

Benefits of Incorporating the Patient Perspective in Research Initiatives



CHILD-BRIGHT
Network



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Today's session:

Benefits of Incorporating the Patient Perspective in Research Initiatives

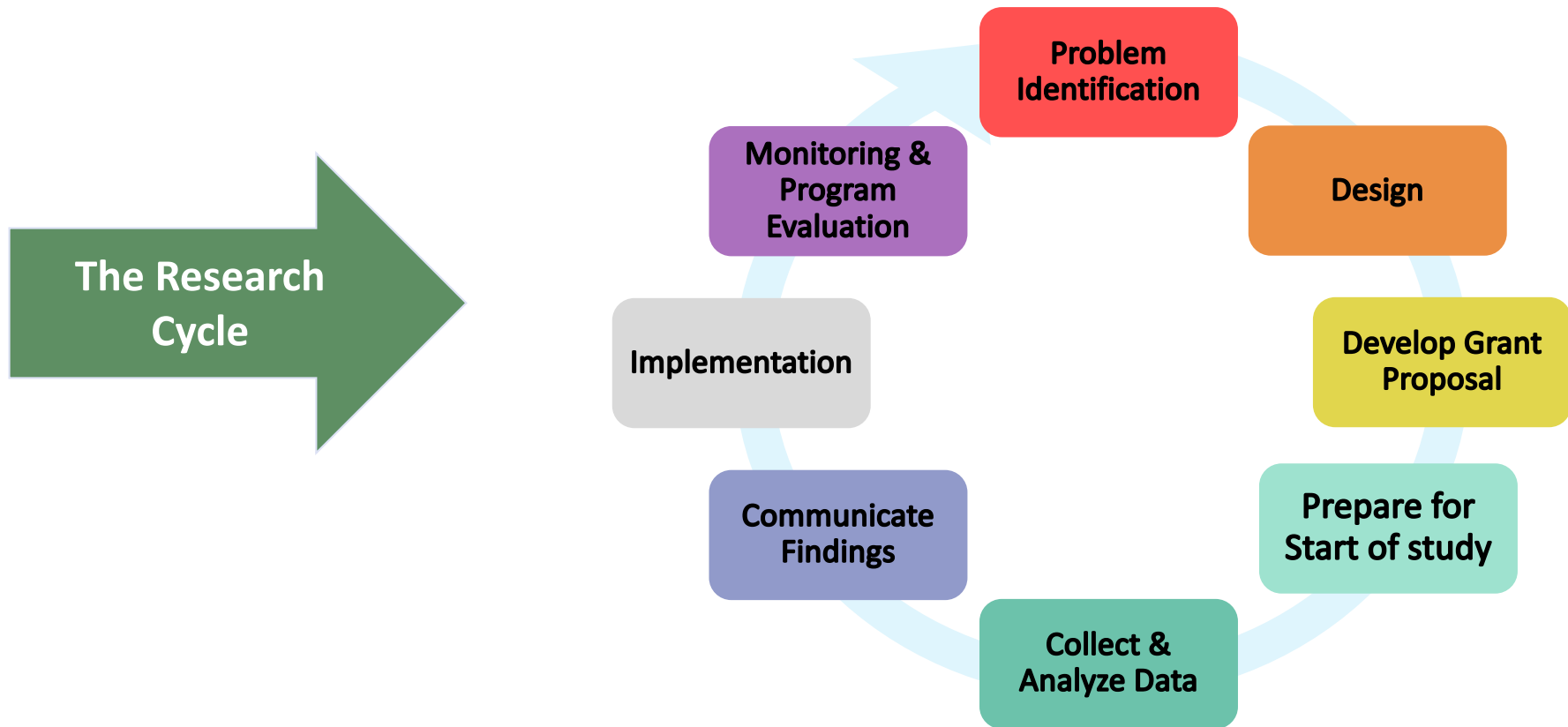
Revisit research cycle

Review Brett *et al.* 2012 findings

Open Q&A session



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Brett et al 2012:

