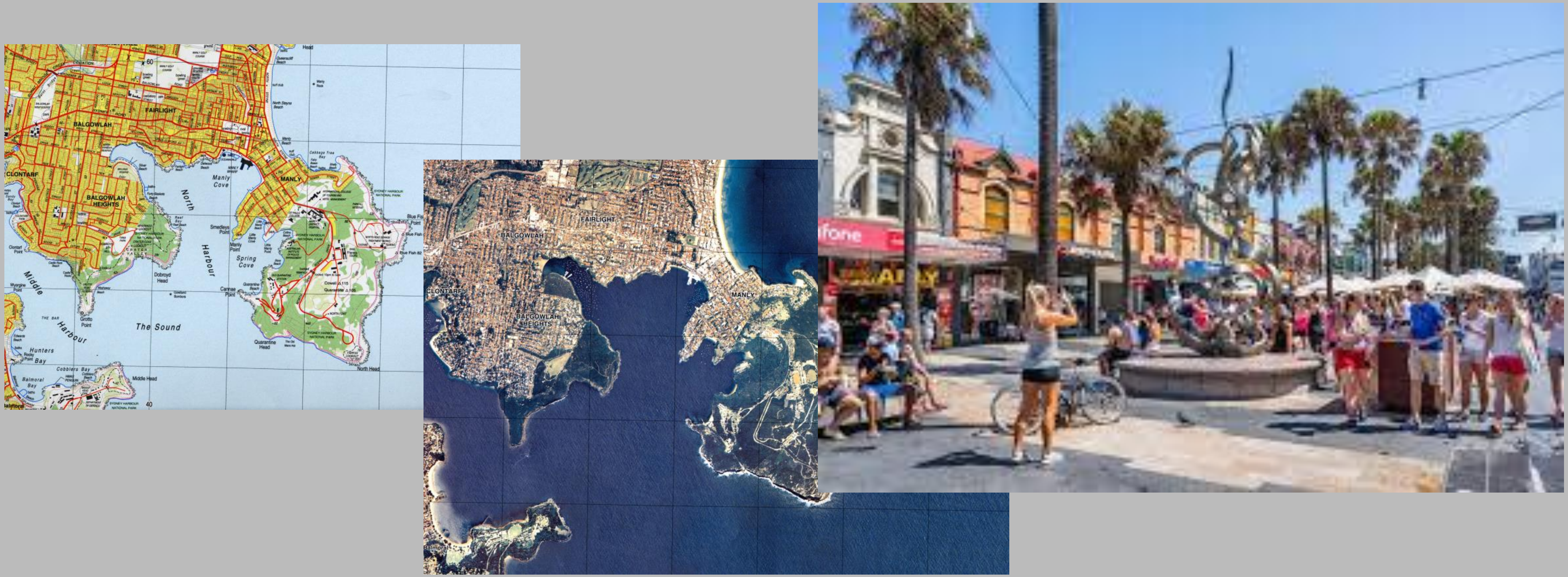
WHY QUALITATIVE RESEARCH?

Overview

1. Why qualitative research?
2. Research with vulnerable groups - not quite ‘damned if you do, damned if you don’t’ but certainly not easy
3. A long history of abuse
4. And invisibility
5. What you can do as researchers

