

# PUBLIC PARTICIPATION IMPACT: THE OTHER PPI

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# TO COVER

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- Ground rules
- What can we do right now?
- What can't we do?
- Where are the pinch points?
- How can we move forward?



# POLL – WHO ARE YOU?

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- Location (What country are you in?)
- Stakeholder group
  - Researcher
  - Person with lived experience – ex. Patient, Caregiver, Family Member
  - Decision / Policy maker
  - Health Professional
  - Other
- Experience of impact assessment of research
  - No experience
  - Some experience
  - Fair experience
  - A lot of experience

# GROUND RULES

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- Terminology
  - **PPI - Patient and Public Involvement:** Research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.
  - **Patient-Oriented Research:** Engaging patients, their caregivers, and families as partners in the research process.
  - **“Patient”:** Broad term used to encompass patients, caregivers and family members.
  - **Research Impact:** The demonstrable contribution that excellent research makes to society and the economy. This can involve academic impact, economic and societal impact or both.
- Approach for the session
  - Interactive presentation followed by mutual learning discussion

## POLL

- What are your thoughts on these four terms and their definitions – place a check mark on the poll if you agree with how they are defined.



# WHY DO WE NEED TO MEASURE IMPACT?

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"How come 'because' is not an answer,  
but 'because I said so' is?!"

<https://andertoons.com/kid/cartoon/3601/how-come-because-not-an-answer-but-because-i-said-so-is>

# Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5804082/>



*“...limited evidence of the clear role and scope of patient engagement in research is coupled with a lack of evidence about its impact resulting in a ‘catch-22’ situation”*

*“Evaluation frameworks and sufficient evaluation data to measure near, intermediate and long-term outcomes of engaging patients across health research activities are needed. Successful and sustained adoption of meaningful engagement is hinged on reliable outcomes”*

# ONE EXAMPLE LIST OF BENEFITS OF INVOLVING PATIENTS IN RESEARCH (FROM ALBERTA INNOVATES)

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## Research/Researchers

- Improved quality of research design
- Increased participant enrolment and decreased attrition;
- Wider impact and application of research findings
- Stronger rapport with patient communities
- Better understanding of and insight into gaps and priorities in the research area
- Overall improved research effectiveness.

## Patients

- Influencing the questions that are researched and explored
- Developing their own voice by knowing they are valued and have power to influence
- Gaining confidence about research and other life skills
- Building trust and rapport with clinicians, researchers, or both
- Receiving improved care through the implementation of research findings more relevant to them

# REASONS TO ASSESS IMPACT

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Whether we are doing PPI for moral reasons, an obligation to tax payers or for so-called instrumental reasons, we may need to consider:

- Are we fulfilling goals of engagement in research? Is PPI accomplishing what we said it would?
- Accountability to funders?
- Is our engagement approach of selected patient partners achieving the broader goals for the whole patient population?
- Knowledge for knowledges sake?



# CONTENTIOUS ISSUES

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- **Are the benefits of participation “worth” the costs?**

*“It is unlikely that outcomes of PPI can be translated into the type of single monetary, effectiveness or utility measures required by traditional methods of economic evaluation, and attempts to do so would be complex and **contentious**”* – Pizzo et al 2015



What if we find costs outweigh benefits??

## PATIENT AND PUBLIC INVOLVEMENT: HOW MUCH DO WE SPEND AND WHAT ARE THE BENEFITS? – PIZZO ET AL. 2015

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- “The lack of an appropriate analytical framework, data recording and understanding of the potential costs and benefits of PPI, especially from participants' perspectives, represent serious constraints on the full evaluation of PPI.”
- “...there is very little detailed analysis...with benefits largely assumed or taken for granted.”
- Not clear how to connect dots from engagement to service, research and policy change.
- No broadly accepted methods or evaluation frameworks for engagement process and outcomes



