



BEAT  CKD

BETTER EVIDENCE AND TRANSLATION IN CHRONIC KIDNEY DISEASE

Principles and strategies for involving patients in research in chronic kidney disease



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“ Nothing about us
without us”



Why should we involve patients in research?



Reduces waste through
aligning research priorities
(Chalmers 2014)



Recommended by global
organisations e.g. WHO



Improves practices (recruitment,
retention, communication)
(Crocker 2016, Domecq 2015)



To get published e.g. BMJ



Improves translation to practice
and policy
(Domecq 2015, McKenzie 2016)



To get funded e.g. NHMRC



Context

▶ CKD patients

- Lifelong, mortality x100, poor QoL, relentless symptom burden

Aim: To describe patient and health professional perspectives on how to effectively engage and involve patients in research in kidney disease

Workshops

- ▶ 3 workshops: Sydney, Adelaide and Brisbane
- ▶ 17 breakout discussion groups
- ▶ Invited through BEAT-CKD Investigator networks and KHA
- ▶ 105 patients/caregivers + 43 clinicians/researchers

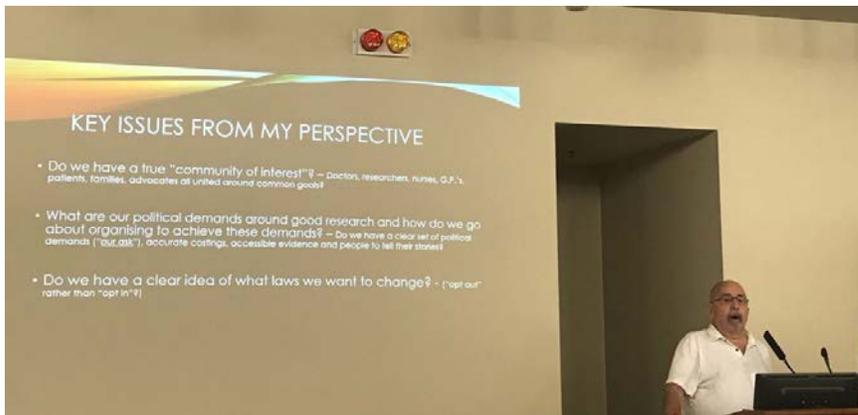




Results

“It’s about spinning it around and not talking about the clinical stuff. It’s talking about the patient reasons of why it’s important – what’s in it for the patient”

Health professional, Female



Identified 5 themes



“The power of people’s lived experience is
immediate” journey I’ve been involved in, and
they’ve taken a lot of information from me,
but I’ve never heard back about what the
outcomes are...as a consumer that makes me
disengage.”

Patient, Female

Respecting
patient
expertise and
commitment

- Valuing unique and diverse experiential knowledge
- Clarifying expectations and responsibilities
- Equipping for meaningful involvement
- Keeping in the loop with results and impact



“Once the patient is happy and healthy, then
I’m saving my annual leave for my
transplant.”
they’ll be able to go on and do research”