Mapping the impact of patient and public involvement on health and social care research: a systematic review



Systematic review on
the impacts of public
engagement (PE) on
health and social
research

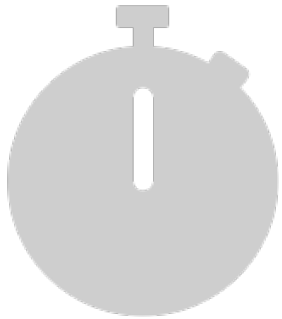
1st international
piece of evidence
that PE impacts all
stages of research

Why is PE important?

Users/patients/family/caregivers
have a **unique perspective** to
offer to a research project



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Learning Activity

“Active involvement of service users in research can lead to research of greater quality and relevance owing to the **unique perspective** that [patients] can bring to a research project.”

How are the experiences of patients different from researchers, doctors, and other healthcare professionals



Patients are experts in ways researchers are not

How can these unique experiences help shape better quality research



Working together will lead to better quality research because it will incorporate a variety of perspectives.



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Impact of PE on INITIAL STAGES

BENEFITS

- Identified & prioritized research topics most relevant to users
- Select research proposals that are patient-relevant for funding

CHALLENGES

- Research agenda to strays away from scientific methods
- Risk of tokenistic practice of PE
- Conflicts may arise...
 1. due to differing opinions b/t researchers & patients
 2. Researchers unwilling to relinquish control

How to
minimize
these?

- Provide training to users so they understand why certain research procedures must be followed
- Researchers need to recognize that PE adds value to research
- Take time to develop honest relationships between researchers and patients



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Impact of PE when Undertaking the research

BENEFITS

- ensure research protocol/design is relevant and appropriate to users
- enhance informed consent
- adapting scientific language for a lay audience

CHALLENGES

- decrease in the level involvement of patients as the project progresses
- Reluctance to become involved due to patient confidentiality
- Users deviating from research protocol
- Users may become too research-like such that they lose their unique patient perspective

How to
minimize
these?

- Involving users from the very start & throughout
- Make patient partners aware that their contributions are being valued



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Impact of PE on Dissemination & Implementation

BENEFITS

- dissemination of research findings is easier with PE
- increasing the credibility of results
- Patients convey more powerful messages about research findings because they are able to relate it to their own experiences

CHALLENGES

- Researchers refraining from reporting PE in their research articles due to word limits
- Want to prevent users from publicizing results before they have been published in academic journals

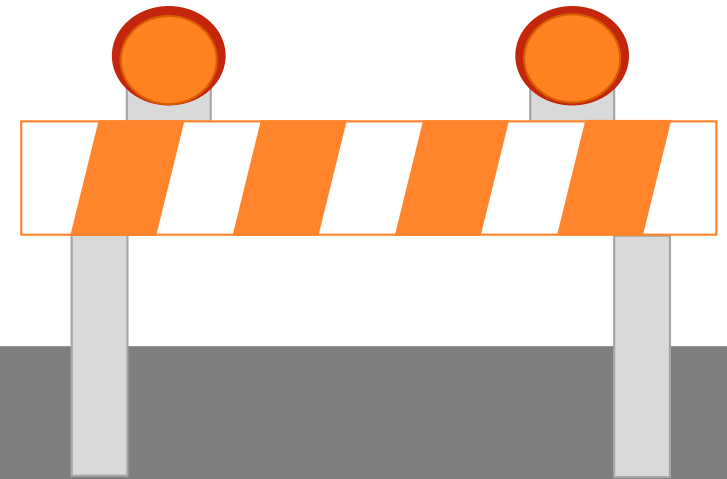
How to
minimize
these?