Qualitative research adds



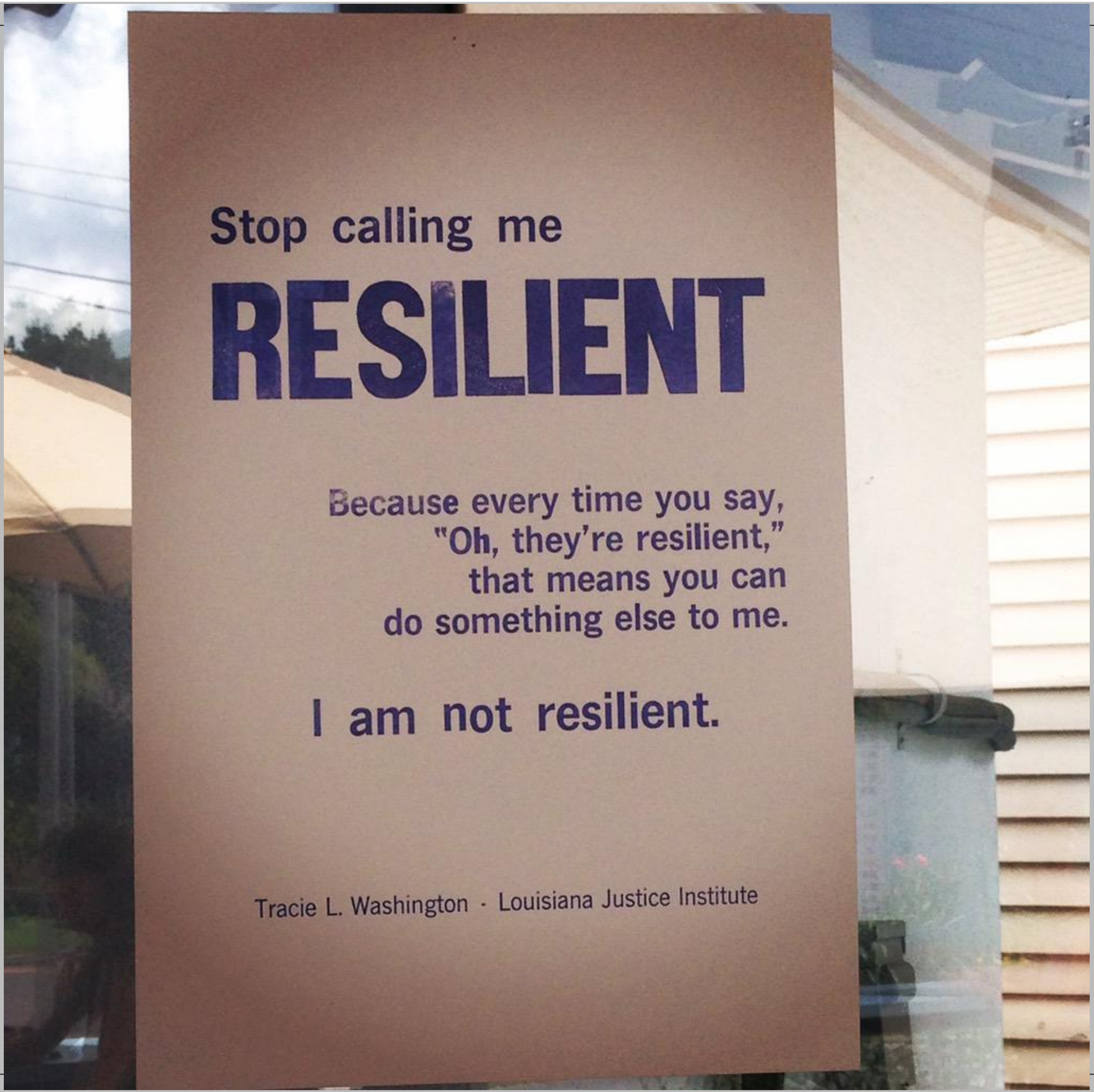
Qualitative research adds to our understanding of the context and complexity of issues and the worldview and experiences of those involved

What we need to consider (particularly, but not only in research with vulnerable groups)

how … problems are identified and dissected; … how concepts are included and excluded when circumscribing problems; … how … we uncover and re-discover forgotten problems and solutions …

Heikes DK. (2016) *Rationality, Representation, and Race*.
London: Springer. Pg 1

Good things cast shadows



Stop calling me

RESILIENT

Because every time you say,
"Oh, they're resilient,"
that means you can
do something else to me.

I am not resilient.

Tracie L. Washington · Louisiana Justice Institute

RESEARCH WITH VULNERABLE INDIVIDUALS AND GROUPS

What is vulnerability?

