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Sharing space at the research table: public and patient involvement in an evidence synthesis priority setting partnership

Nikita Burke: Programme Manager, Evidence Synthesis Ireland

Maureen Smith: Public Co-author, Cochrane Consumer Network Executive, Ottawa, Canada

Andrew Worrall: Public Co-author, Staffordshire, UK & Evidence Synthesis Ireland

www.evidencesynthesisireland.ie

email: esi@universityofgalway.ie  [@EvidSynIRL](https://twitter.com/EvidSynIRL)

www.ireland.cochrane.org

 [@CochraneIreland](https://twitter.com/CochraneIreland) #EvidenceSynthesis





Healthcare decisions should always be informed by the best available evidence.

When making informed decisions about health, it is important that we don't rely on the results from a single study.





A single study can be inaccurate or misleading and does not always give the full picture

And sometimes we only hear about surprising or dramatic findings

However, by carefully combining the results of multiple studies investigating the same thing, we can get a fuller picture of the evidence



This method is called

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In association with
 James
Lind
Alliance
Priority Setting Partnerships



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Cochrane
Ireland



COVID-END
COVID-19 Evidence Network
to support Decision-making



A rapid review is a form of evidence synthesis.






Rapid reviews

SPEED UP

the process of conducting a
conventional systematic review





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Burke *et al.*
Research Involvement and Engagement (2023) 9:29
<https://doi.org/10.1186/s40900-023-00438-1>

Research Involvement
and Engagement

RESEARCH

Open Access

Sharing space at the research table: exploring public and patient involvement in a methodology priority setting partnership



Nikita N. Burke^{1,2*}, Derek Stewart³, Theresa Tierney⁴, Andrew Worrall⁵, Maureen Smith⁶, Jim Elliott⁷,
Claire Beecher^{1,2}, Declan Devane^{1,2,8} and Linda Biesty²





What is methodological research?

- Research that aims to improve the quality of research
- Also known as “**research on research**”
- Example – a study that focuses on what we need to do to improve the **recruitment** and **retention** of patients in clinical trials (priorityresearch.ie)





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Andrew Worrall



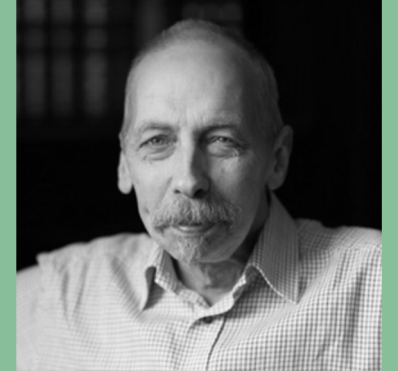
Maureen Smith



Jim Elliott



Theresa Tierney



Derek Stewart

Public Partners



Nikita Burke



Linda Biesty



Declan Devane



Claire Beecher

Researchers



Public and patient involvement

- Patient and public involvement (PPI) aims to improve the **quality, relevance, and appropriateness** of research
- PPI can involve patients at all stages of the research process, from identifying research priorities to disseminating findings

PPI is defined as research conducted ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (NIHR)





Why should we involve the public in methodological studies?

- Real-world perspectives can increase the **relevance** and **value** of research
- Involvement can improve research **processes, transparency and impact**
- And the public have a **right** to be involved, as research is in the **public interest**



What are the challenges involving the public in methodological research?

- Communicating the nature and relevance of methods research, which may have no immediately obvious clinical relevance
- Perceptions amongst some methodological researchers that PPI may not be useful
- Lack of established methods/approaches for PPI in methodological research





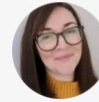
Why?



Dr Elaine



It is tricky and takes a lot of planning and support, but imo it's crucial. We work in health research for the end goal of improving patient and public health outcomes, so I think we have a duty to consider how and where PPI can be done even for methodological research.



Katie

May 9



Lay people pay for research in many instances (through tax) so should they not have the opportunity to discuss ideas for how the money is spent (irrespective of how complex)?



Derek Stewart

May 10



Hi I don't necessarily want be a part of the statistical research. I am more than happy for you to do your job yet as you say when it involves understanding terminology, looking at uncertainty and risk then I think there is a real need for us to share space.



