

PAETARA O TE ORA: Regional Transplant Hui

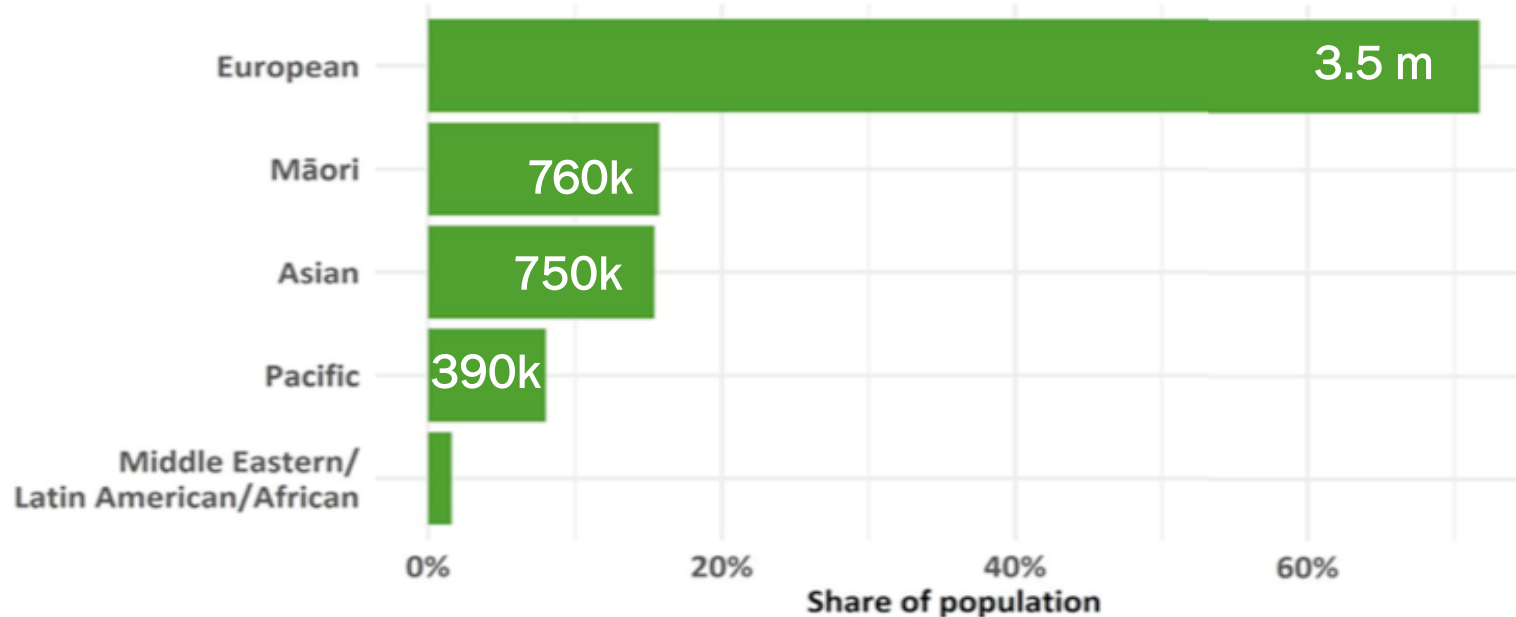
KIDNEY TRANSPLANTATION AND INEQUITY

TTOH 16 Oct, 2019

Māori and Indigenous Research, EIT

Renal disparities in NZ: ESRF, dialysis and transplants

SHARE OF POPULATION BY ETHNIC GROUP, 2018



Note: Shares do not sum to 100% as people can identify with more than one ethnic group.

SOURCE: STATS NZ, POPULATION PROJECTIONS.