# CONTENTIOUS ISSUES

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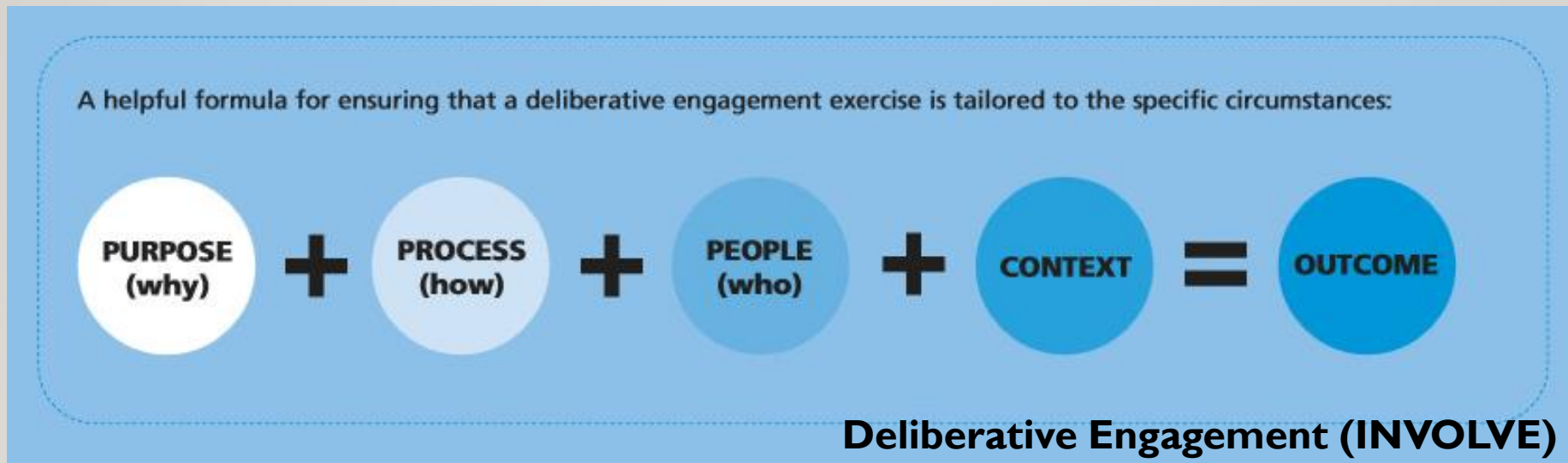
- We don't systematically measure the impacts of many "types" of research



# CONTENTIOUS ISSUES

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- We will never be able to creating an evaluation framework which captures the complexity of PPI and that applies in every context



# CONTENTIOUS ISSUES

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- The procedures for measuring impact, the system in which measurement will occur and the assessment of outcomes is currently not defined from the perspective of the patient.



# CONTENTIOUS ISSUES

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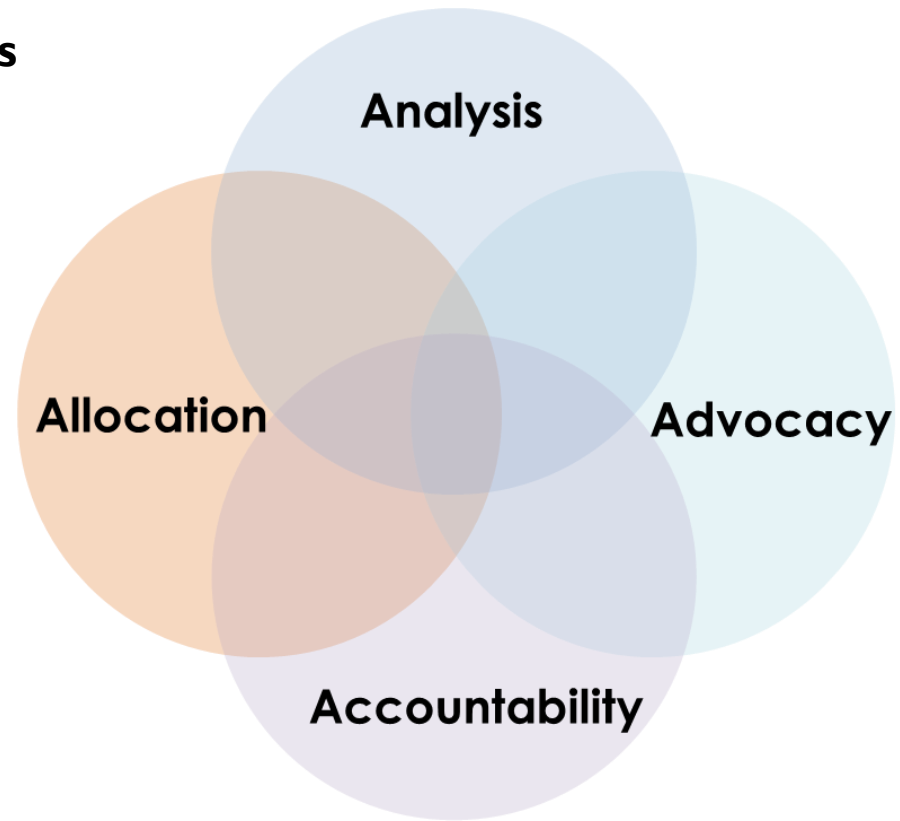
- Public Good vs. Publicly Good  
– is there an ‘inclusion imperative’ that shapes our impact assessment?



