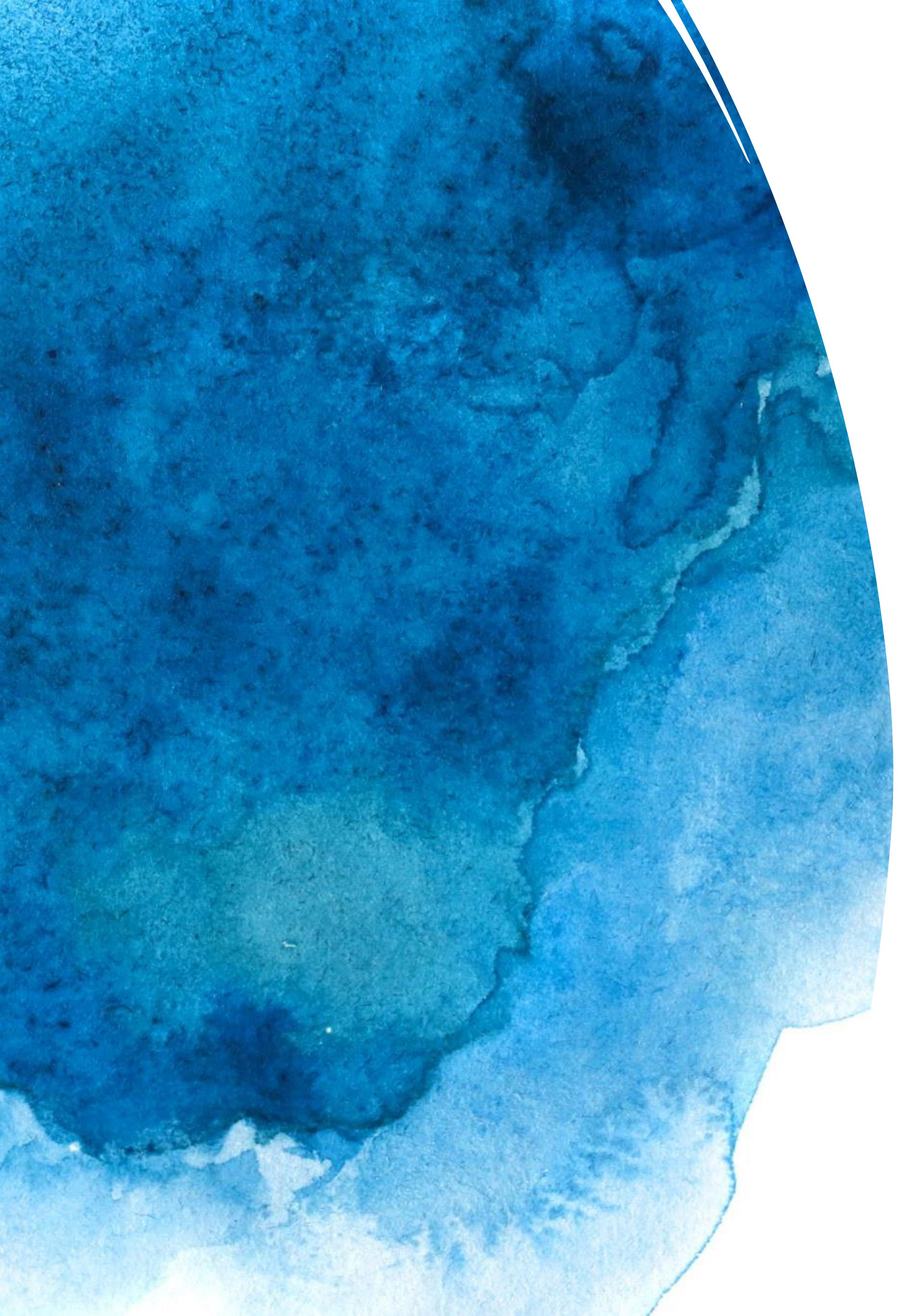

Consumer Engagement in Research

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NHMRC WORKSHOP 15 NOV 2022

Acknowledgement of Country

ACCESSCR

My Reflections

- Why consumer involvement & partnership matters
- Where and how
- Moving forward….