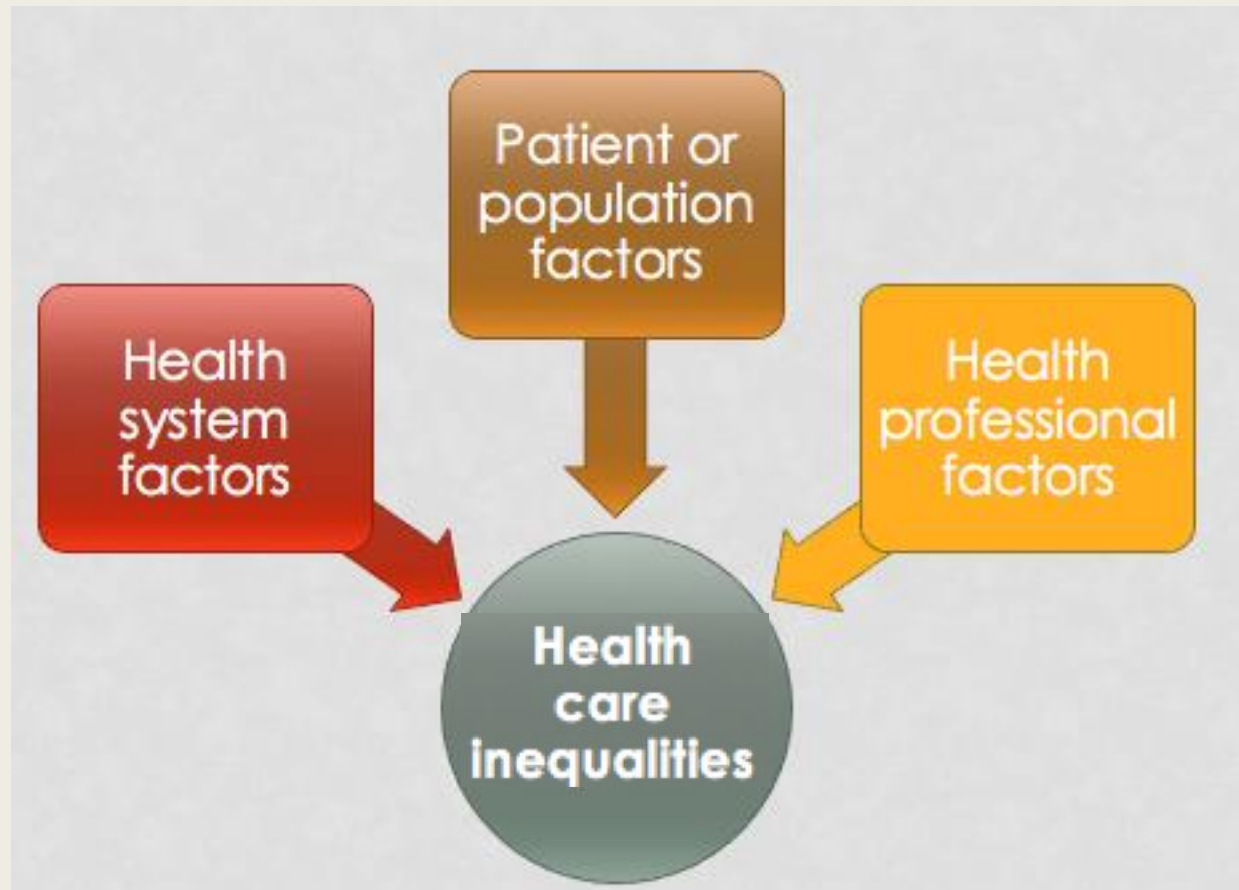
15% pop

2/3 ESRF

1/3 all dialysis
Beds

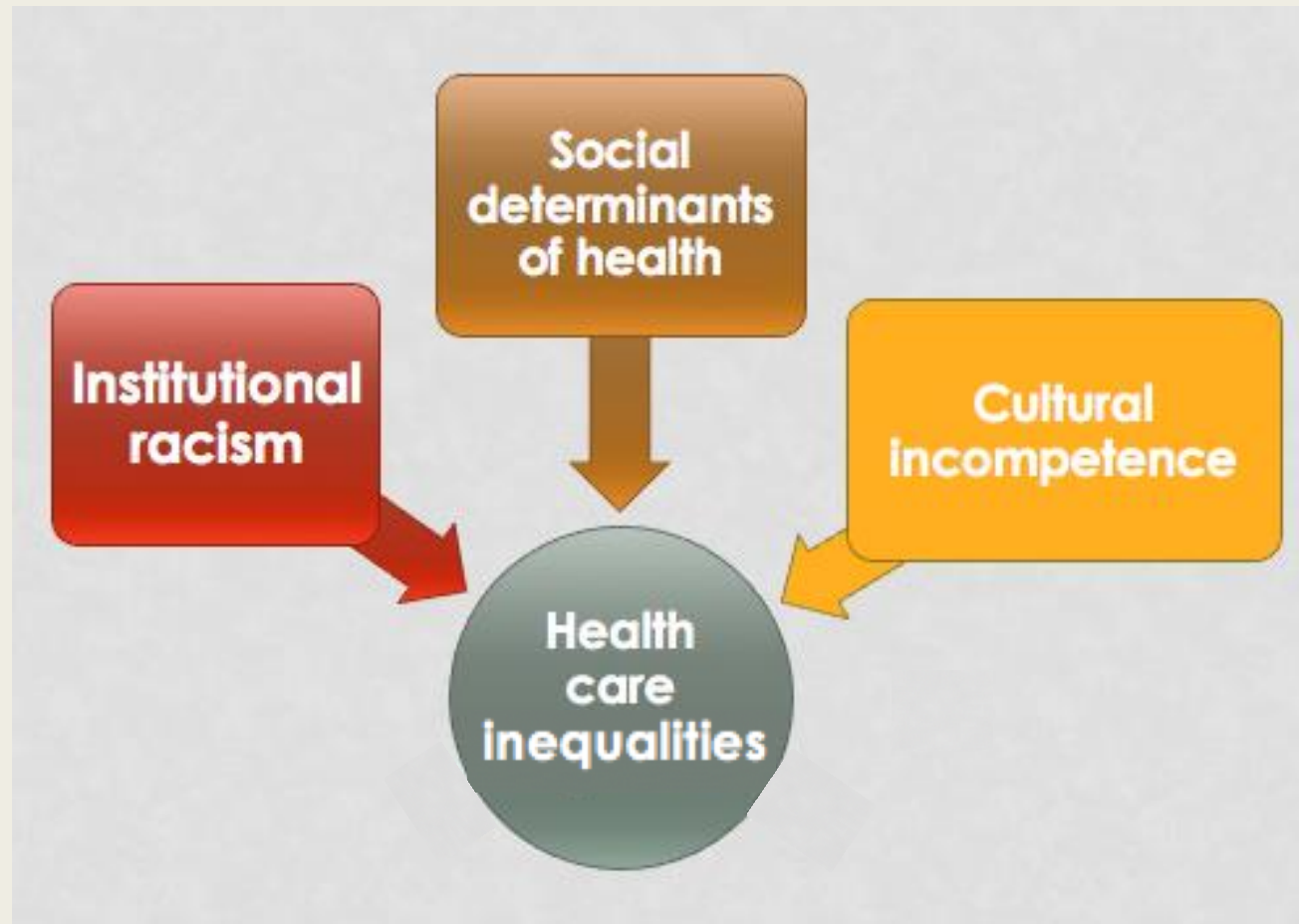
10% of all
'transplants as
first Rx'

What are the causes of ethnic health disparities/inequalities?

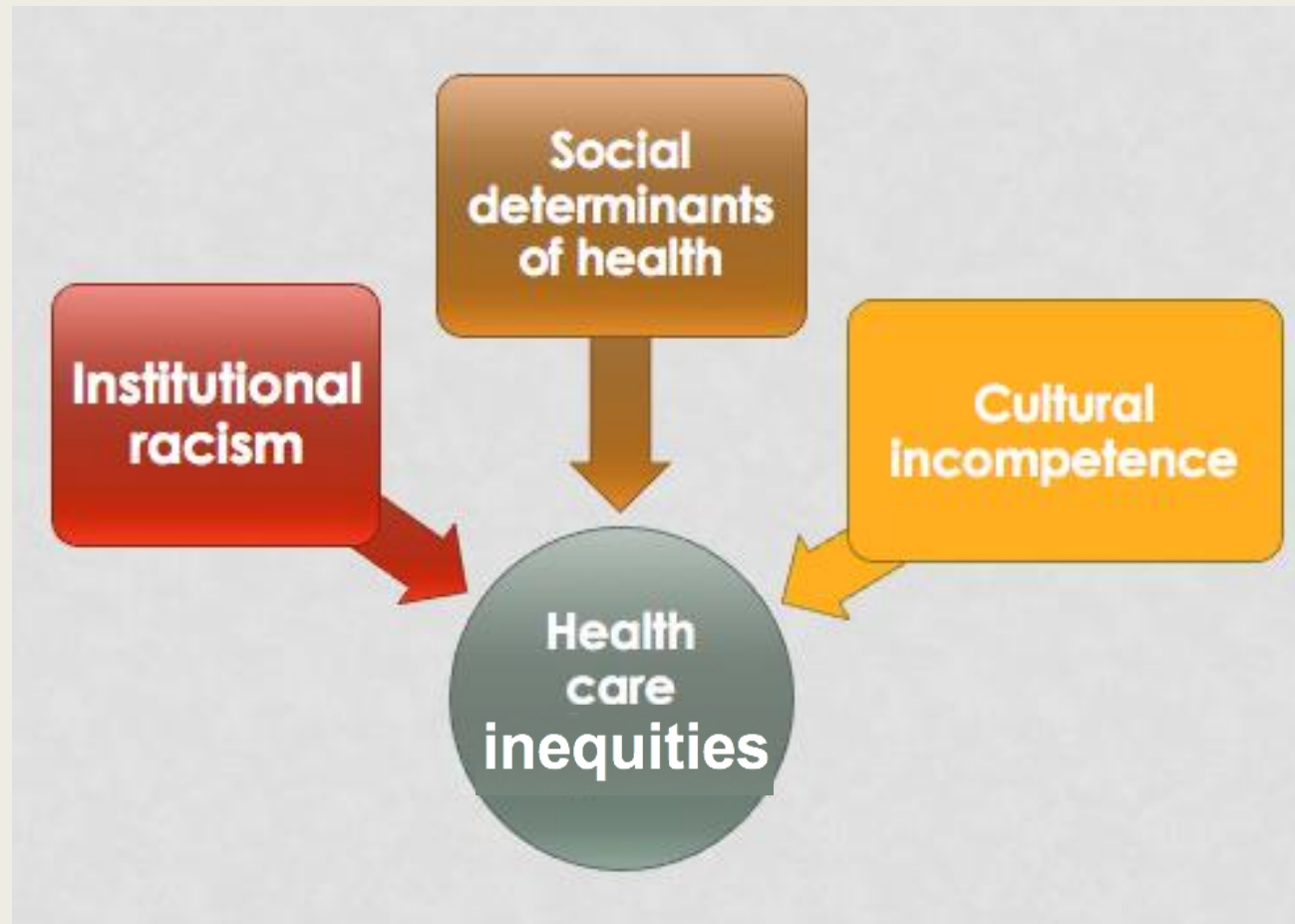


Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. Editors Smedley BD, Stith AY, Nelson AR, editors. Washington (DC): National Academies Press (US); 2003

What are the causes of Māori health disparities/inequalities?



What are the causes of Māori health inequities?