Patient, Female
Patient, Male

Respecting
patient
expertise and
commitment

Valuing unique and diverse experiential knowledge

Clarifying expectations and responsibilities

Equipping for meaningful
involvement

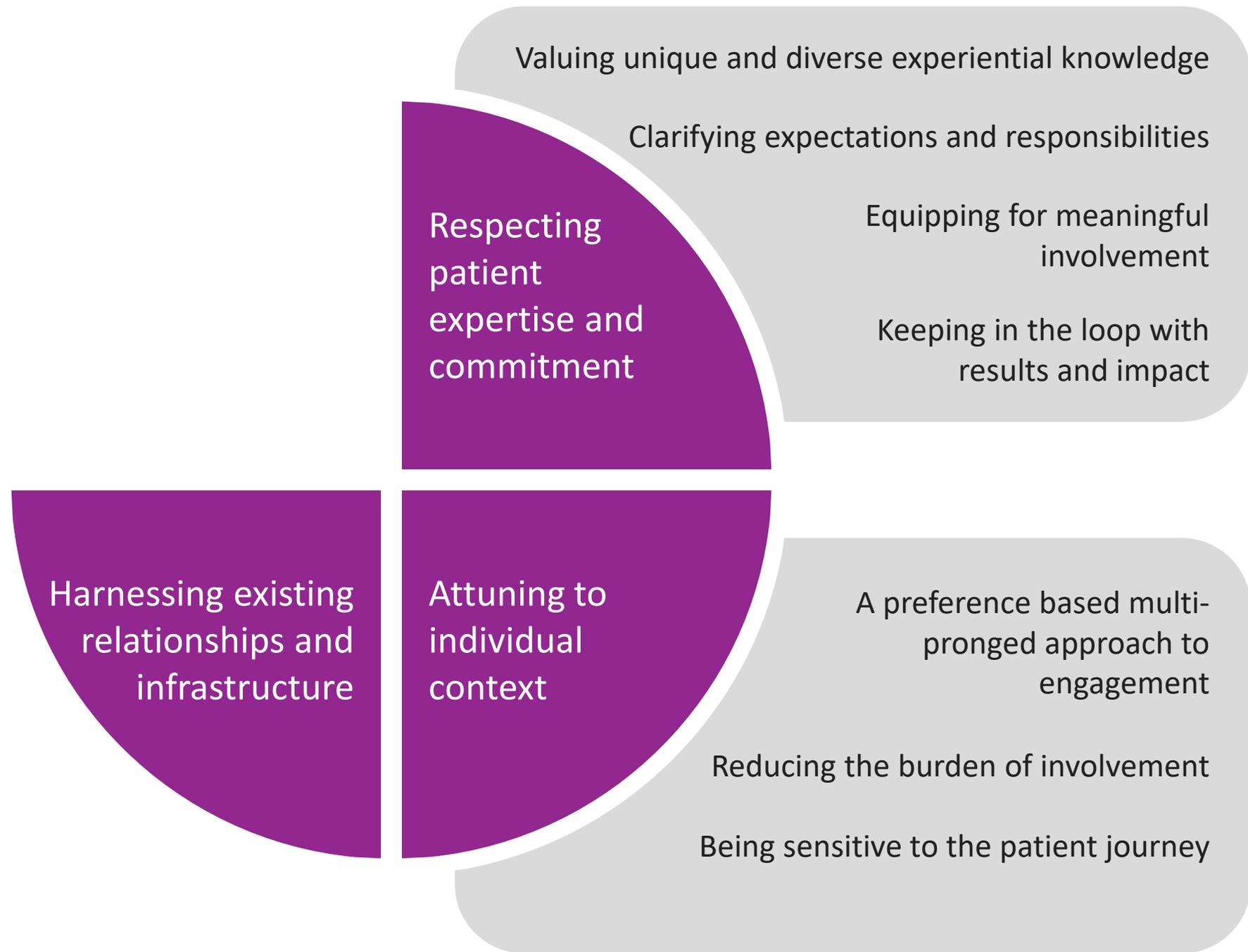
Keeping in the loop with
results and impact

Attuning to
individual
context

A preference based multi-
pronged approach to
engagement

Reducing the burden of involvement

Being sensitive to the patient journey





Partnering with trusted clinicians

Increasing exposure in clinical settings

Mentoring patient to patient

Extending reach through established networks

Harnessing existing relationships and infrastructure

“They were set up in the [hospital] foyer for kidney health week, we’ll take your blood pressure.”
People who come to the hospital already know they’ve got high blood pressure. You should be outside Bunnings’.”