Different perspectives

- Scientific or clinical question
- How to collect/store
- How to use/process
- Reproducibility/quality of result
- What the result means for research/clinical decision making

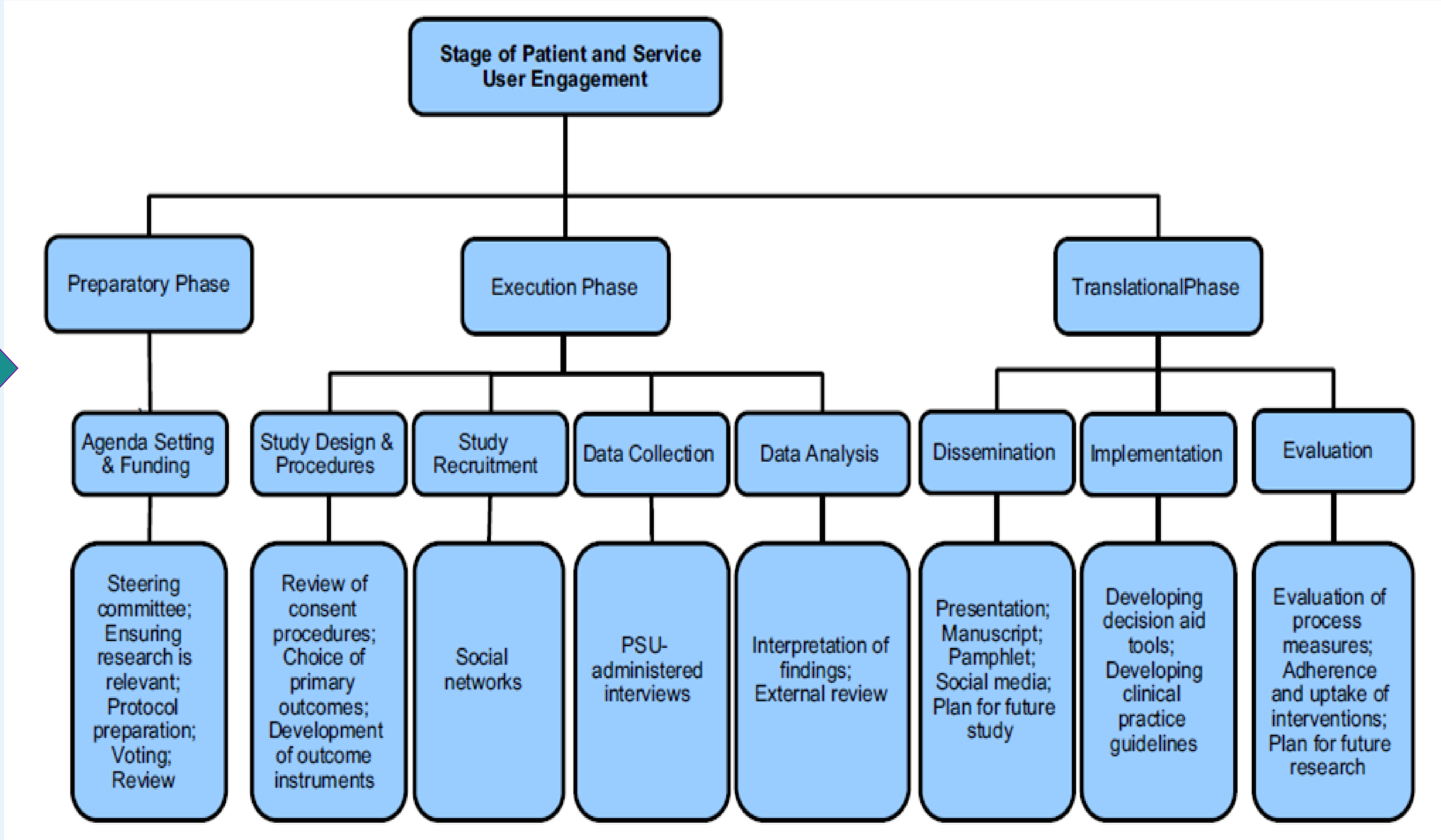
- How do I access the test? When?
- Will it hurt?
- Where will I need to go?
- How much time will that take?
- Who pays?
- Will I get the result (& do I want it?)
- How will I get the result? Will I understand the result?
- What will the result mean for my care? For my children/relatives?

Where to Involve?