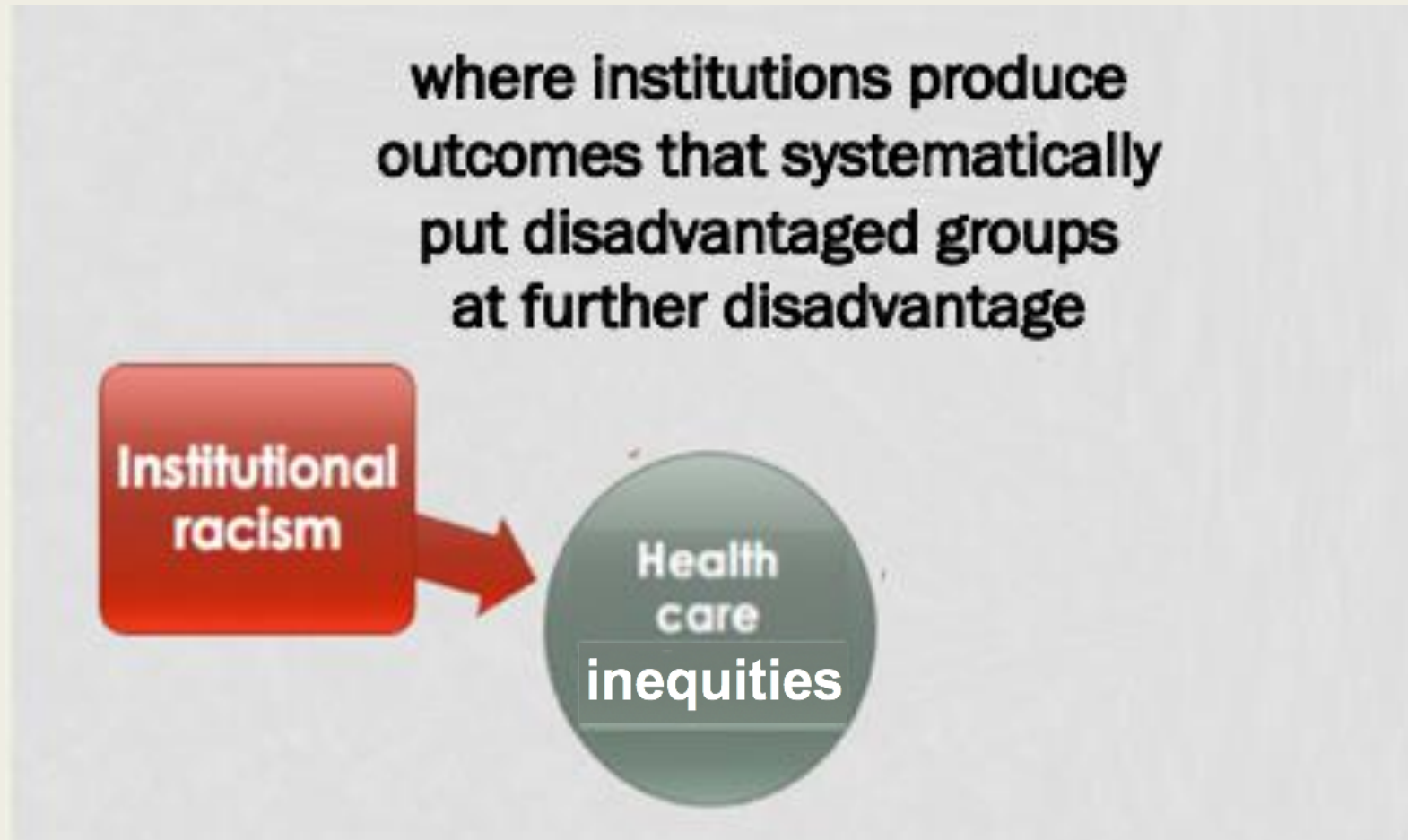


Inequities are
avoidable
unjust
and
preventable

Historical trauma: another cause of Māori health inequities



What are the causes of Māori health inequities?



What are the causes of Māori health inequities?

'New Zealand is racist as f***' - Taika Waititi

09/04/2018

Newshub reporter

 Reddit

 Tweet

 Share



Photo credit: Getty

Newshub, 09.04.18

What are the causes of Māori health inequities?

Racism likely at play in low Indigenous kidney transplants, AMA says

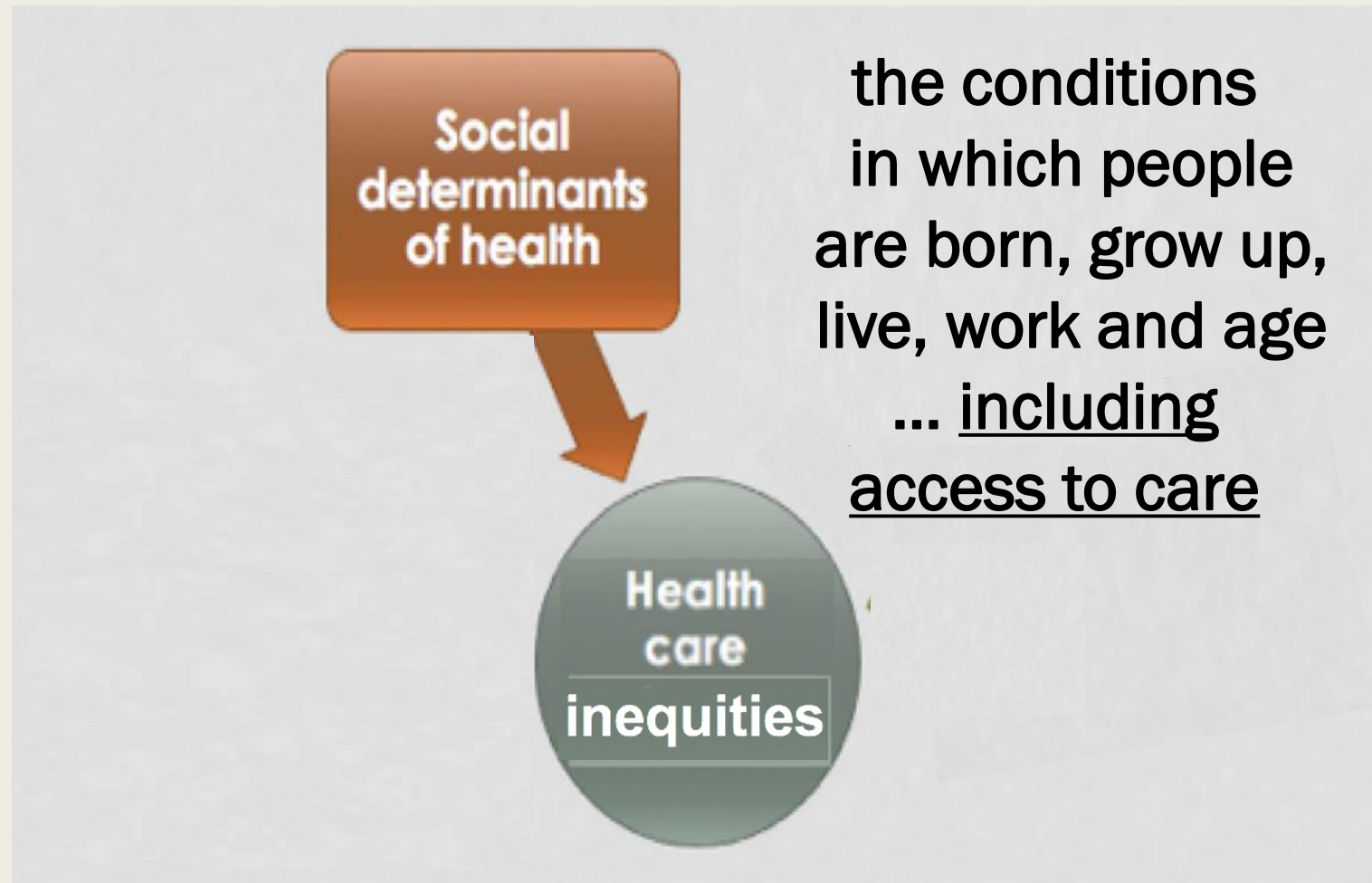
By Indigenous affairs reporters [Bridget Brennan](#) and [Isabella Higgins](#)

Updated 14 Dec 2017, 10:37am

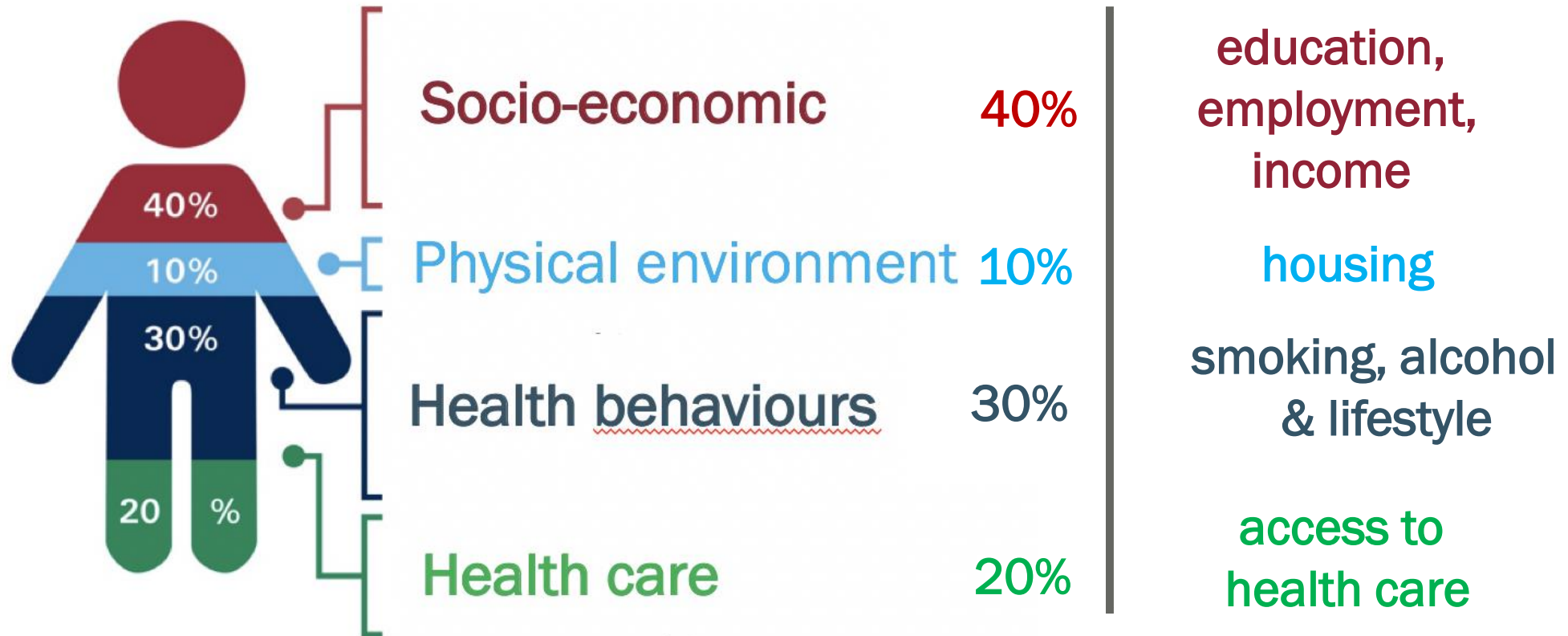


ABC News 14 Dec, 2017

What are the causes of Māori health inequities?