Patient, Male



Power in the collective and united voice

Systematic approach for equitable inclusion

Streamlining access to opportunities and trustworthy information

Developing a coordinated approach

Partnering with trusted clinicians

Increasing exposure in clinical settings

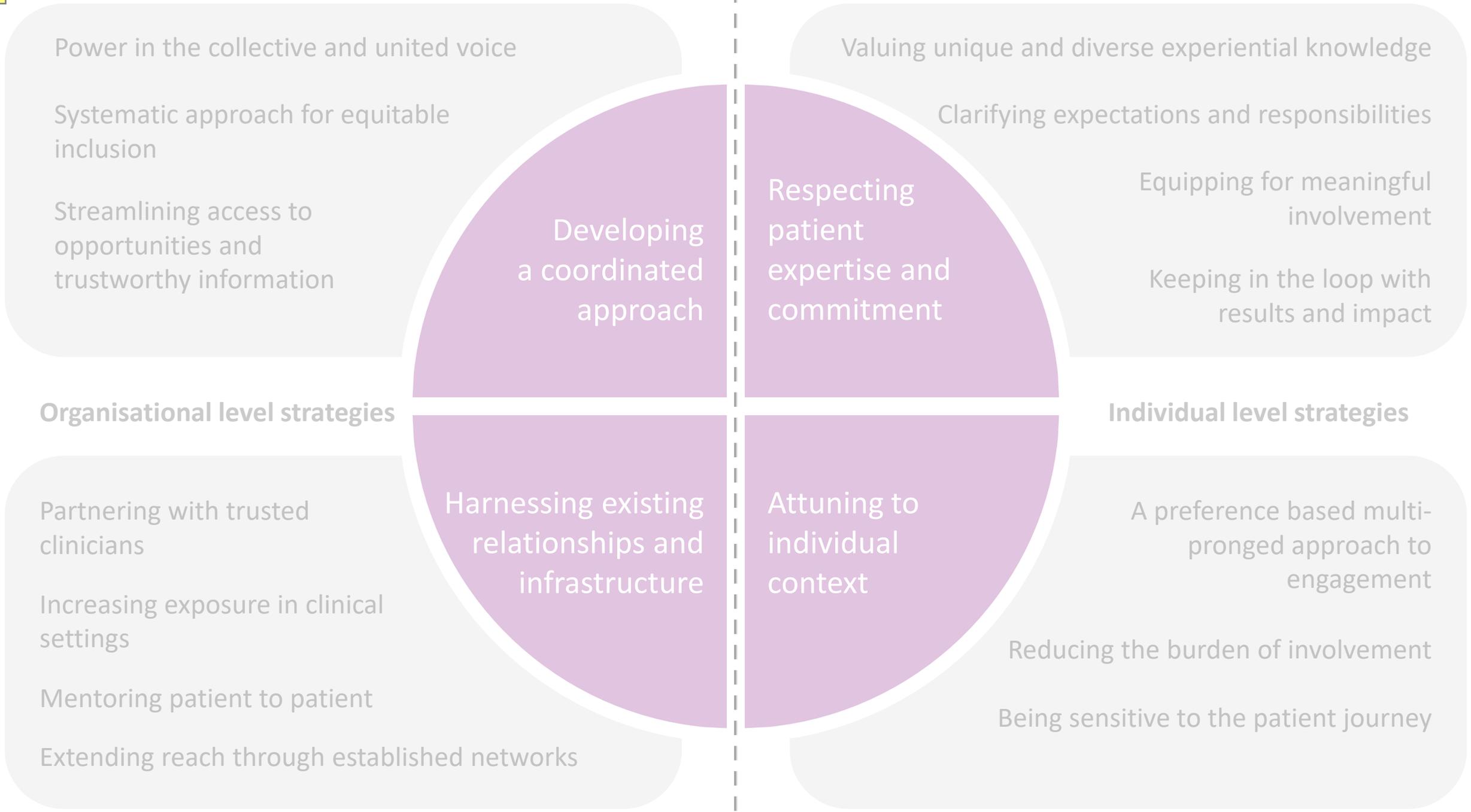
Mentoring patient to patient

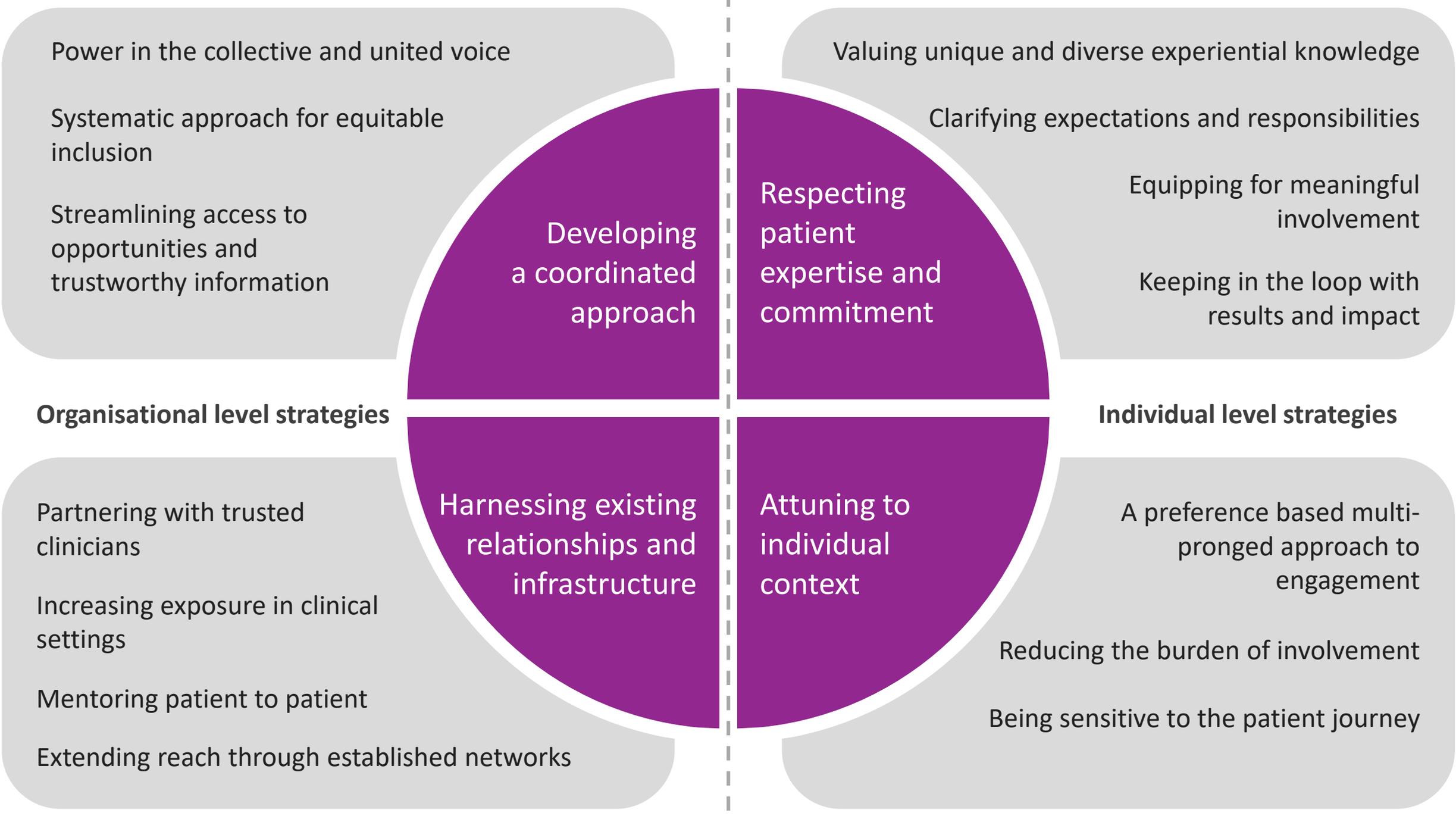
Extending reach through established networks

Harnessing existing relationships and infrastructure

“In some cases it’s always the same person diluting the power of the communication who puts themselves forward, and they may as well there doesn’t appear to be one umbrella organization that is driving communication to the consumer site they’re on this treadmill of being on all these different things.”

