?

- Share your thoughts. You can complete the survey
- here: https://forms.office.com/e/ddVA9qL9fG

- Share the survey with your networks!

- **We appreciate your support!**

- **Let's work together to ensure that Personal and Public Involvement in Health and Social Care research truly makes a difference**

Acknowledgements

Steering Group Member	Organisation
Alan Drennan	PPI Contributor, PIER member
Anne McGlade	Social Care Council
Debbie McGrory	Health and Social Care, Research & Development
Fidelma Carter	Chest, Heart and Stroke
Katherine O'Neill	IReach
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Ian Stafford	PPI Contributor, PIER member
Janet Diffin	Health and Social Care, Research & Development
Jonathan Jackson	Northern Ireland Clinical Research Network
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Martin Quinn	Public Health Agency
Maryrose Tarpey	James Lind Alliance
Ruth Boyd	Northern Ireland Cancer Research Forum
Sonia Patton	PPI Contributor, PIER member
Stephanie Cathcart	Chest, Heart and Stroke
William Crowe	Health and Social Care, Research & Development

THANK YOU

Any Questions?