Social Determinants of Health



What are the causes of Māori health inequities?

... the attitudes, skills and knowledge needed to function effectively and respectfully when working with and treating people of different cultural backgrounds.

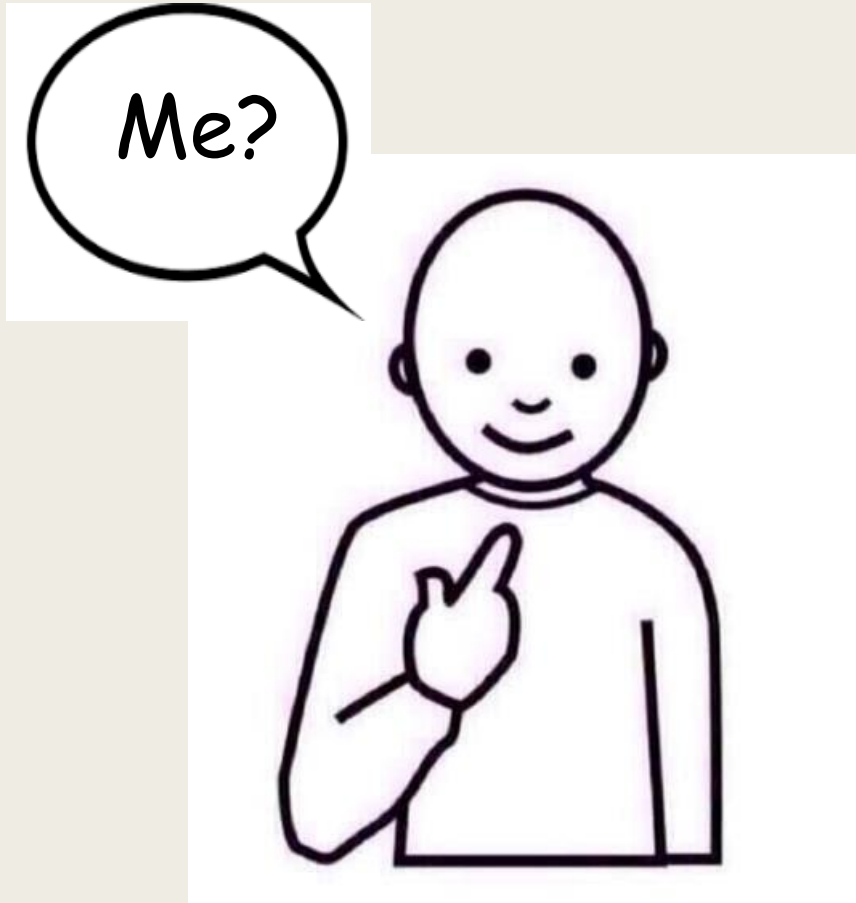
Cultural
incompetence



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graph TD; A[Cultural incompetence] --> B((Health care inequities))
```

Health
care
inequities

Whose fault?



“But I treat all my patients the same...”

Smokes

**Won't take
my pills**

**Eats the
wrong foods**

**Can't keep
appointments**

**Bad
Genes**

**Doesn't
exercise**

**Comes
in too
late**

What are the causes of Māori health inequities?

Less appointment time

Fewer investigations

Fewer diagnoses

Less treatment

Fewer referrals to 2^o care

Fewer interventions

**Is it any different
in the renal service?**

Crengle et al. Nat MedCa (2005). Jansen et alHe Ritenga Whakaaro (2008.) Walker et alThe road we travel (2008). Jansen et alMāori experiences of health care (2006)

Thinking through the barriers to care

- Patients need to ‘be deserving’ of transplant
- Māori described as ‘naughty’ and ‘difficult’
- Perception of few ‘live donors’
- Recruitment is patient responsibility
- Exclusion criteria BMI and co-morbidity
- ‘Culture’ viewed widely differently and cultural co-ordinators most often NOT involved

What are the causes of Māori health inequities?

depression, self-destructive behavior, suicidal thoughts, anxiety, low self-esteem, anger and difficulty recognising and expressing emotions



What are the causes of Māori health inequities?

War(s) related

Land loss related

Language loss related

SE marginalization

Alienation from mainstream society

Intergenerational trauma

Systematic
baby uplift

Incarceration

Physical and
mental illness



What are the causes of Māori health inequities?



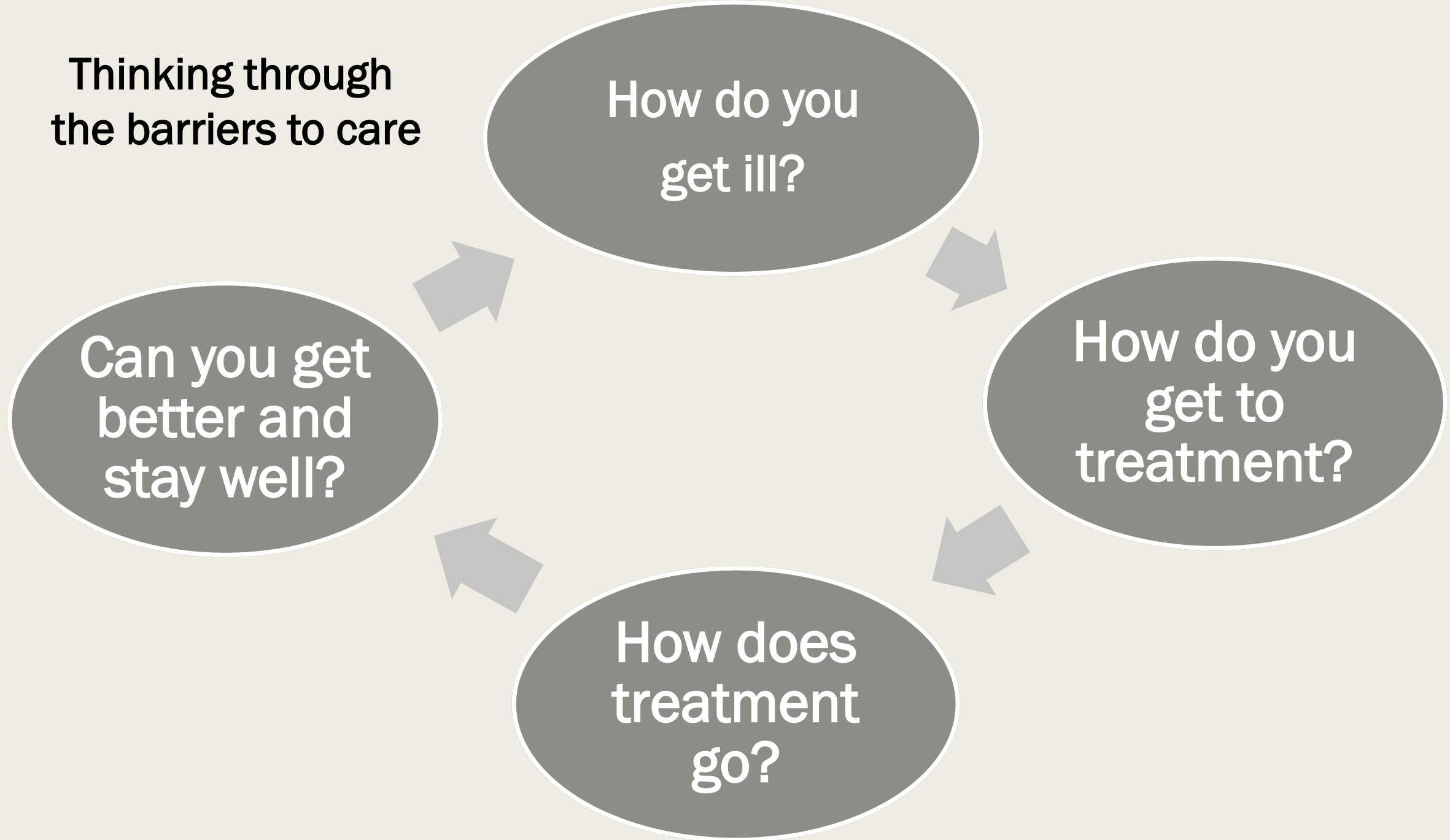
**Thinking through
the barriers to care**

**How do you
get ill?**

**How do you
get to
treatment?**

**How does
treatment
go?**

**Can you get
better and
stay well?**



'Pre-disposed' to ill health

Historical
trauma

Social
determinants
of health

How do you
get ill?

Institutional
racism

Access to care is inequitable

Historical
trauma

Social
determinants
of health

Cultural
incompetence

Institutional
racism

How do you
get treatment?

Quality of care is inequitable

**Social
determinants
of health**

**Cultural
incompetence**

**Institutional
racism**

**How does
treatment go?**

Historical
trauma

Social
determinants
of health

Institutional
racism

Can you get
better and stay
well?

Excluded from care by
co-morbidity and
medical criteria

What are the causes of Māori health inequities?

2/3 of all kidney failure and only 10% of all
'transplants as first Rx'