*Patient, Male
Patient, Female*





Power in the collective and united voice

Systematic approach for equitable inclusion

Streamlining access to opportunities and trustworthy information

Organisational level strategies

Partnering with trusted clinicians

Increasing exposure in clinical settings

Mentoring patient to patient

Extending reach through established networks

Developing a coordinated approach

Valuing unique and diverse experiential knowledge

Clarifying expectations and responsibilities

Equipping for meaningful involvement

Keeping in the loop with results and impact

Individual level strategies

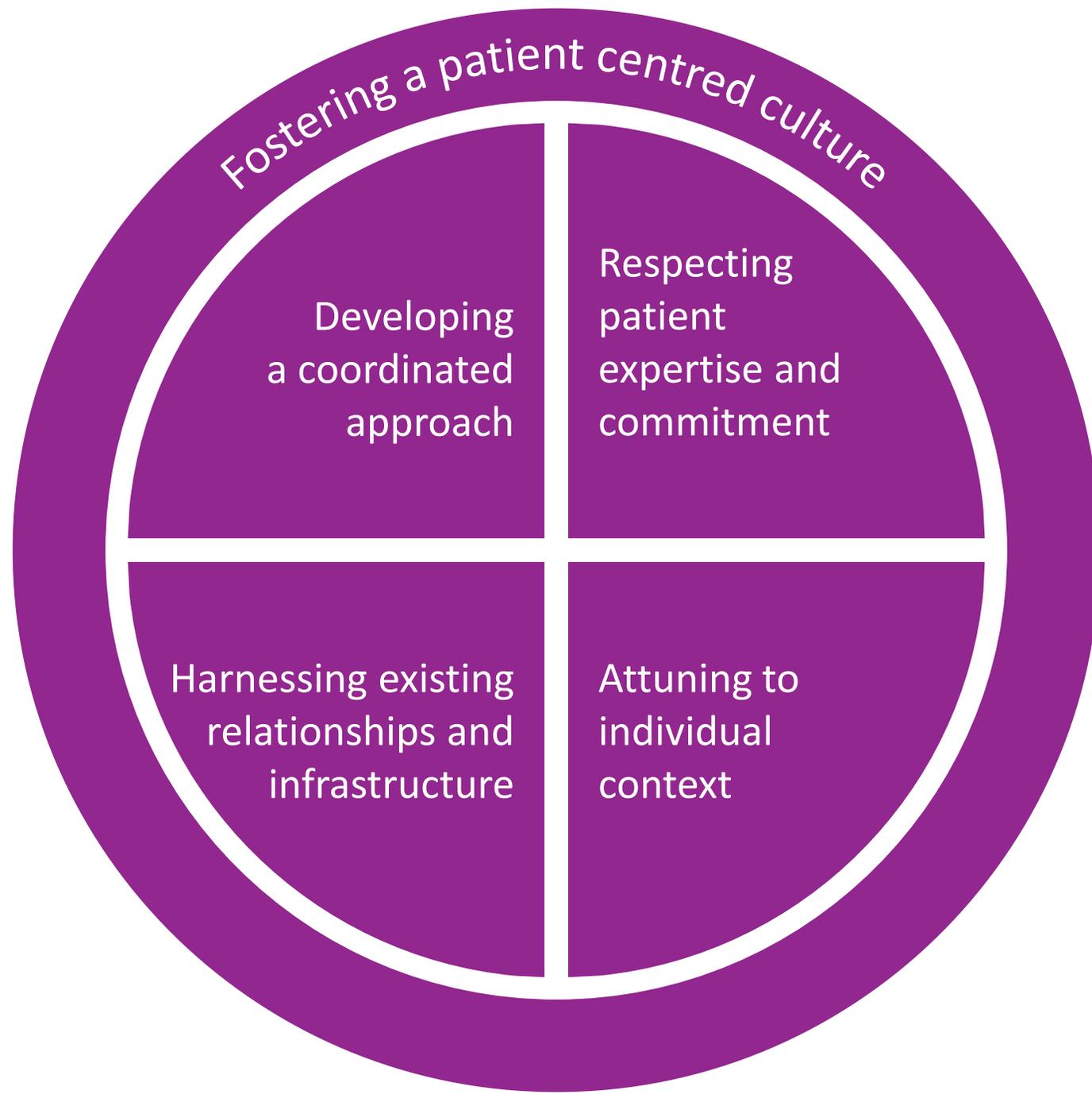
A preference based multi-pronged approach to engagement