HOW DO WE  
CONCEPTUALIZE THE  
NEED FOR RESEARCH  
IMPACT ASSESSMENT?

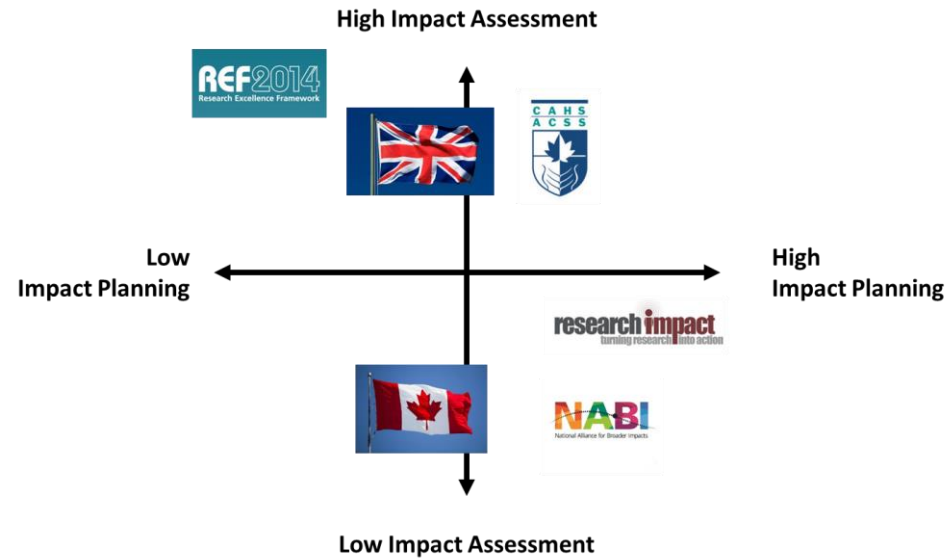
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### The 4A's



# WHAT CAN WE DO RIGHT NOW

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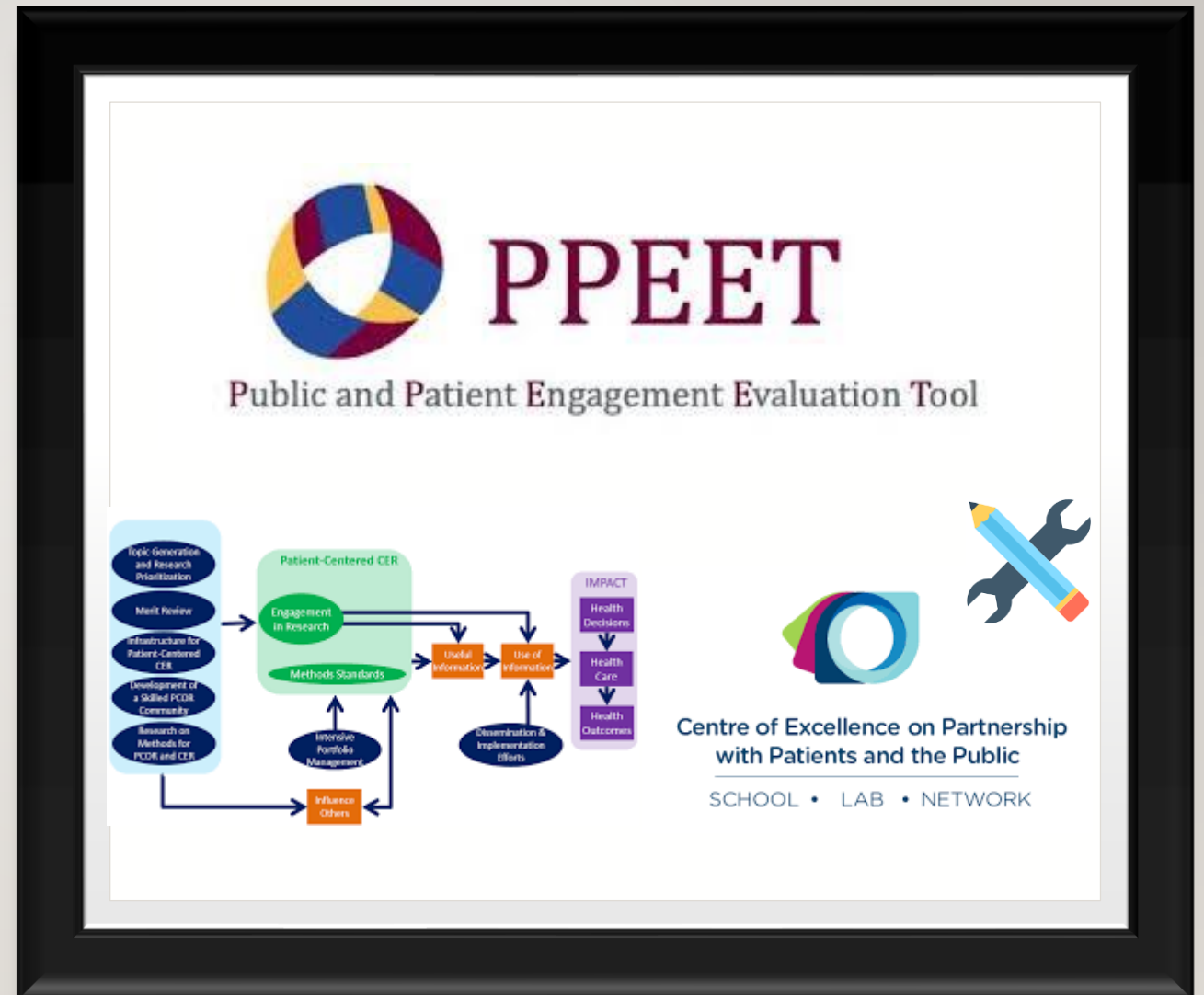
- Where are we with impact evaluation of research?
  - Research impact assessment and evaluation are now common in many countries
  - Tend to be either (a) metric driven, or (b) narrative driven
  - Still contentious with the research community