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Priority III

Setting priorities for rapid
review research



Context

- Priority III was a **Priority Setting Partnership (PSP)** that identified the top 10 unanswered questions on how we plan, do and share the results of **rapid reviews**
- International Steering Group (n=26)
 - Public partners, researchers, clinicians, policymakers, funders & JLA
- Initial survey, an interim survey, and a consensus workshop





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Priority III

Setting priorities for rapid
review research



Qualitative Case Study



July 2020

June 2021

Sept 2020

March 2022

- As the focus of Priority III was on the **methodology of rapid reviews**, there was learning in the approach to public involvement that happened
- The public partners felt it was important to capture this learning and share it with others



Qualitative Case Study

We used a case study approach to reflect on the processes and learning that took place.

We collected data using

- *Participant Observation*
- *Documentary Analysis*
- *Interviews (one-on-one and Focus Groups)*

All members of the Priority III Steering Group were invited to participate in this study

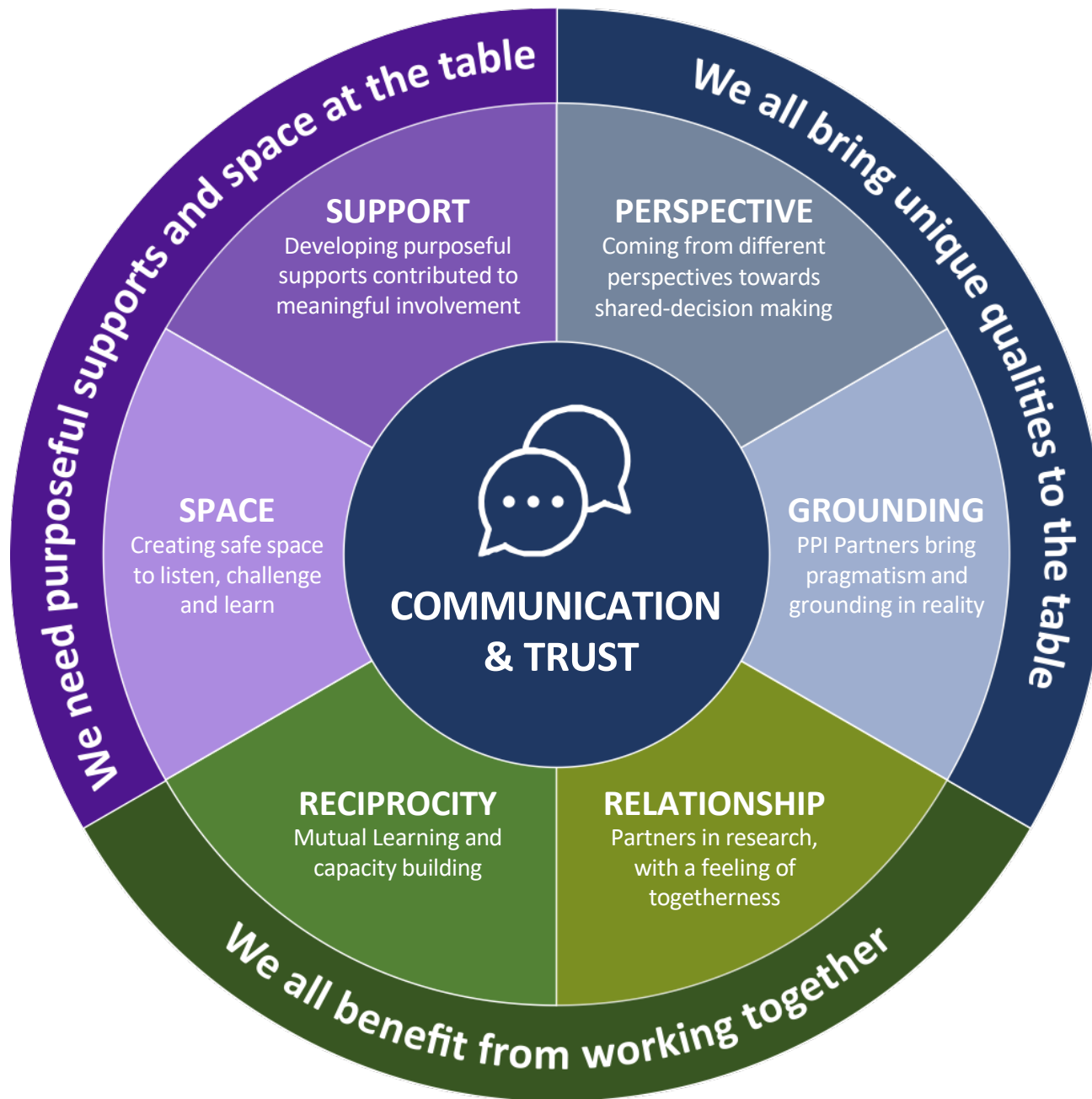


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Aim

- To explore public involvement in the Priority III Priority-Setting Partnership, to give practical insights to inform practice in public involvement in priority-setting for future methodological research





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Theme 1

We all bring unique qualities to the table



“I’ve learned that everyone has some perspective to share.

Even if I spent a lot of time at the start just listening and learning, that it’s a really respectful atmosphere.

No one should feel that they don’t have enough to say or enough background to not become part of the process.”

Public Partner





“...there’s almost a surprising contribution of the public partners to the Steering Group in terms of a focus on feasibility or pragmatism. I didn’t expect that.