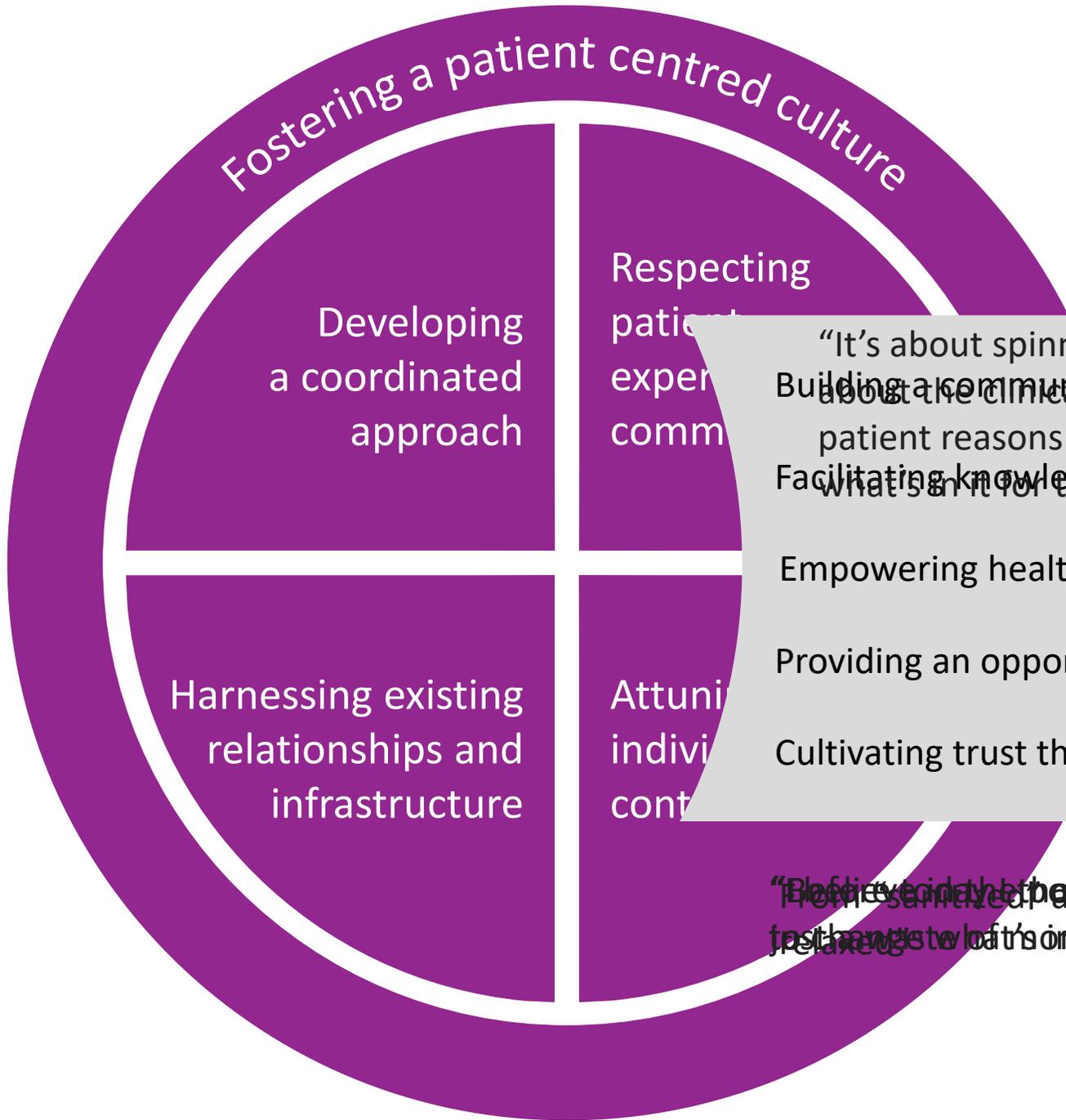
Reducing the burden of involvement

Being sensitive to the patient journey

Respecting patient expertise and commitment

Attuning to individual context





Fostering a patient centred culture

Developing a coordinated approach

Respecting patient experience and community

Harnessing existing relationships and infrastructure

Attuning individual content

Building a community
 “It’s about spinning it around and not talking about the clinical stuff. It’s talking about the patient reasons of why it’s important – Facilitating knowledge exchange and translation what’s right for the patient”