- As supplementary information, submit details outlining how PE was facilitated and what effect this had on the project
- Communicate the importance of maintaining academic & publishing integrity; detail why prematurely releasing data could have negative consequences



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Major Inhibitors of Effective PE:
TIME & COST CONSTRAINTS



SOLUTIONS

- these constraints must be taken into account when planning for research projects
- Be mindful that some patients can only commit for a short period of time, while others may hop on or off as the project progresses
- Funders/commissioners should recognize the importance of PE
- PE should be a condition of receiving funding



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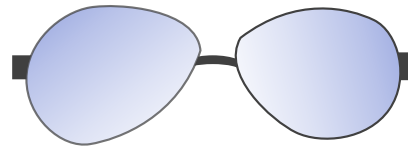
Research Tools

PE Enhances...

Interpretation of Results

- Improve user-friendliness
- Detect if wording/research design is appropriate
- Identifies points of inquiry that were not considered by researchers
- more insightful data obtained through research interviews

- Can interpret results differently to identify findings that are most relevant to users
- Study findings will be more appealing to stakeholders, which increases the chances of implementing policy change





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Impact of PE

Context

Are the right conditions
in place for PE to work?

Process

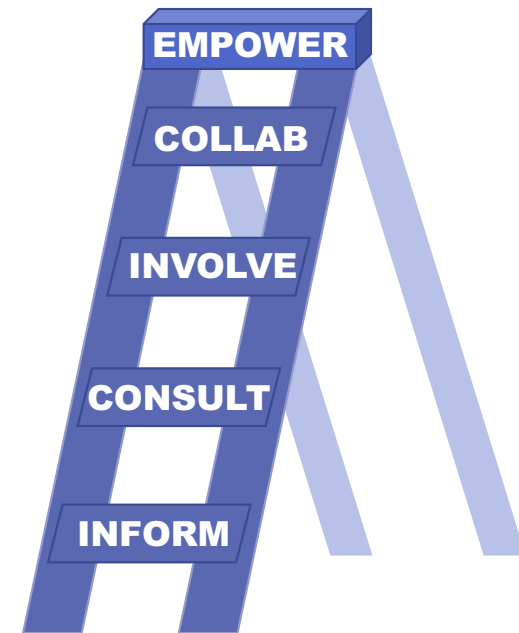
How is PE being
conducted?



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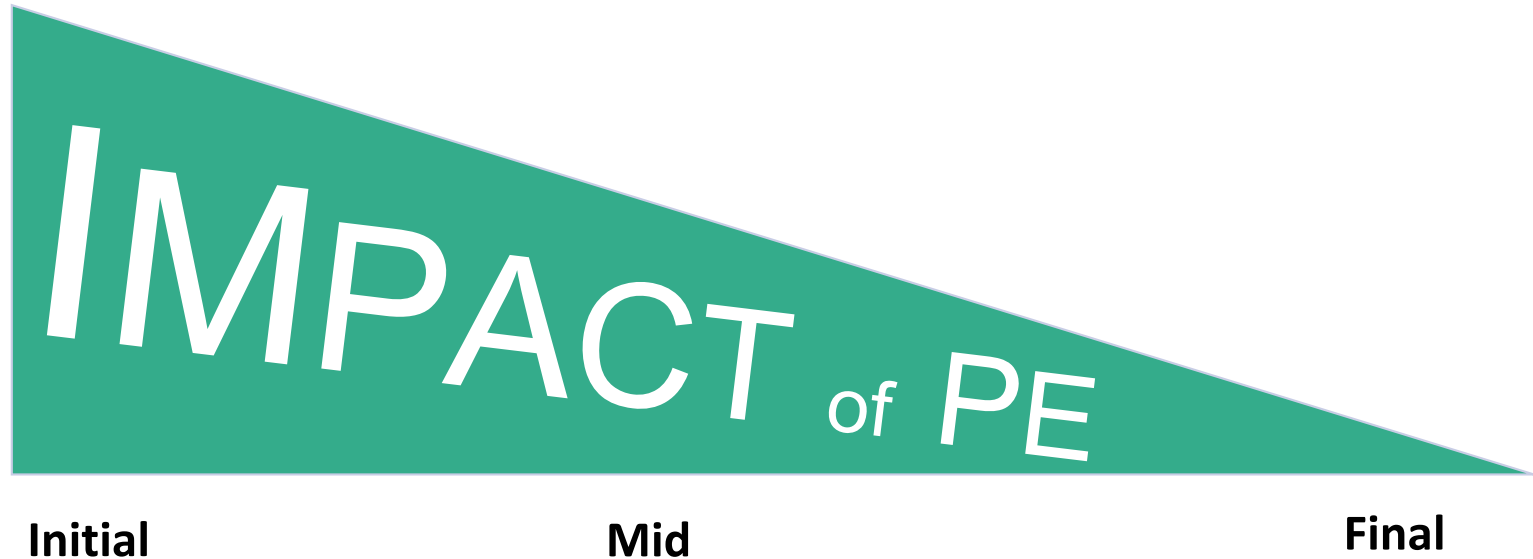
PROCESS