- A functional definition of vulnerability is an individual or groups' susceptibility to harm. Vulnerability can be identified as occurring as a result of one or more social, structural or situational causes

- Vulnerability has been called the elephant in the room of healthcare and unlike risk is under-researched (Hurst, 2008)

- Little et al (2000: 495) define vulnerability as "*…susceptibility to any kind of harm, whether physical, moral or spiritual, at the hands of an agent or agency*"

- Vulnerability "*needs to be recognised and negotiated in health care transactions.*"

- This definition introduces both three important additional concepts:
  - the role of an external agent or agents
  - the notion of harm (either purposive or unintentional) and
  - the widening of the types of harm and safety beyond that of purely physical

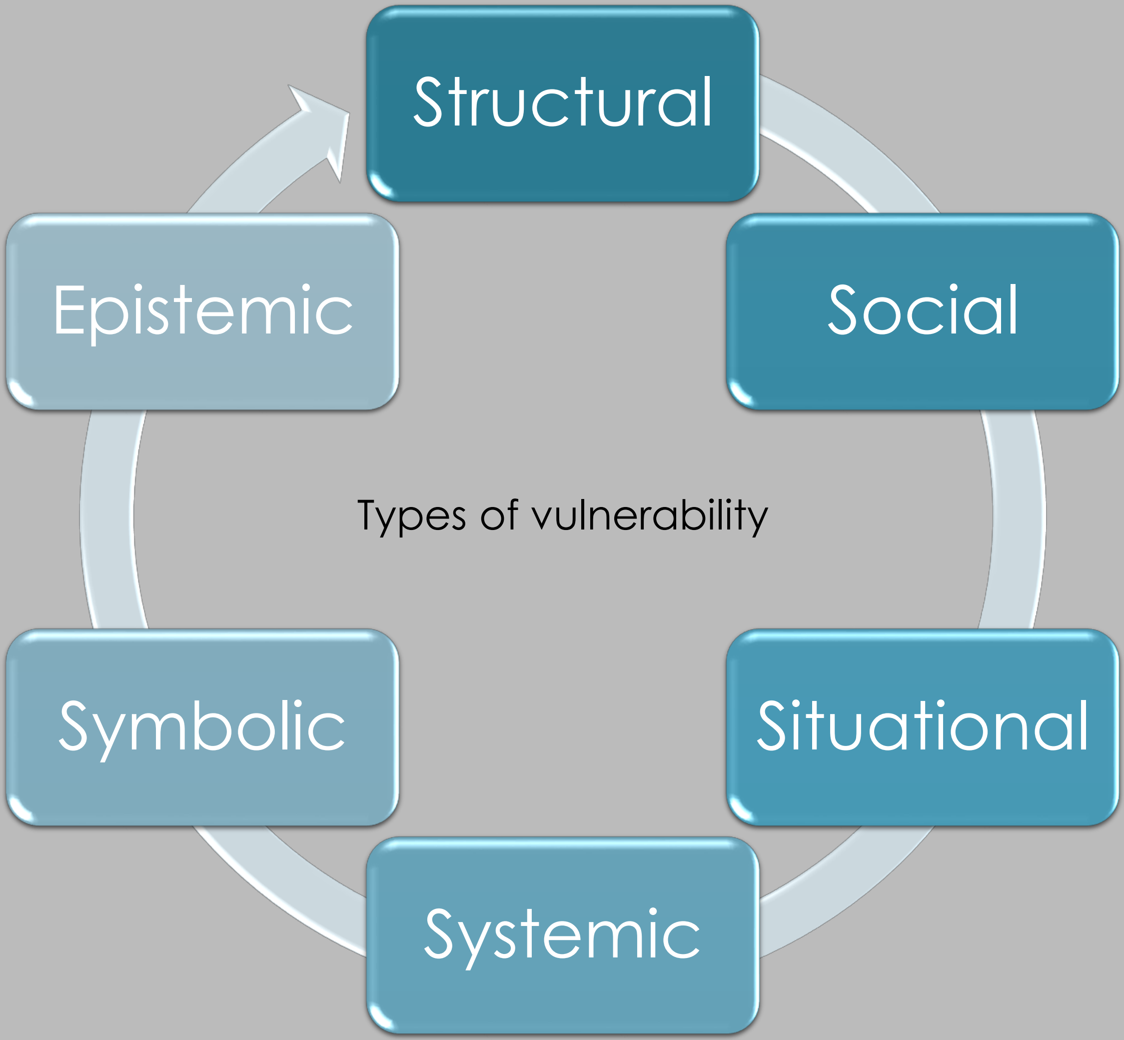
Vulnerability in qualitative research applies to potential conditions of research participants in which the participants, by virtue of some psychological, cognitive, physical, medical, legal, socioeconomic, or age-related status, are deemed to be more susceptible to lack of full understanding, manipulation, exploitation, or some other possible harm within the research process.