“free, frank and fearless discussions in which there is **zero** tolerance for white fragility and racism, and in which there is an understanding that **Māori & Pacific leaders’ knowledge and expertise** will be **privileged** rather than undermined.”

Rhys Jones

Chin et al. Lessons for achieving health equity comparing Aotearoa/New Zealand and the United States. *Health Policy*. 2018; 122: 837-853. doi:10.1016/j.healthpol.2018.05.001.



Experiences, perspectives and values of Indigenous peoples regarding kidney transplantation

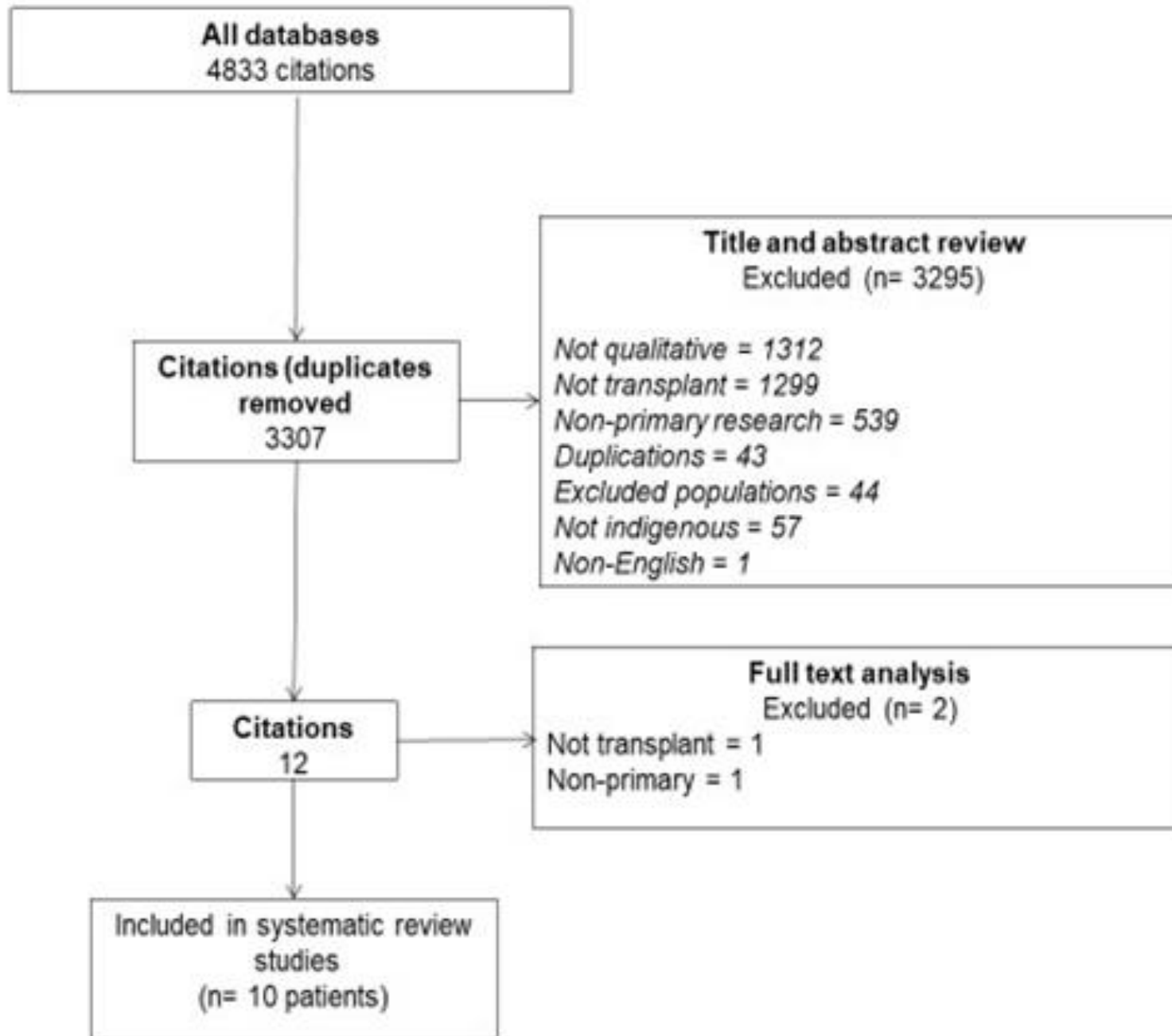
Systematic review and thematic synthesis of qualitative studies

R Walker, S Abel, A Reynolds, S Palmer, C Walker, & D Tipene-Leach



Methods

- Systematic review of qualitative studies involving Indigenous adults who have experience with or perceptions of kidney transplantation.
- We utilised thematic synthesis to analyse data.





Findings

- Eight studies involving 225 Indigenous participants were included
- 2 studies from Australia
- 4 studies from Canada and US
- 2 studies from Aotearoa (13 Māori)

Strong desire for transplantation

- Seeking normality and freedom from dialysis
- Wanting to reduce burden of disease within community

Lack of partnership in shared decision-making

- Inadequate education
- Ineffective communications

Cultural considerations

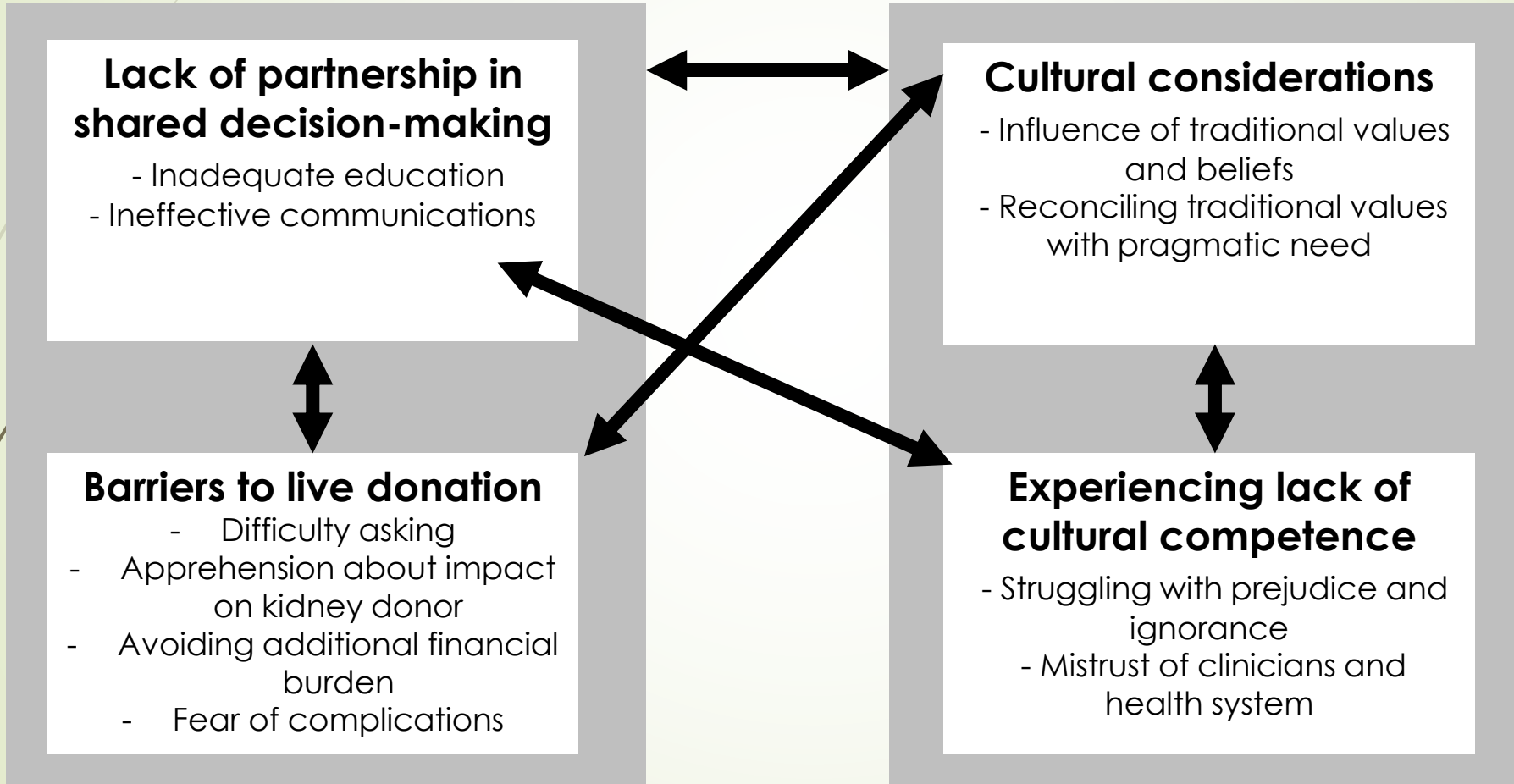
- Influence of traditional values and beliefs
- Reconciling traditional values with pragmatic need

Barriers to live donation

- Difficulty asking
- Apprehension about impact on kidney donor
- Avoiding additional financial burden
- Fear of complications

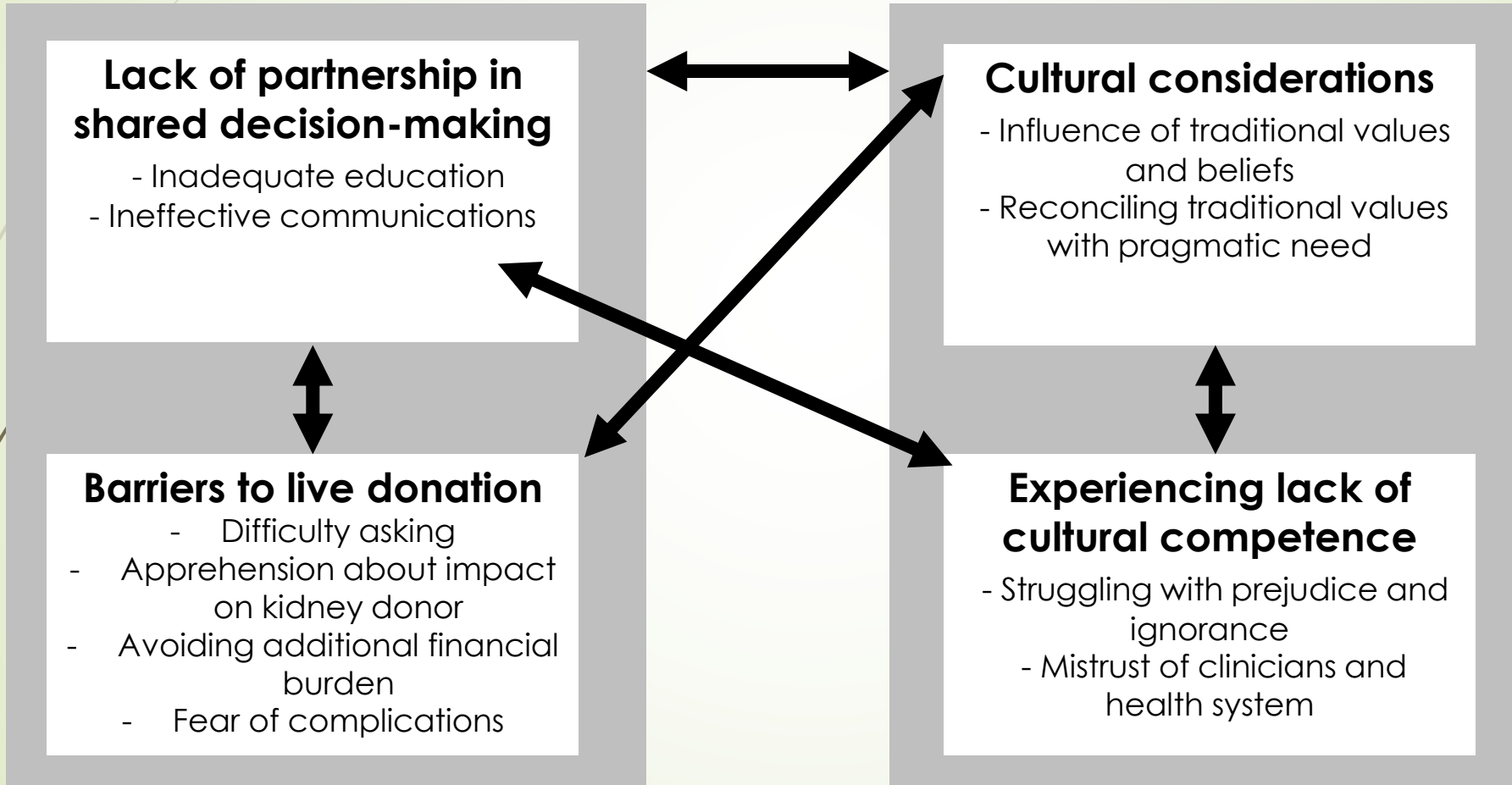
Experiencing lack of cultural competence

- Struggling with prejudice and ignorance
- Mistrust of clinicians and health system



Strong desire for transplantation

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1. Strong desire for transplantation

Seeking normality and freedom from dialysis

- Profound benefits for themselves, family and community.
- The only opportunity to be released from the restrictions of dialysis and to reclaim independence, freedom and improvements in their quality of life.
- Enabled a return to 'normality' and a resumption of family and cultural responsibilities.
- Allowed a return home.

"I'd like any kidney, as long as it would keep me alive, I could get back to [home] then ... My family depends on me."

"I'm really missing my friends and my family...I really want to be able to go home"

1. Strong desire for transplantation

Wanting to reduce burden of disease within community

- The principal motivation for donors was the desire to give.
- Some saw saving a life as ensuring cultural continuity.
- Awareness of the increasingly high need for kidney transplants within communities. Those who had first-hand knowledge of a loved one's need for a kidney were particularly keen on donation.

“saving somebody's life... they'd have their life back”