Research Design, Conduct & Translation

Program/ Org Strategy/ Governance

Policy, Process & Funding



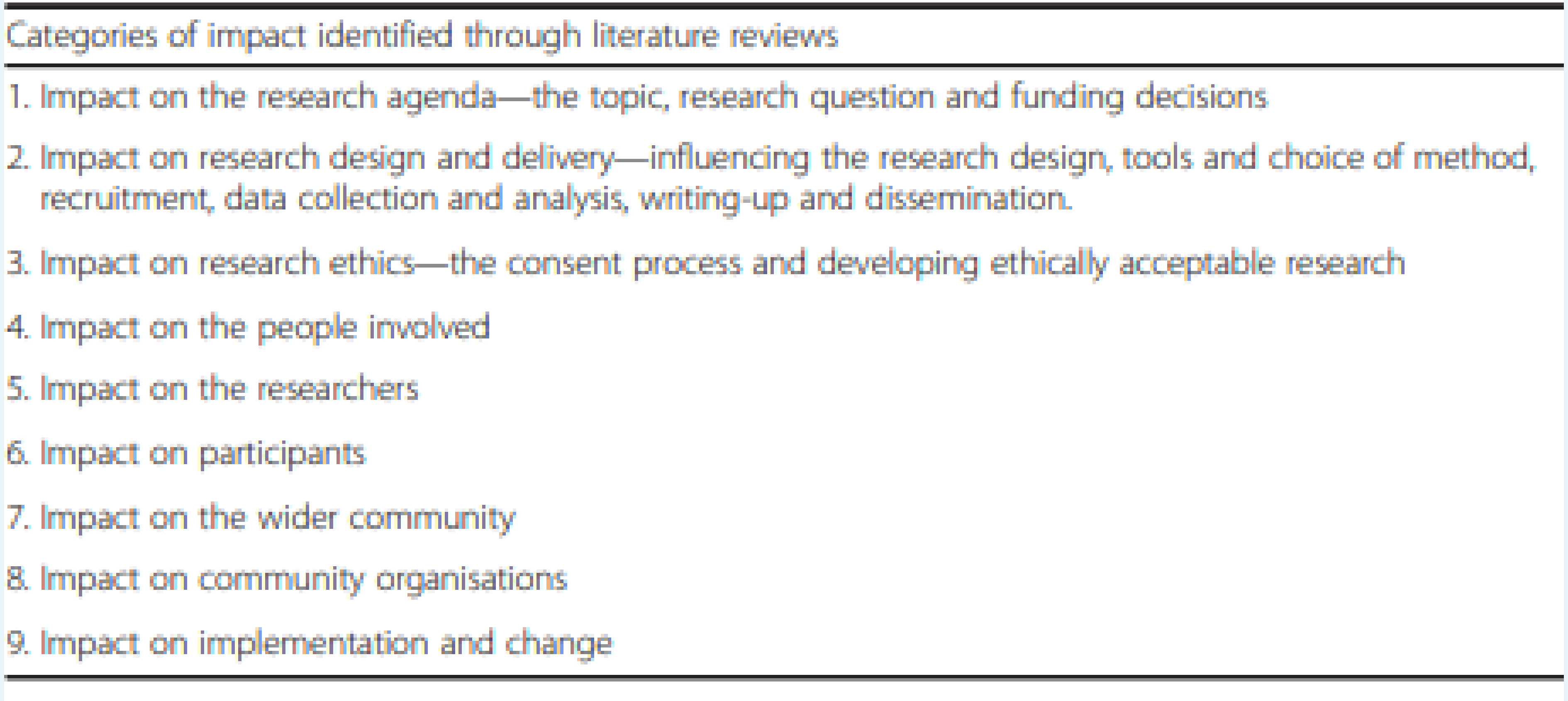
Inspired by: http://dx.doi.org/10.1136/ bmjqs-2016-005476

Source: HealthExp 2015 ND Shippee et al doi: 10.1111/hex.12090

Value

Source: Moving patient-oriented research forward: thoughts from the next generation of knowledge translation researchers.
Bishop *et al.* Research Involvement and Engagement (2018) 4:23 https://doi.org/10.1186/s40900-018-0110-6

Where does it impact?



Categories of impact identified through literature reviews
1. Impact on the research agenda—the topic, research question and funding decisions
2. Impact on research design and delivery—influencing the research design, tools and choice of method, recruitment, data collection and analysis, writing-up and dissemination.
3. Impact on research ethics—the consent process and developing ethically acceptable research
4. Impact on the people involved
5. Impact on the researchers
6. Impact on participants
7. Impact on the wider community
8. Impact on community organisations
9. Impact on implementation and change

Source: ‘Is it worth doing?’ Measuring the impact of patient and public involvement in research
K Staley, Research Involvement and Engagement (2015) 1:6 DOI 10.1186/s40900-015-0008-5

Potential Impacts (e.g. Trials)

Is it the right question?
Does it matter to patients?
Is it an unmet need?

→ Relevance

Right comparators?

→ Grounded in reality

What outcomes matter to patients ?

→ QOL, Pt reported outcomes, Relevant endpoints

Communicating effectively with participants?

→ consent, assessment tools, updates, results

Are eligibility criteria practical?

→ Diversity, Inclusive, Real world, avoid protocol amendments

Practical logistics?

→ Recruitment, retention

Burden of trial schedule?

→ Adherence, Retention

Is the developing safety profile acceptable?

→ Go/No-go decisions

What is the patient population's risk tolerance?

→ Ethics, Acceptability

How to spread the word about a trial?

→ Recruitment

Are the results relevant?

