



CHILD-BRIGHT
Network



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Ice-Breaker Activity

Other suggestions?

HELLO
my name is

- To the degree that you are willing, share something interesting/unexpected that you have experienced.
-



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Today's Session:

Exploring Some of the Barriers and Drivers of Public Participation in Research

Explore what is meant by “*patient*” and “*patient engagement*”

Iap2 Public Participation Spectrum

Review Snape *et al.* findings





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Defining the term “patient”:

How do you define the term *patient*?



The SPOR engagement framework considers patients to be:

Individuals with personal experience of a health issue and their informal caregivers, including family and friends

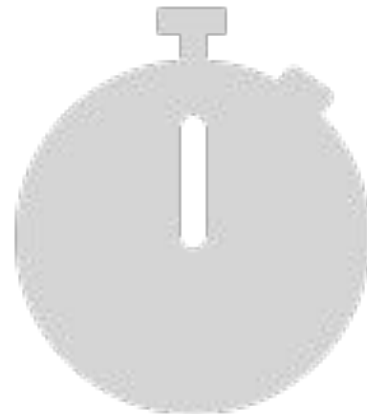


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Learning Activity

What does *“Patient Engagement”* Mean to You?

Are the terms **involvement**, **engagement** and **participation** synonymous?
If not, what are the differences?





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Patient Engagement

Under the SPOR Strategy, Patient Engagement is defined as:

Meaningful and active collaboration in:





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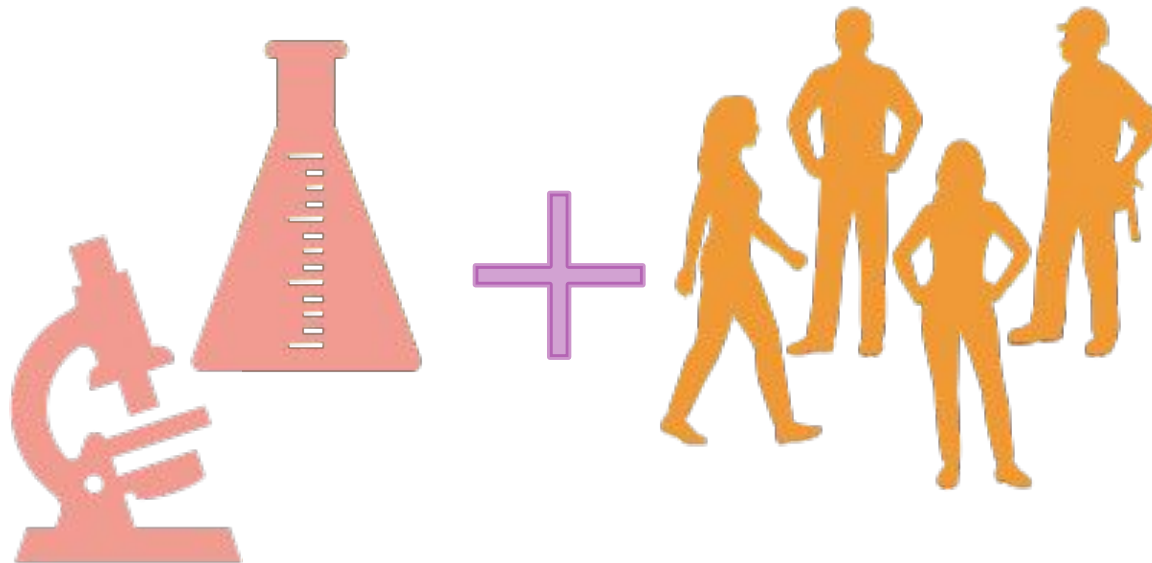


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Patient Engagement

Another way to look at it is as

“...research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.”



INVOLVE



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Questions?





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LEVELS OF PARTICIPATION

COLLABORATE – Partnering with stakeholders for advice and innovation in formulating alternatives and identifying the best solutions

INFORM – Telling people what is planned or describing what has been done

INVOLVE – Working with people throughout a process to develop alternatives

EMPOWER – People have the power to decide

CONSULT – Listening to people's concerns and aspirations



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Can you put the following in order
from lowest to highest level of
participation?



Levels of Participation

COLLABORATE – Partnering with stakeholders for advice and innovation in formulating alternatives and identifying the best solutions

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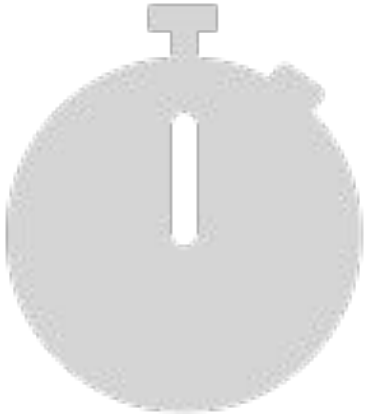
Levels of Participation

iap2 public participation spectrum

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.	To obtain public feedback on analysis, alternatives and/or decision.	To work directly with the public throughout the process to ensure that public issues and concerns are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and issues are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advise and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.



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Can you think of examples for each level of public participation?

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
EXAMPLE TOOLS					



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Snape et al debrief: Summary

There were high levels of consensus about the most important barriers & drivers to patient engagement (PE)

Although difficult to execute, there are high levels of consensus about the need to assess impact of PE

No consensus that PE necessarily improves research quality and relevance

Typically:

MOST ENDORSED DRIVERS OF PE = POLAR OPPOSITES OF THE BARRIERS



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Critical Consensus
Clear Consensus

Snape et al debrief

BARRIERS TO EFFECTIVE PE

The attitudes of academic researchers/clinicians to involving the public in research

The lack of support from funders for public engagement in research

The scientific language used in research

The lack of research experience of members of the public

The perception that members of the public have biased views

The perceived importance of patient engagement generally in research *

The attitudes of academic researchers/clinicians to relinquishing control and power over the research



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Snape et al debrief

Critical Consensus | Clear Consensus

DRIVERS OF EFFECTIVE PE



The perceived importance of patient engagement generally in research*

Designated funding for patient engagement

Training for academic researchers/clinicians about patient engagement

The attitudes of academic researchers/clinicians to involving the public in research

Clear communication between research team members

The ability to be flexible and open to difference

Recognizing members of the public are individuals w/ something of value to contribute

Time to build up partnerships and trust between the public and academic researchers



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Snape et al debrief

Potential Impacts of PI in the Research Process

No consensus that PI in research improves the quality and relevance of research:

Public Involvement does not necessarily lead to health research of greater quality and clinical relevance

Members of the public were more likely to disagree with this statement
55%



**Why the discrepancy?
Values?**

Academic researchers were less likely to disagree
32%



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Questions?





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Main Takeaways:

- Different levels of patient engagement exist
- Effective patient engagement is embedded in partnership



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Next steps:

- Next webinar scheduled for **Thursday August 17th, 2017.**
- Reminder: term project due August 31st
- Please complete the post-webinar survey
- Review the next set of readings and participate in the assigned discussion questions