You’ve got public partners saying, well hang on a second, we need to take a step back from this, it would be ideal if we could do this but [lead research team] have said that the impact of that would be four, five weeks.

So let’s think about could we all live with this?”

Researcher



Bumps in the road

- Language – *“what do you mean by rapid review?”*
- Iterative process – balancing needs
- Challenging context





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Theme 2

We need purposeful supports and space at the table

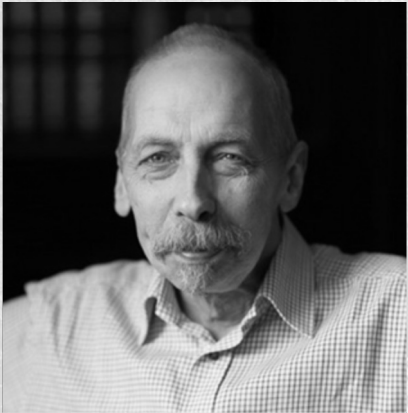





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Peer Support



A group of people are holding hands in a circle outdoors, likely at sunset or sunrise, given the warm, golden light. The people are out of focus, with the foreground showing a person's arm in a yellow sweater and another in a brown puffer jacket. The background shows several other people in a grassy field, all holding hands and looking towards the center of the circle.

“When you’re in something which is outside the comfort zone - you can’t bring a specific lived experience to methodology research. So it’s thinking more what do I bring? That can seed doubts and then you might not speak up. Whereas we’re encouraged by others. I think peer support is more important in areas that aren’t related to your lived experience.” **Public Partner**



Payment process

Phase	Task	No. of hours
Steering Group engagement	6 steering group meetings @ 1.5h per meeting + 1.5h prep	18
	6 PPI meetings @ 1h per meeting + 1.5h prep	15
	Review minutes and decisions made including confirmed questions for inclusion in survey	2
Protocol development	Comment on protocol draft	2
	Comment on protocol to HRB Open	2
Initial online survey	Feedback on survey & publicity materials	2
	Take and comment on pilot survey	2
	Read progress reports that will note demographics of respondents and consider any necessary targeted publicity	2
	Total	= X
	Number of days at 7.5h per day x ST£150 per DAY	= £X