# WHAT CAN WE DO RIGHT NOW

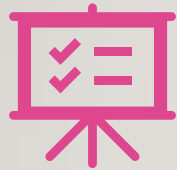
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- Where are we with evaluation of PPI / Patient Partnership?
- Lots of movement on the process of PPI, less so on the impact
  - Impact evaluations tend to only identify the need for better impact evaluation.



# WHAT CAN'T WE DO RIGHT NOW?

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## **Solid metrics / measures of impact for PPI?**

E.g. measuring the right things at the right time – where are our biases?



## **Attribution of impacts to research**

E.g. policy changes reflecting PPI over other inputs?



## **Collate information across PPI evaluations**

E.g. comparing apples and oranges...

# WHERE ARE THE PINCH POINTS?

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## Poll

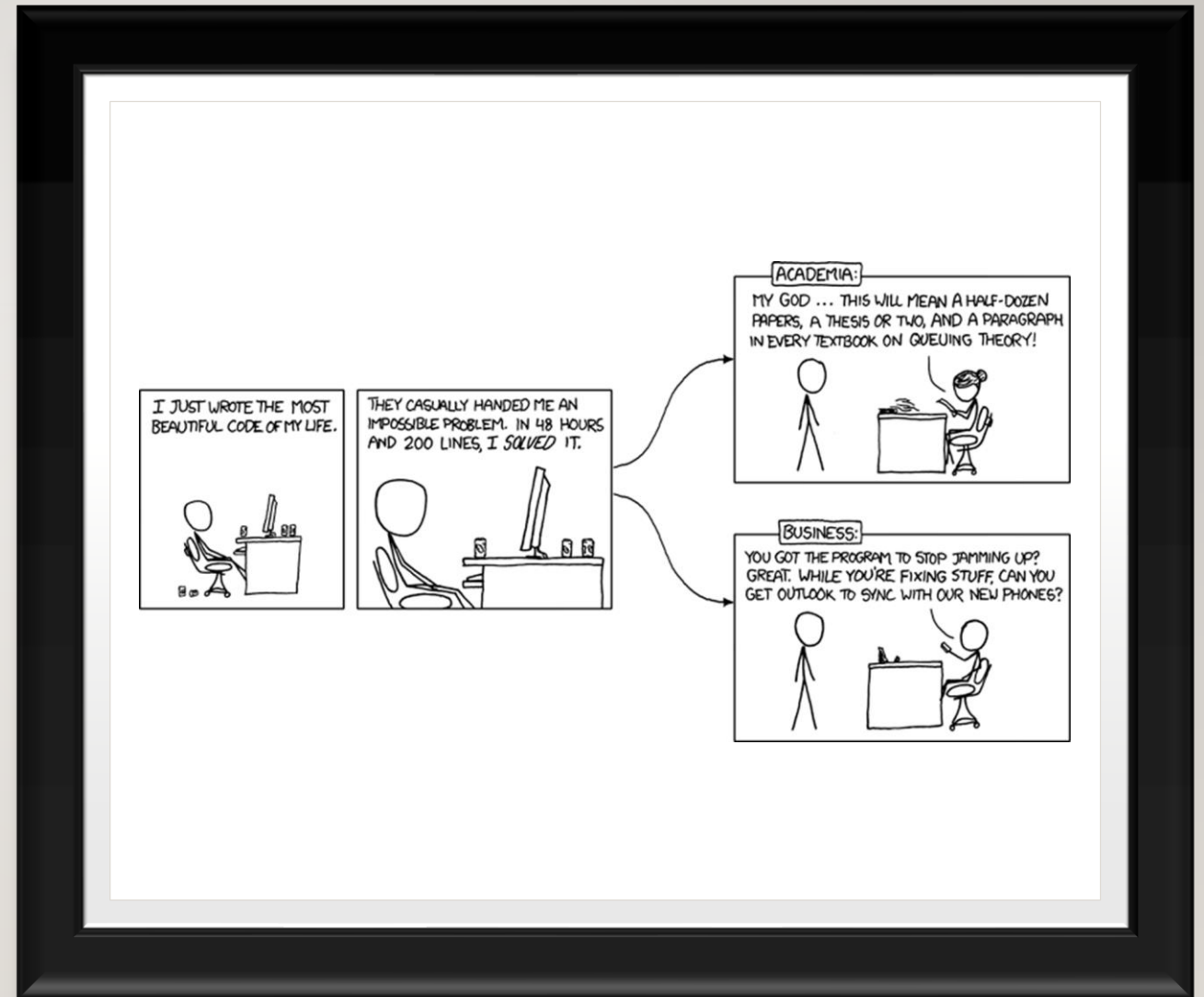
- Of the following, what are the three most important impacts of PPI you might want to know?
  - Impacts on health outcomes?
  - Impacts on well-being?
  - Impacts on healthcare costs?
  - Impacts on healthcare delivery approaches?
  - Relevance of impacts to patients and the public?
- Comparing what we “want” to measure with what we “should” measure
  - The transferability of the JLA approach...



# WHERE ARE THE PINCH POINTS?

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WHO'S VALUES ARE WE REFLECTING  
IN PPI IMPACT ASSESSMENT?





"Remember the Magic Bean Project  
that we shut down last week?"