“Attitudes need to change, because your own people are needing these body parts”

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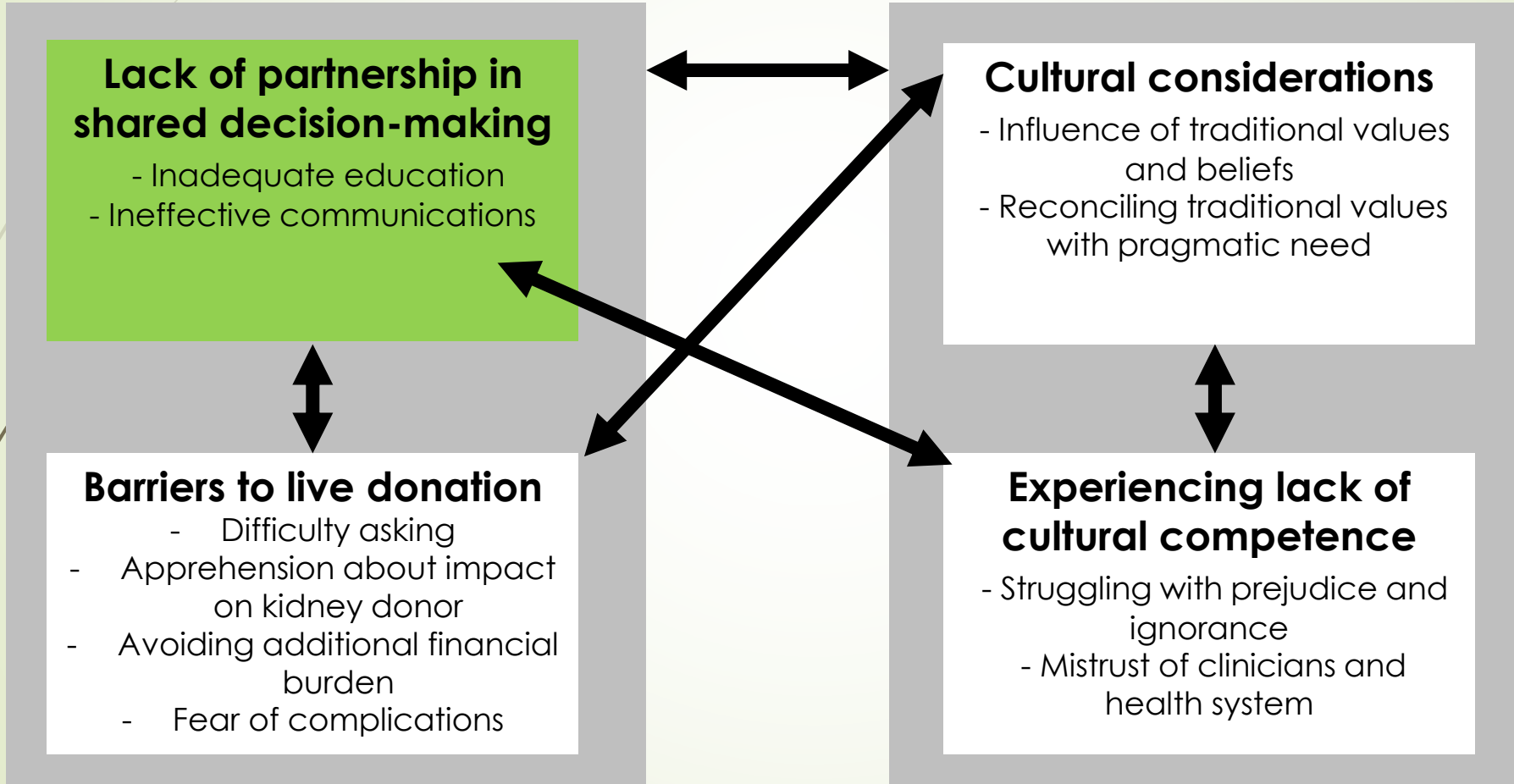
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2. Lack of partnership in shared decision-making

Receiving inadequate information

- Lack of sufficient information about transplantation and its processes at both community and individual levels
- Reported very little, if any, awareness of or information about kidney transplantation provided to communities who therefore had insufficient knowledge about the possibility and processes to donate.
- Indigenous participants reported not receiving timely information about their eligibility for kidney transplantation as a treatment option
- One participant reported not being informed about transplant as an option until *“about two years after [starting] my dialysis treatment”*.

“There is fear just because there’s not enough education on it”



2. Lack of partnership in shared decision-making

Ineffective communication

- Ineffective communication by health professionals - medical jargon
- Feeling too intimidated to ask for clarification.
- Language reported language as a barrier and inadequate strategies used in clinical care to ensure that core issues were communicated effectively.

“They [staff] don’t give it [information] the right way...When they come across like that everyone’s too scared to ask them questions, so then they just shut up”

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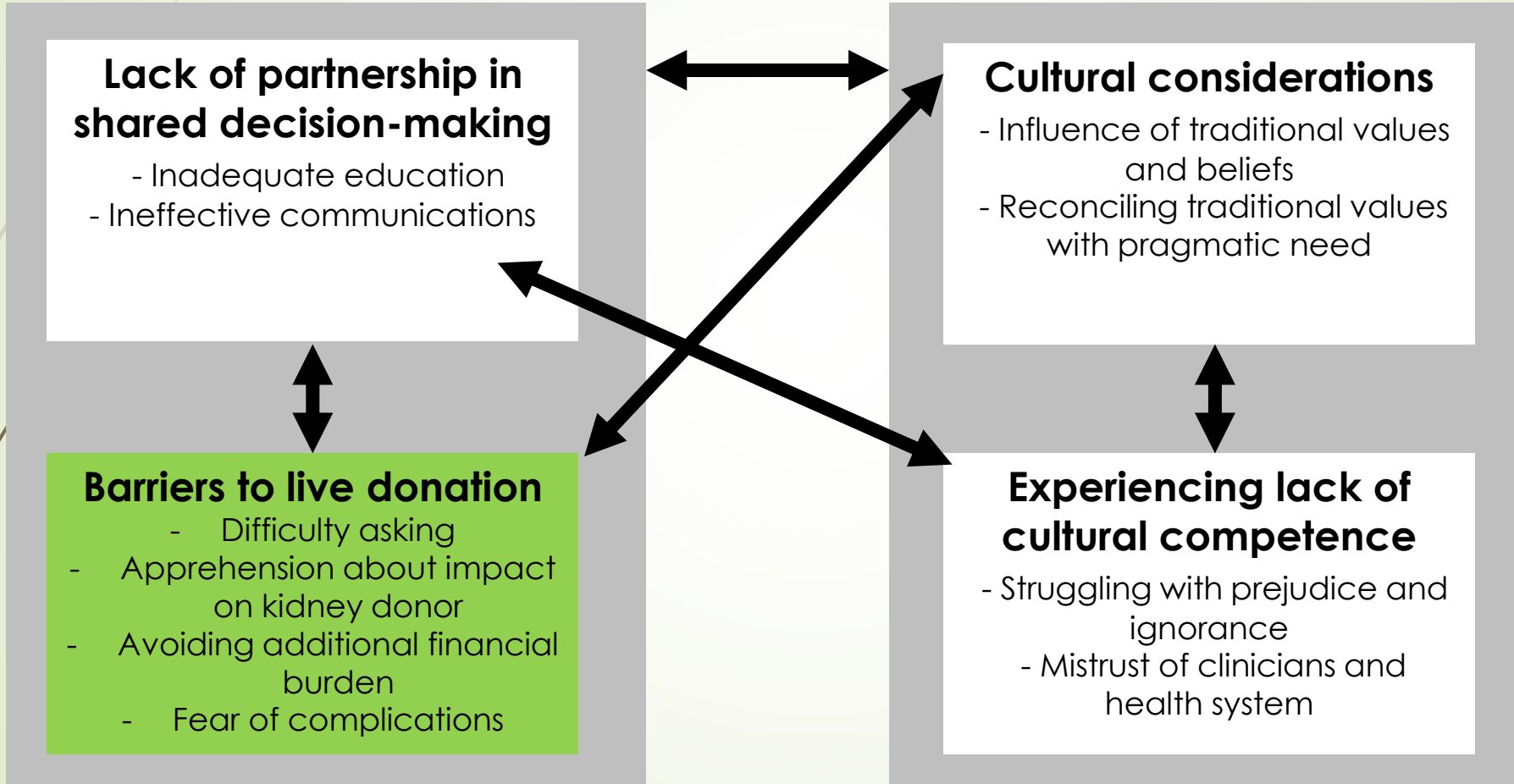
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3. Barriers to live donation

Difficulty asking

- Difficulty in asking family or others to be assessed as a directed kidney donor. Hoped that someone would offer without being asked.
- Challenges of a high level of shared medical comorbidity within families and communities
- Reciprocity as an important cultural value and another source of reluctance was not wanting to feel indebted to the donor

“No-one’s offered...like I’m from a family of nine, and none of them have offered me a kidney. So if they’re not gunna offer, I’m sure as heck not gunna ask”

3. Barriers to live donation

Apprehension about impact on donor

- Concerns about the impact on the health of the donor.
- Some also worried that younger (more worthy) family members may later require their potential donor's kidney.

"If my Pa donates, and then he dies on the day, well then it's all on me"

"I mean, who knows...In years down the [track], their kidneys might fail and [but for] that one kidney that you might take off them, they could be alive"

3. Barriers to live donation

Avoiding additional financial burden

- Acknowledged the burden of direct costs associated with transplant.
- Particularly onerous if they were already struggling financially and/or from rural close-knit Indigenous communities who needed to be in town for long periods.