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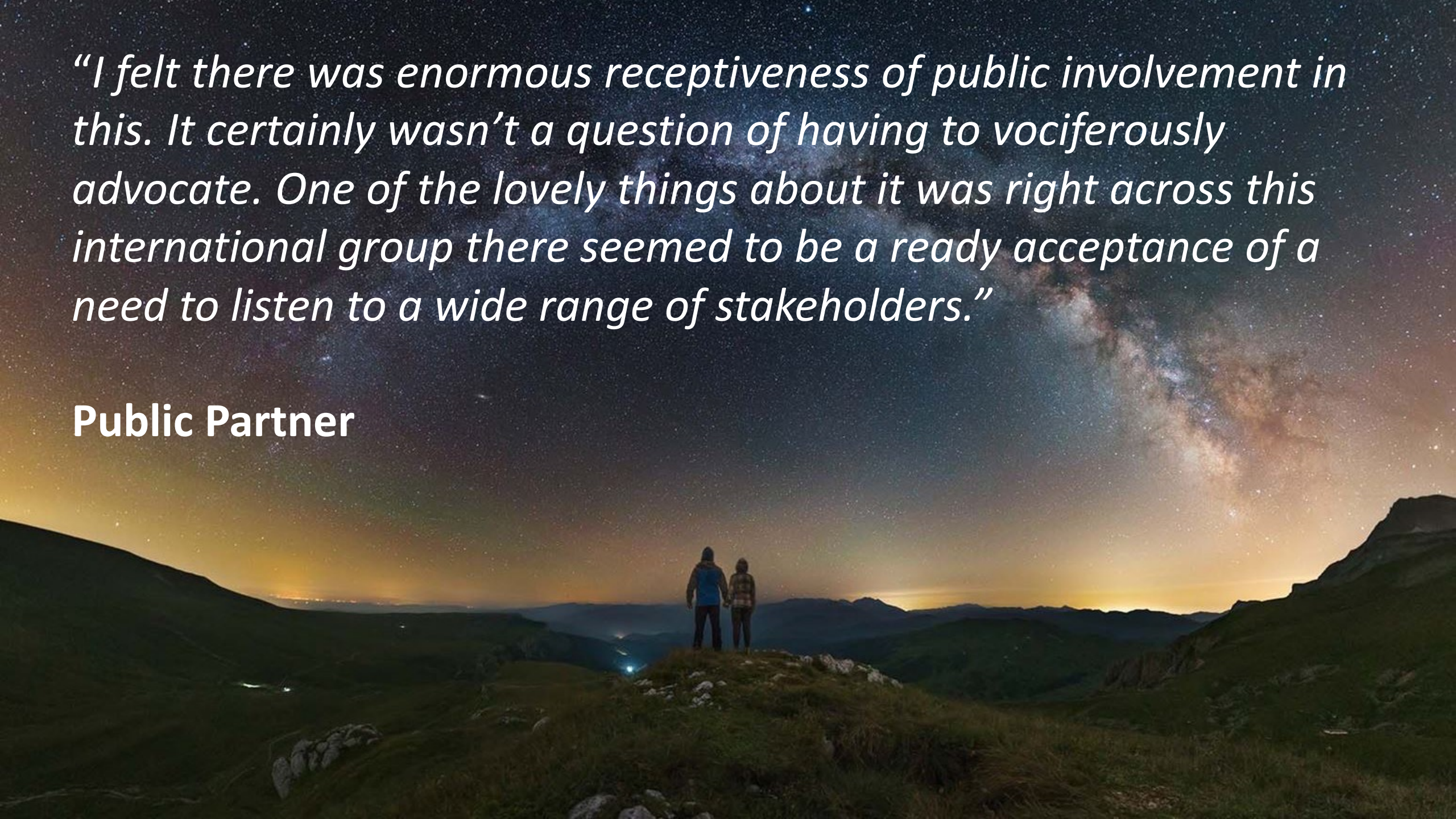


Pre Meetings



“I felt there was enormous receptiveness of public involvement in this. It certainly wasn’t a question of having to vociferously advocate. One of the lovely things about it was right across this international group there seemed to be a ready acceptance of a need to listen to a wide range of stakeholders.”

Public Partner





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Theme 3

We all benefit from working together



“Listening to the different PPI people & researchers was a huge learning experience.

It served to grow my confidence. Including not be afraid of looking foolish when asking something. And the kindness and respect everyone has shown me.

It helped grow my trust in the system for future research.”

Public Partner





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Impact



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Influence of PPI in Priority III

