IMAGINATION AT WORK

FROM INSIGHT TO ACTION

A pragmatic, participatory approach to improving cancer clinical trial systems

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I would like to acknowledge the Larrakia people who are the traditional owners and custodians of the land and sea on which we meet today.

I would also like to pay my respects to Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander people here today.

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Cancer Data & Intelligence



Clinical Trials



Care Navigation & Optimal Care Pathways



Prevention



Capital Purchases - for better patient care

Improving Cancer Outcomes in Aboriginal People

State & National Cancer Priorities

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Our starting challenge

Develop a shared understanding of how the system operated and identify agreed priorities for improvement

The system challenge

- Many interacting issues
- Different perspectives and boundaries
- Competing priorities
- Distributed authority and ownership
- No obvious place to begin

The process challenge

- Understand how the system operated in practice
- Build a sufficiently credible shared picture
- Identify where the team and stakeholders had scope to act
- Maintain trust while the broader direction developed

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Pragmatic & Participatory Approach

1



OPENING DIALOGUE & FOCUS

Explore broadly with stakeholders and identify an initial focus.

2



INVESTIGATE

Governance and ethics selected for deeper investigation.

3



TEST & INTERPRET

Return findings to stakeholders to challenge, validate and refine.

4



TRANSLATE & PRIORITISE

Connect problems to improvements and assess initial actions.

5



ACT & LEARN

Progress initial actions and use learning to inform wider reform.

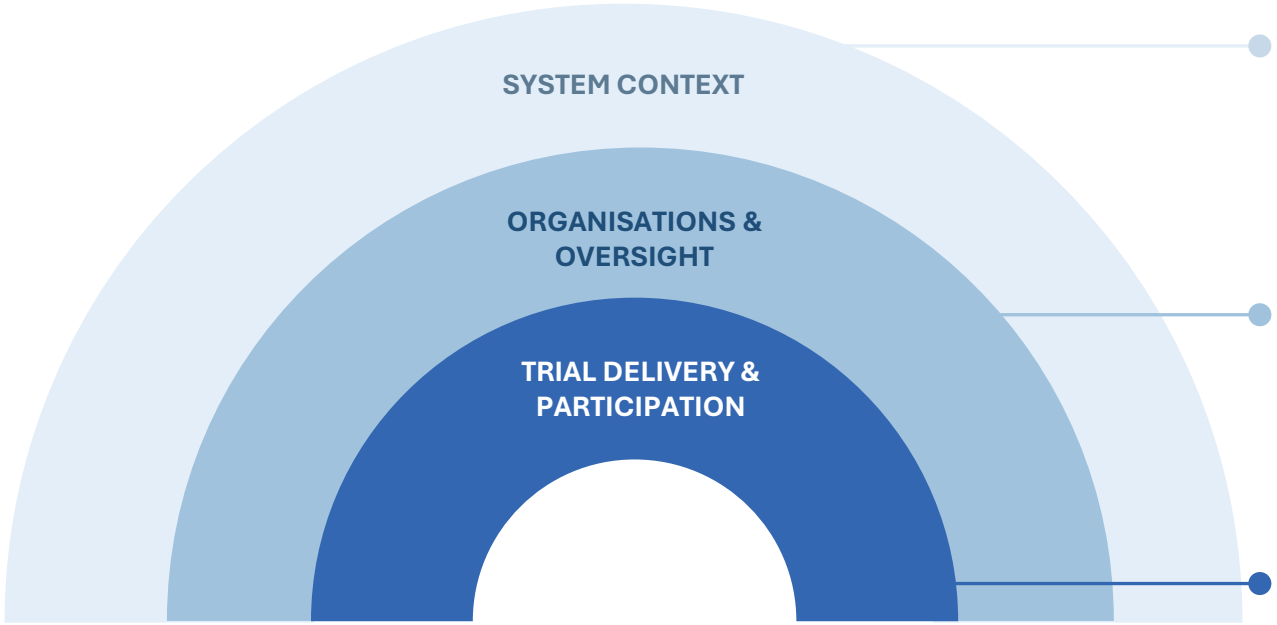
Governance and ethics deep dive: Identify tangible actions, demonstrate progress and build trust.

Broader ecosystem development: Gather evidence, review models and develop the wider reform direction.