“I was still employed on the island, but I had to miss a lot of work. Moreover, the expenses involved in transportation, accommodations, and meals were extremely distressing”

“It was very tempting at times to feel desperate as if all odds were against going through the transplant, given the costs and geographical travelling challenges”

3. Barriers to live donation

Fear of complications

- Concerns about the safety of the transplantation surgery, which were exacerbated by reports of poor transplantation outcomes by community members.
- Specific fears such as “psychic fragmentation” because of “serious cultural transgression” were voiced by some participants.
- Those returning to remote areas feared insufficient medical care after transplantation could lead to poorer clinical outcomes.

“What if things went wrong, what if one of us dies during the surgery, what if the kidney fails...? My mind was in a spin”

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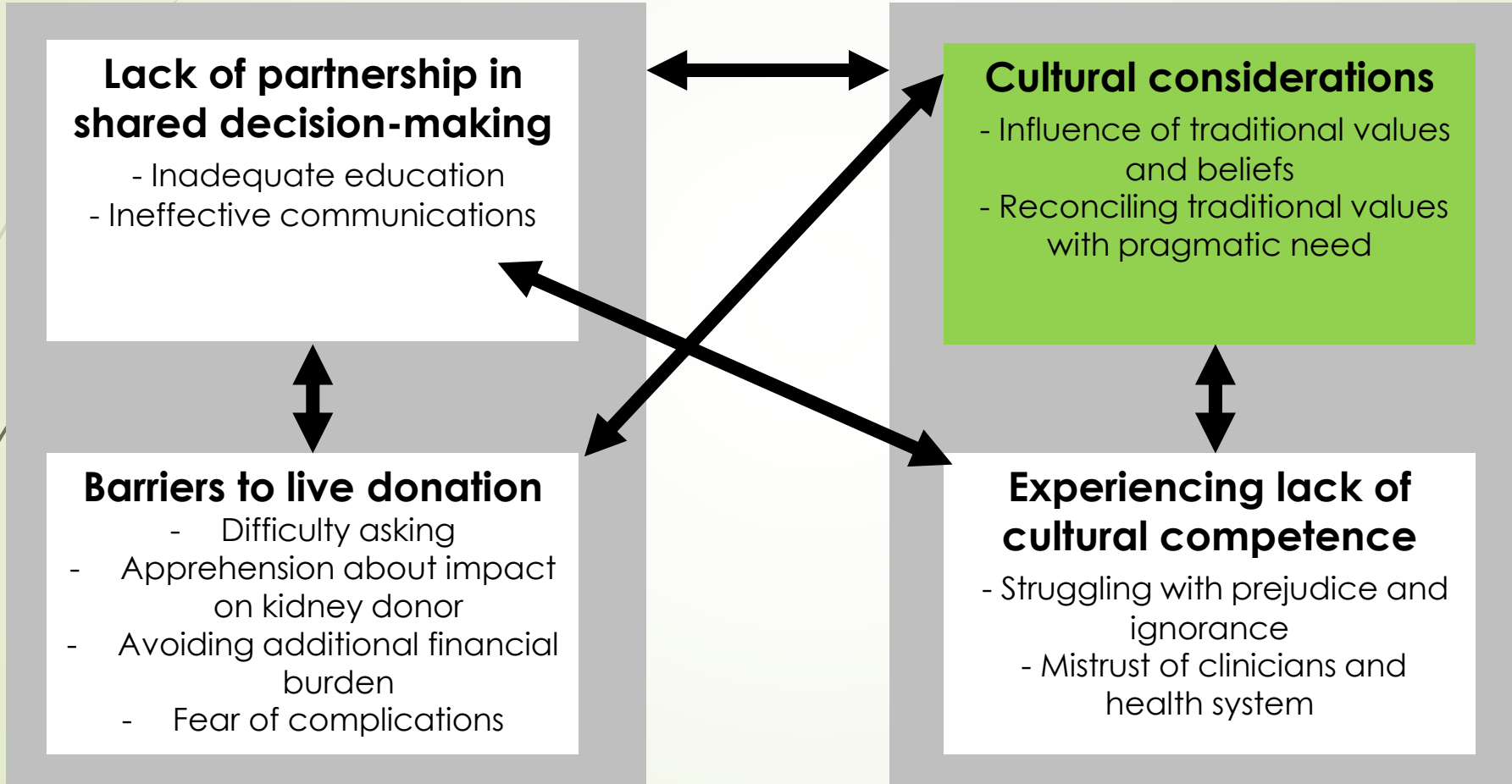
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4. Cultural considerations

Influence of traditional values and beliefs

- Importance of having an '*intact body*' at death
- A few groups were also wary of transplantation, believing that traits of the donor could influence the recipient in some way.
- Other cultural values directly supported the act of giving or receiving a kidney as a form of spiritual interconnectedness.

"I was made with the parts I have and that's the way I want to go and I wouldn't donate my parts either because they're mine not anybody else's. You come into this world with your own parts and you leave with your own parts"

"If there was any trouble, it would be a throw-back from that transplant... just as if a spirit had taken over an action"

4. Cultural considerations

Reconciling traditional values with pragmatic need

- Tension between traditional values and beliefs that precluded kidney transplantation versus the desire for transplantation to prevent death or very limited quality of life on long-term dialysis.
- Those who were concerned about the implications of cultural transgressions used specific strategies (such as prayer or ritual) to mitigate any potential negative effects.

“No, some may have [reservations], but there is that many people with renal disease that that should overcome any cultural things.”

“If I’m gonna get well, I gotta get (a kidney)... I’ll do a karakia (prayer), and make use of the new one”

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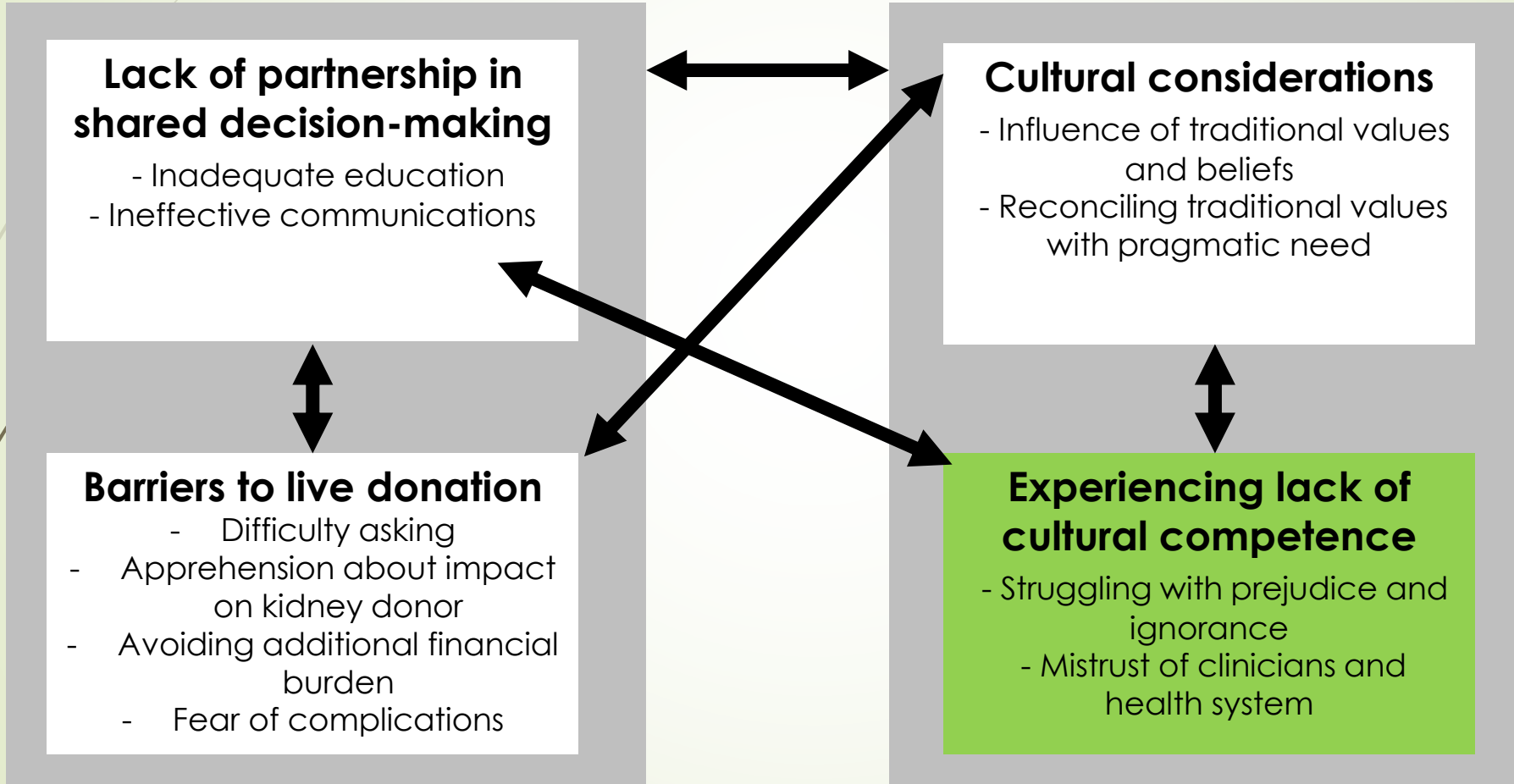
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5. Experiencing lack of cultural competency in clinical care

Struggling with prejudice and ignorance