→ Credibility, Implementation

Patient Engagement: Original Research

DIA

Therapeutic Innovation
& Regulatory Science
2018, Vol. 52(2) 220-229
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Assessing the Financial Value of Patient Engagement: A Quantitative Approach from CTTI's Patient Groups and Clinical Trials Project

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and Joseph DiMasi, PhD[2]**

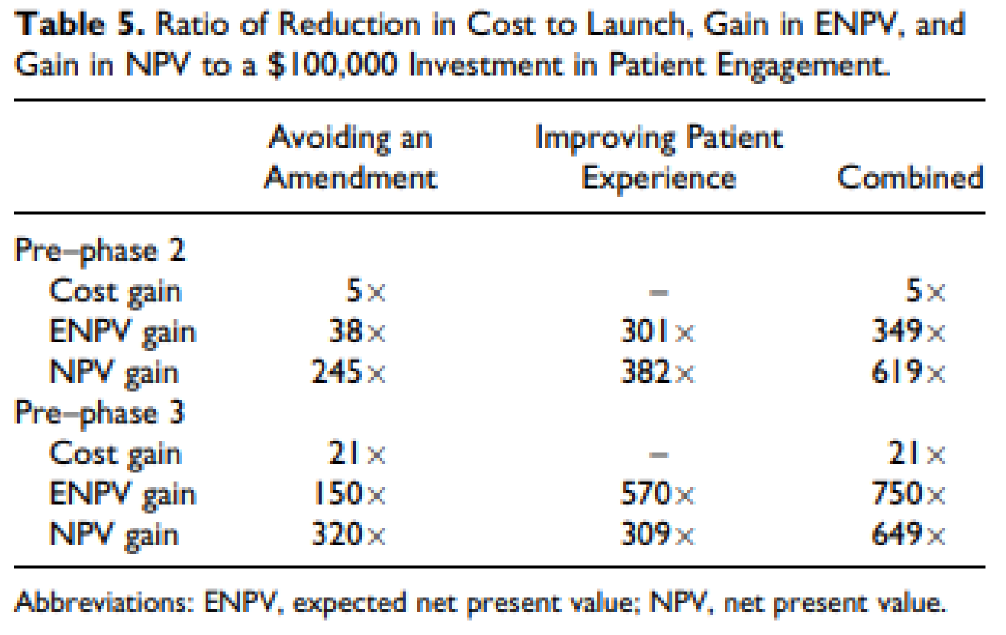

Table 5. Ratio of Reduction in Cost to Launch, Gain in ENPV, and Gain in NPV to a $100,000 Investment in Patient Engagement.

	Avoiding an Amendment	Improving Patient Experience	Combined
Pre–phase 2			
Cost gain	5×	–	5×
ENPV gain	38×	301×	349×
NPV gain	245×	382×	619×
Pre–phase 3			
Cost gain	21×	–	21×
ENPV gain	150×	570×	750×
NPV gain	320×	309×	649×

Abbreviations: ENPV, expected net present value; NPV, net present value.

Engagement activities with the potential to avoid protocol amendments and/or improve enrollment, adherence, and retention may add considerable financial value.

Source: Assessing the Financial Value of Patient Engagement: A Quantitative Approach from CTTI's Patient Groups and Clinical Trials Project. Therapeutic Innovation & Regulatory Science. 2018;52(2):220-229. https://journals.sagepub.com/doi/pdf/10.1177/2168479017716715

As the Statement currently stands...

Forward

…Consumers and the community offer unique and valuable insights as research is framed, conducted and translated, helping to ensure research quality and relevance. *And improve the experience.*

…The Statement recognises that the form and degree of community involvement must be appropriate to the research activity and requires consumers and community members with differing backgrounds, interests and perspectives.

Our values: *Shared understanding, respect and commitment*

Best and worst experiences

- Checkbox ticking – seen to be doing
- Dismissive
- Poor communication
- Respect for time
- Loss of identity
- Financial impact

- Collaborative
- Shared goals
- Feeling valued
- Knowing the impact

Vision – Does it ask enough of medical research?

- *Consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.*

↓

- *Health and medical research advances the knowledge, health and wellbeing of all Australians in a way that is scientifically rigorous and transparent, relevant to and inclusive of the needs of a diverse Australia, and respectful of those that participate and contribute to it.*

Code – Responsible Conduct of Research

- P1 Honesty in the development, undertaking and reporting of research
- P2 Rigour in the development, undertaking and reporting of research
- P3 Transparency in declaring interests and reporting research methodology, data and findings
- P4 Fairness in the treatment of others
- P5 Respect for research participants, the wider community, animals and the environment
- P6 Recognition of the right of Aboriginal and Torres Strait Islander peoples to be engaged in
- research that affects or is of particular significance to them
- P7 Accountability for the development, undertaking and reporting of research
- P8 Promotion of responsible research practices

Source: Australian Code for the Responsible Conduct of Research 2018 https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018