Better
communication

Advocated for
underserved
groups

Critical decision-
making

17% of all survey
responses from
public/patients

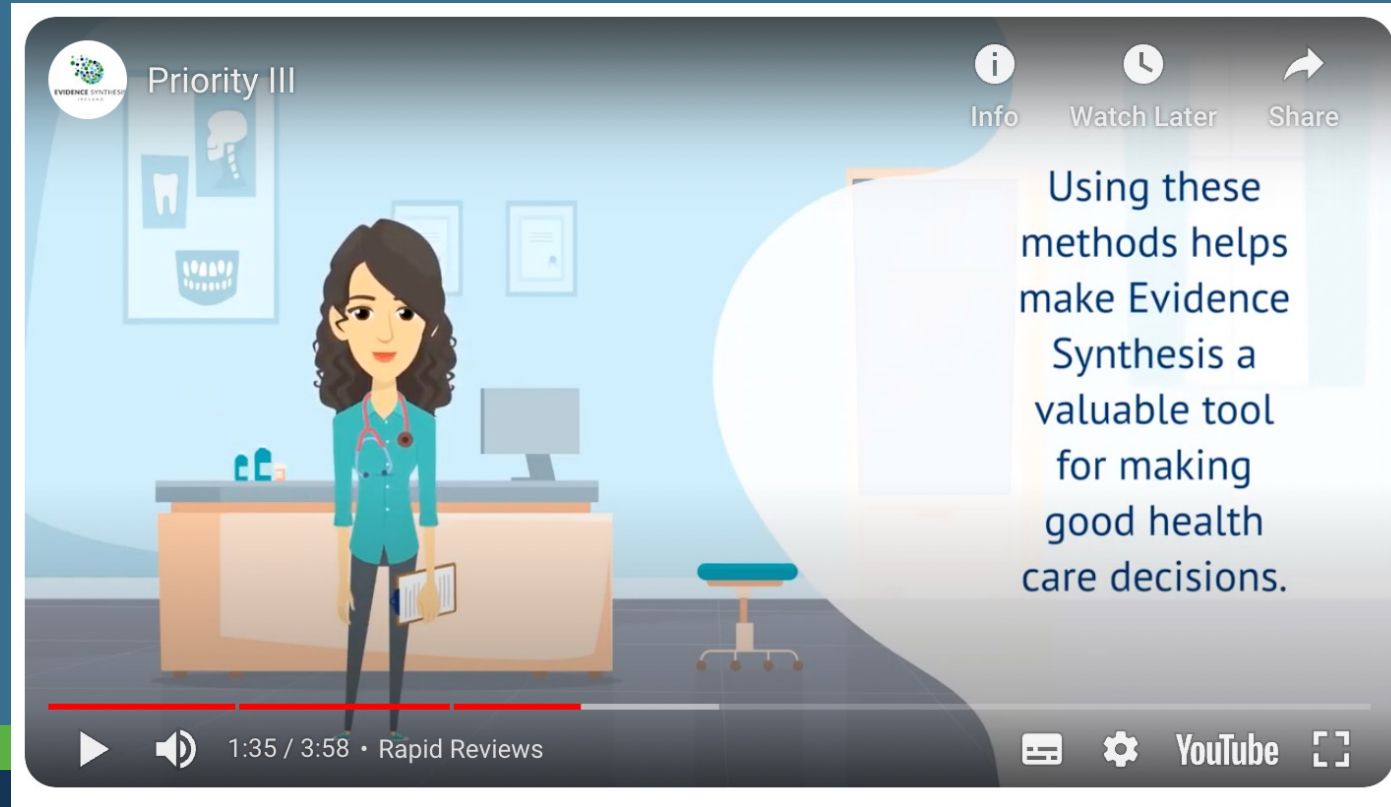
Recruitment for
consensus
workshops (Kenya,
Cameroon, CAN)



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Priority III
Setting priorities for rapid
review research



Priority III

Info Watch Later Share

Using these methods helps make Evidence Synthesis a valuable tool for making good health care decisions.