- Level of involvement users have
- What stage they are involved in
- Protocols to improve chances of success





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Stages of a research project in which patients can be involved

PE has the greatest impact if done early on, throughout, & if patients are being involved as partners/part of the research team



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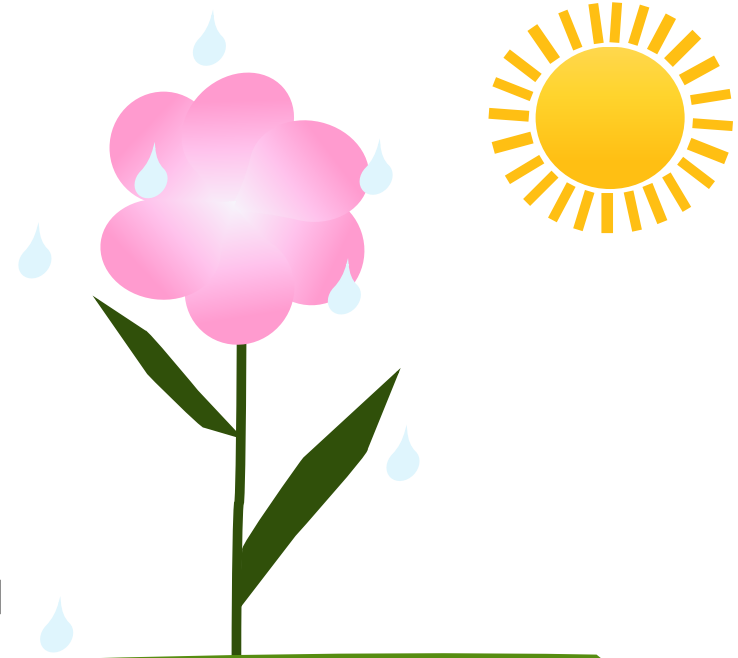
CONTEXT

Ingredients for PE to have a positive impact:

- Training
- Planning & procedures
- Clearly defined roles
- Positive attitude towards PE
- Trust & respect b/t the different stakeholders involved

Success of PE depends on the environment

- The right conditions must be in place for PE to thrive
- Funding, policy, physical environment, attitudes of researchers





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Congratulations!

Thank you for participating in our webinar sessions!

We truly value your input and will incorporate your feedback into future iterations of our studentship.

We hope that the sessions will get you to think differently about how research can be done in partnership with patients.



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Q&A panel





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Next steps:

- We'll circulate your certificates of completion in the next few days
- Reminder: term project due **today**
- Please complete the post-webinar & studentship surveys
- Connect with your PI/ Research Coordinator about the personal reflection piece that's to be submitted for funds to be released (no strict deadline; check with them when they plan to submit their paperwork)

THANK YOU!