## WHERE ARE THE PINCH POINTS?

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TIMELINE ISSUES FOR RELEVANT  
AND MEANINGFUL IMPACTS

# WHERE ARE THE PINCH POINTS?

- Top down vs. bottom up in identifying impacts

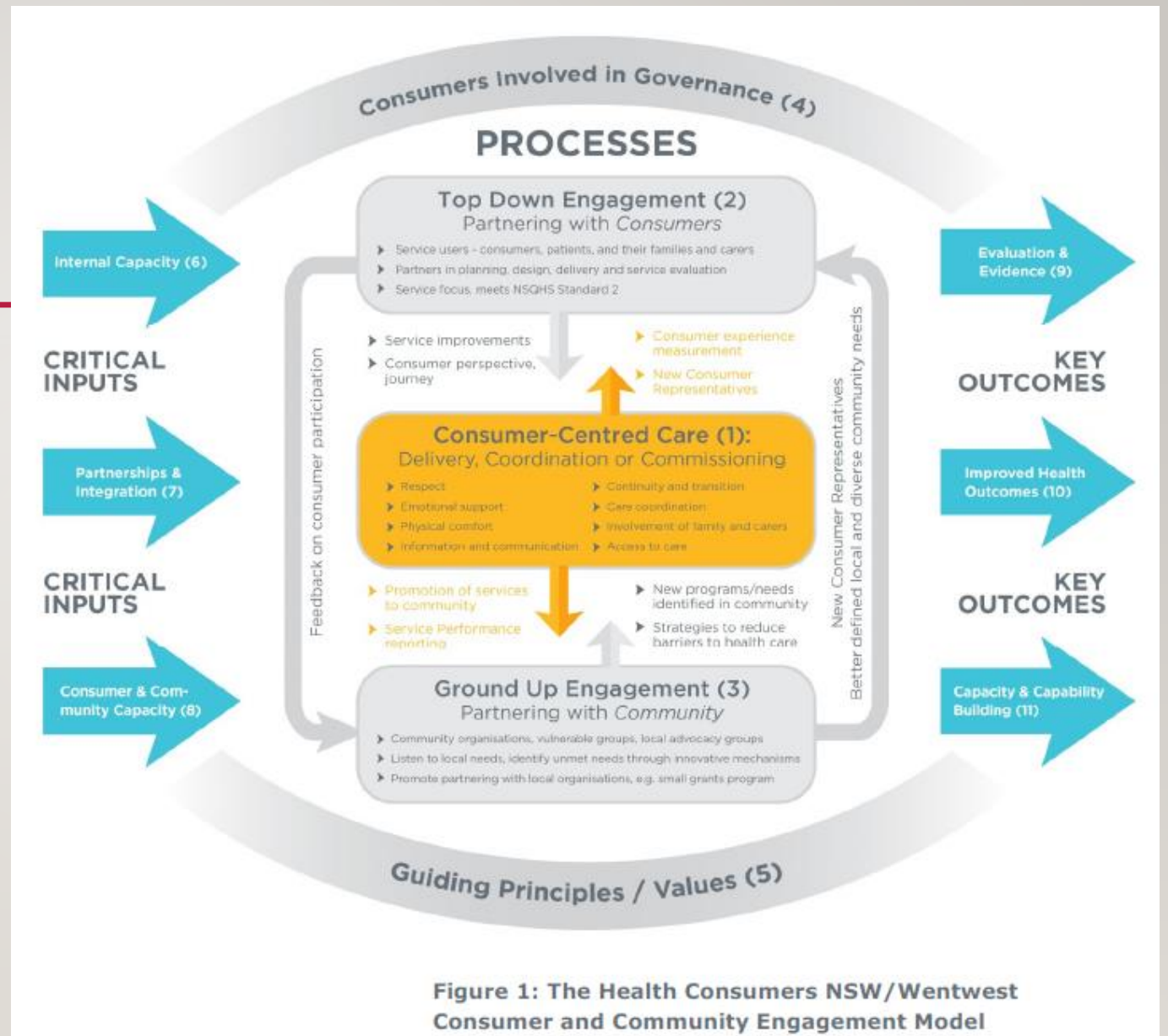


Figure 1: The Health Consumers NSW/Wentwest Consumer and Community Engagement Model

# HOW CAN WE MOVE FORWARD?

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- EN<sup>2</sup> thoughts on potential starting points to move forward with this...
  - Ability to look at existing approaches to research impact assessment and compare / contrast PPI research with non-PPI to understand where our bias might be
  - Meta-analysis of existing evaluations of PPI to identify potential cadre of impacts arising from PPI
  - Return to first principles and build a new framework / approach built on whatever are shared / agreed upon values for PPI across relevant stakeholders
  - Those of us who do PPI - start reflecting on this as part of PPI processes within individual projects WITH patients.
  - More recording and reporting of process (including above). Make use of reporting frameworks like GRIPP-2 for PPI, REPRISE (just out Dec. 2019 for reporting on priority setting) so we can have more standardized descriptions to help when reviewing literature/landscape.

# OPEN DISCUSSION

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- What are your thoughts and experiences around impact assessment for patient and public inclusion in research?
- How do you think we can move forward on this issue (if we should)?





# SOME FURTHER READING

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- Sunderji, N., Nicholas Angl, E., Polaha, J., & Gao, C. (2019). Why and how to use patient-oriented research to promote translational research [Editorial]. *Families, Systems, & Health*, 37(1), 1–9. <https://doi.org/10.1037/fsh0000405>
- Aubin D, Hebert M, Eurich D. (2019). The importance of measuring the impact of patient-oriented research. *CMAJ*, 191(31): E860-E864. doi: 10.1503/cmaj.190237
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- Greenhalgh, T., Jackson, C. and Janamian, T. (2016). Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study. *Millbank Quarterly*, 94(2): 392-429. doi.org/10.1111/1468-0009.12197
- Tina Cook, Jonathan Boote, Nicola Buckley, Sofia Vougioukalou & Michael Wright (2017) Accessing participatory research impact and legacy: developing the evidence base for participatory approaches in health research, *Educational Action Research*, 25:4, 473-488, DOI: [10.1080/09650792.2017.1326964](https://doi.org/10.1080/09650792.2017.1326964)
- Also See other links throughout presentation