- Discomfort and a some lack of culturally safety in the care they received - intimidated by the system, believing their cultural beliefs were not well understood or respected by health professionals and that clinicians' poor communication was based on negative or prejudiced judgments about the person.
- Lack of culturally appropriate resources and education about kidney transplantation.
- Participants reported a need for better cultural understanding by health service providers and improvements in kidney donation cultural protocols.

"I think it's a cultural thing too. They [renal staff] don't know whether it's culturally appropriate to even ask that sort of thing"

5. Experiencing lack of cultural competency in clinical care

Mistrust of clinicians and health system

- General lack of trust and fear based on previous experiences.
- Fear that cultural views would be misunderstood, ignored and overridden
- Feeling patronised and poorly informed by health professionals, a sense that information was being deliberately withheld and a perceived lack of transparency about the allocation of kidneys on the deceased donor list.

"It just seems like people's bodies are kept for longer periods of time [at the hospital] if they are organ donors and I don't think I want my body to be held up. I want it to be put to rest."

"There's a whole lot of us who just don't understand what's going on. They know though, the doctors and the nurses know, but they don't tell us. They don't talk with us and we're oblivious"

"They sit behind closed doors"



Recommendations

- Promote cultural safety and competence
- Targeted programs that acknowledge traditional values, include whanau, and promote access to live kidney donation
- Future programs need to promote working together with kaumatua and other knowledge holders to develop responses to the challenges and needs around transplants that both honour tradition and allow flexibility.
- Transplantation programs need to identify and mitigate barriers, such as the financial burden.
- We need to explore more about Māori experiences, beliefs and values around kidney transplantation.



Conclusions:

- Indigenous participants had a **strong desire for a kidney transplant** and recognised the need for more readily available kidney transplants for others in their communities with ESKD.
- However, they faced prejudice and a lack of cultural competence by health workers as well as wider barriers to transplantation in systems that did not support effective and culturally appropriate delivery of information and care.
- In order to address inequity in kidney transplantation we need to address institutional racism, the lack of cultural competence by health workers and unfavourable social determinants.



What next?

- Proposed study:

Interview study to explore Māori experiences, beliefs and values around kidney transplantation.

- Key stakeholders to explore how to break down identified system barriers.

- Recruiting for 2020:

- If interested: rwalker@eit.ac.nz