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Participation across the clinical trials ecosystem



OUTER LAYER | SYSTEM CONTEXT & ENABLERS

- Government and statewide bodies
- Data and digital partners
- Policy, funding and regulatory settings

MIDDLE LAYER | ORGANISATIONS & OVERSIGHT

- Ethics committees and research governance offices
- Public, private and regional health services
- Researchers and universities

INNER LAYER | TRIAL DELIVERY & PARTICIPATION

- People affected by cancer and communities
- Clinicians, investigators and trial units
- Sponsors and contract research organisations

Different stakeholders held different knowledge, influence, interests and readiness for change.

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How we engaged

Broad engagement

- Workshop 1
- Workshop 2
- Surveys

Deeper inquiry

- Interviews
- Pathway mapping
- Document analysis
- Surveys

Ongoing guidance

- Steering committee (5 meetings, 17 members)
- Working group (5 meeting, 20 members)
- Informal discussions

Different activities served different purposes at different stages of the process.

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The journey so far

A simplified view of an iterative and overlapping process

1 OPEN AND FOCUS

Workshop 1

- 65 attendees
- 22 organisations
- Pre-survey and broad exploration
- Governance and ethics chosen as the initial focus

PURPOSE

Set shared priorities and a credible starting point.

2 INVESTIGATE

Governance and ethics current-state inquiry

- 27 structured interviews
- Pathway mapping
- Documents and processes analysed
- Sponsor surveys and informal input

PURPOSE

Understand how the system operated across settings.

3 TEST AND INTERPRET

Workshop 2 and ongoing stakeholder guidance

- 56 attendees
- Findings returned for challenge
- Accuracy and priorities tested
- Working and steering group input

PURPOSE

Build and refine a credible shared picture.

4 TRANSLATE, PRIORITISE AND ACT

Initial action and broader system development

- Findings → opportunity domains
- Models + ecosystem reviewed
- Impact + feasibility assessed
- Initial actions progressed

PURPOSE

Take feasible early action while wider approach was developed.

HAPPENING THROUGHOUT Working group • Steering committee • Informal engagement • Consumer engagement • Broader clinical trials ecosystem development

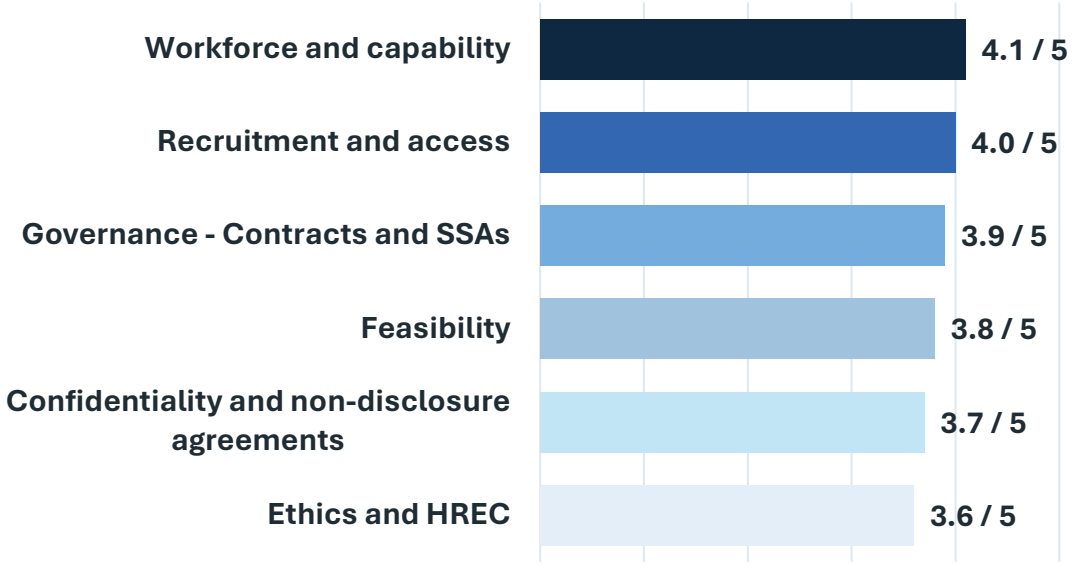
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Testing and validating the emerging picture

VALIDATION OF CURRENT STATE ANALYSIS

Participants ranked how well the current state findings reflected their experience (pathway steps)