Health professional, Female

Empowering health ownership

Providing an opportunity to give back

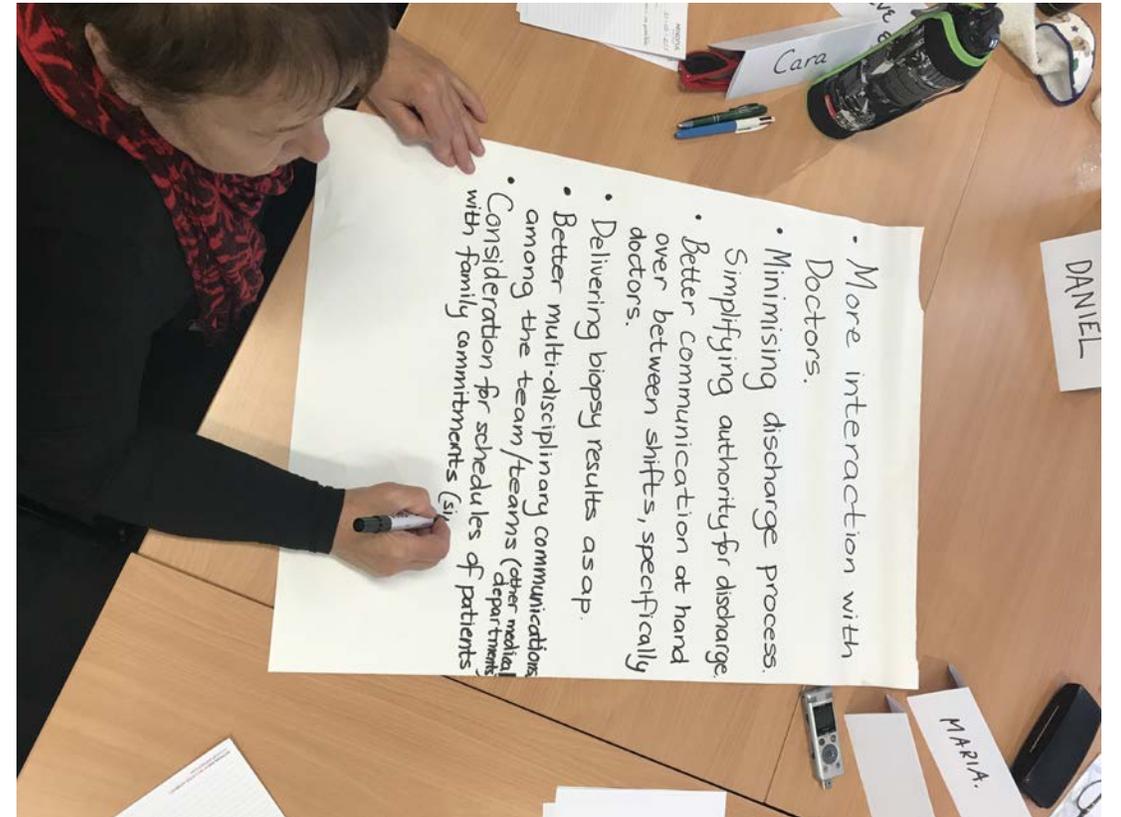
Cultivating trust through transparency

“Definitely the biggest challenge was consumers and how to get them to understand the system and what’s important to us.”

Patient, Female

Summary and Implications

- ▶ Empower for partnership
 - Involve across all stages
 - Multipronged approaches, tailored to preferences
 - Training, resources, financial reimbursement, support
- ▶ Connection and community
 - Online portal/hub
 - Face to face opportunities
 - Registries and ethics of data privacy?
- ▶ Impact
 - Validating contribution and demonstrating change
 - Evaluate “involvement”





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