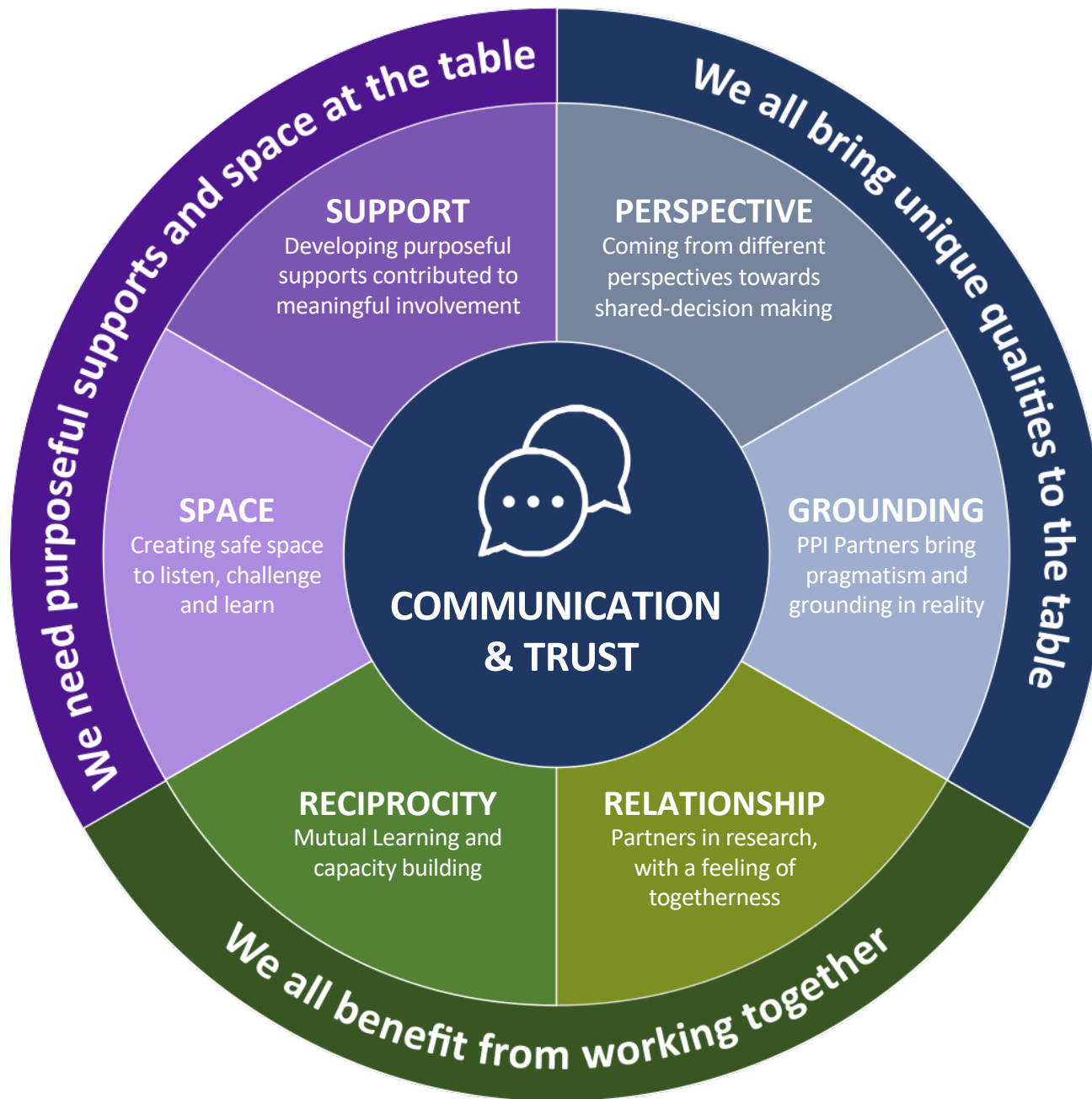
1:35 / 3:58 • Rapid Reviews

YouTube



Q1

What are the best approaches to identify people or groups who will use the results of a rapid review (e.g., stakeholders such as patients and the public, clinicians, policy makers), and how can they have meaningful (i.e., purposeful, relevant) involvement in planning and doing a rapid review, and in reporting and sharing the findings?





Considerations

- **No experience required:** the role is to ask questions & see the big picture
- **Create space** to allow for two-way exchange and shared understanding
- **Peer support**, with diverse mix of experience
- Develop a comprehensive **reimbursement policy**
- Researchers - be **open** and willing to step outside their own **comfort zones**
- Invest in **relationship building** particularly in methodology space



Conclusion

- We have **shared our learning** and **offered practical insights** to inform practice in public involvement in priority-setting for future methodological research topics.
- Our case study contributes to knowledge on public involvement in research by highlighting the **supportive strategies, spaces, attitudes and behaviours** that **enabled a productive working partnership** to develop between researchers and public partners.



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Thank you



www.evidencesynthesisireland.ie

email: esi@universityofgalway.ie  [@EvidSynIRL](https://twitter.com/EvidSynIRL) #EvidenceSynthesis

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