STAKEHOLDER-RANKED THEMES TO ADDRESS ACROSS GOVERNANCE AND ETHICS

Priority order identified through validation (key themes from findings)

1. **Fragmented ethics and governance**
2. Workforce sustainability
3. **Data and systems fragmentation**
4. Timeliness and competitiveness
5. Equity and access

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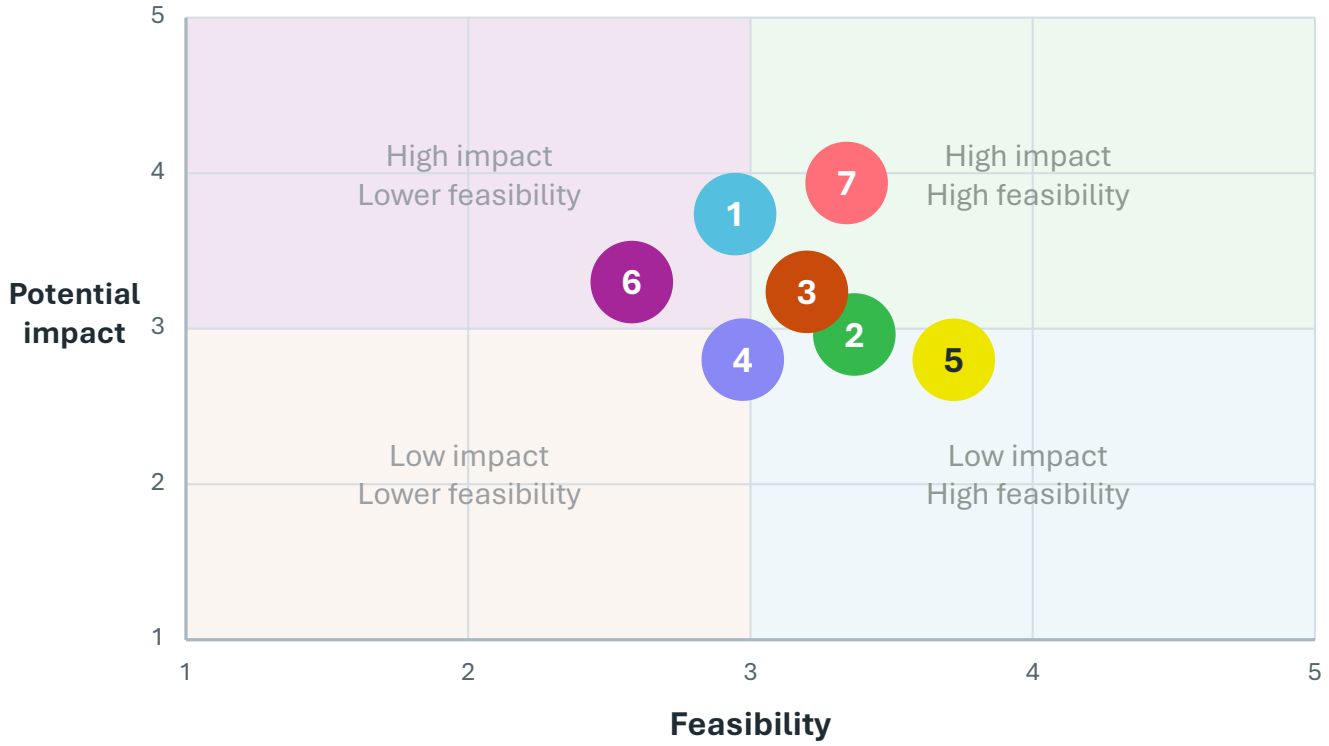
Prioritising initial action

Why start here?

- Respond to repeatedly identified problems
- Achievable within existing arrangements
- Could be commenced immediately

IMPACT × FEASIBILITY

Seven potential actions considered together



Examples

7 Strengthening communication and coordination across the governance and ethics pathway

2 Harmonised feasibility intake and minimum ancillary requirements

1 Statewide confidentiality disclosure agreement and clinical trial research agreement template pack

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Readiness for change

PARTICIPATION SUPPORTED

- Shared language & understanding of problem
- Confidence in the evidence
- Clearer collective priorities
- Relationships and ownership

PARTICIPATION ALSO REVEALED

- Different interpretations
- Conditional support
- Competing interests
- Constraints on action
- Differences in authority and appetite for change

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Reflections and lessons



Be clear what participation is for & engage the right stakeholders

Different stages require different people and different forms of influence.



Make the synthesis visible and close the loop

Shared understanding is essential to trust and buy-in.



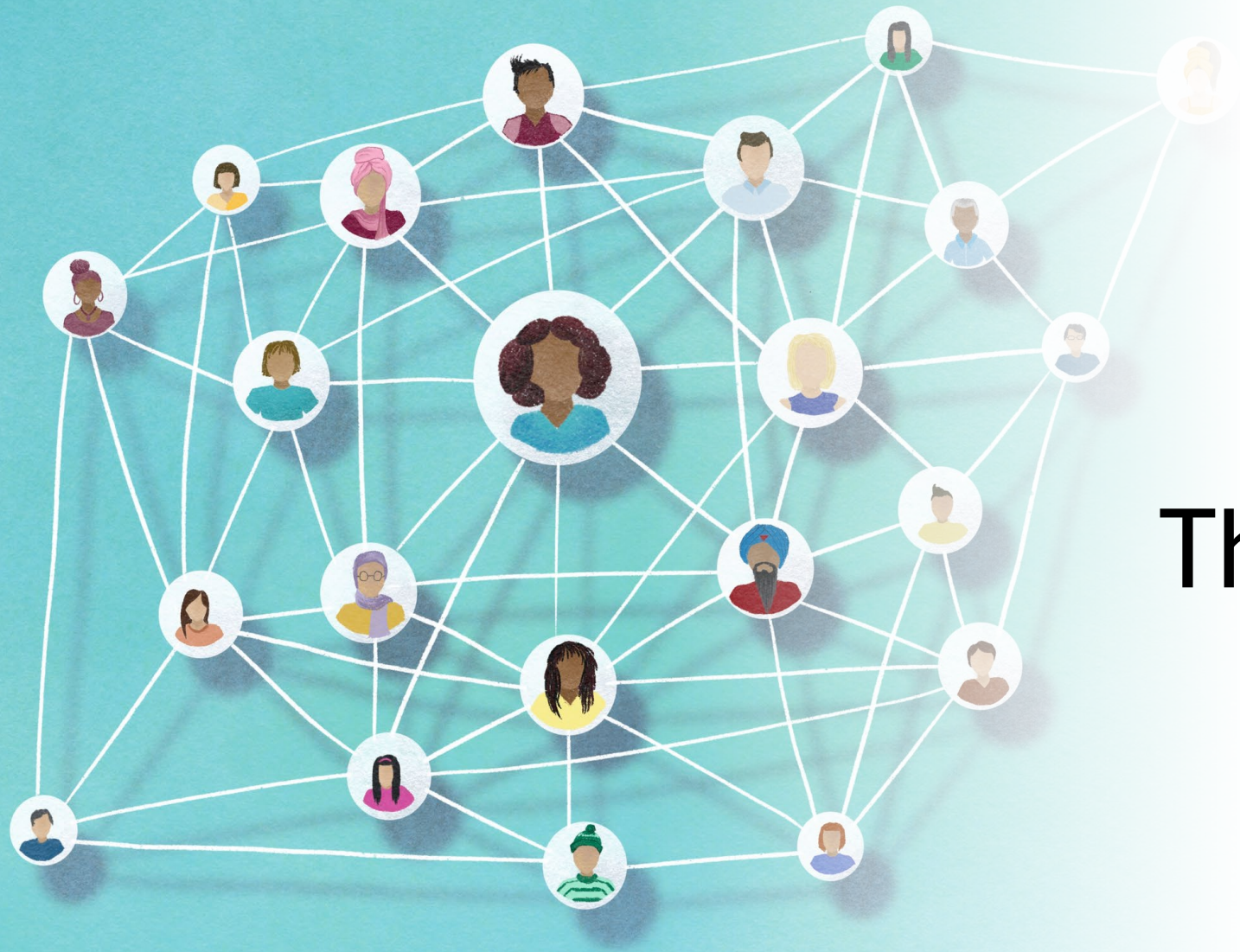
Expect readiness to vary across issues and stakeholders even when stakeholders identified the need for change

Agreement of the problem did not automatically extend to readiness for change.



Collaborative processes need credible early progress, not only continued engagement

initial actions can demonstrate responsiveness and generate learning, while larger structural reform continues.



Thank you!