Methodological challenges relating to vulnerability (Dr Hamish Robertson)

- Variously defined and theorised eg. Blakey, Cutter etc
- No consistent set of metrics
- Are we analysing attributes or processes?
- Measurement at what scale? – time-space implications
- Who decides who is vulnerable?
- Are vulnerable groups visible?
- Are all members in a group (equally) vulnerable?
- Are the vulnerable included in the definition process?
- Who is responsible for addressing social vulnerabilities?
- Finite research and evidence base
- No proof all members of a group are equally vulnerable across disaster cycle

Who is vulnerable (at risk) within healthcare?

1. Clinicians
2. Individuals with complex conditions (co-morbidities and chronic illness, Patients with high acuity and complex system dependence (e.g. dialysis)
3. Patients with liminal status (the homeless, prisoners, people in palliative care)
4. People who are socially vulnerable including
    - Elderly people
    - Indigenous peoples
    - Immigrants – especially those with limited local language skills
    - People with disabilities, especially those with cognitive impairments
    - Babies, children and youth
    - Patients with literacy and communication problems
    - People from lower SES
    - Geographically isolated individuals
    - Socially isolated individuals
    - The homeless
    - The frail and malnourished
    - Prisoners
5. Patients without advocate



Types of vulnerability

Structural

Social

Situational

Systemic

Symbolic

Epistemic

So…

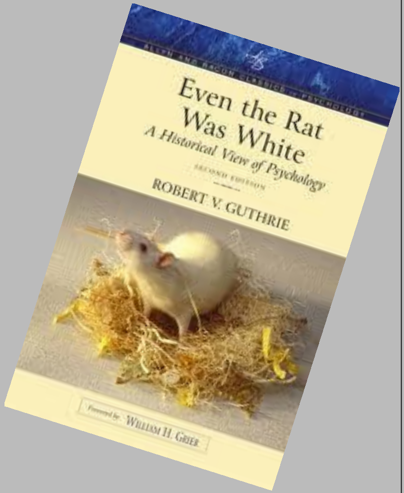
- All research with vulnerable individuals and groups needs to be conducted with the explicit understanding that for most of history (and until the present day)

  Vulnerable groups have either been systematically excluded or unethically ‘included’ in ‘research’

Why history matters in terms of research with vulnerable groups and individuals

- Lack of research into non ‘standardised’ patients (including women, people from immigrant backgrounds and minority backgrounds) in clinical trials (Jones, *Nature* 2009)

- WEIRD (Western, educated, industrialised, rich and democratic) studies predominate – skewed perspective on gold standard research
- A 2008 survey of the top psychology journals found that 96% of subjects were from Western industrialized countries — which house just 12% of the world's population (Henrich, Heine, Norenzayan, *Nature* 2010)



A long history of abuse under the guise of ‘research’ and public health

- Medical experimentation, sterilization of Indigenous peoples and people with disabilities without their consent; ‘acquisition’ of bodies and body parts for study/display without consent
- Nazi doctors (and nurses, and psychologists, and social workers and…)
- Tuskegee ‘experiment’
- The Carwright ‘experiment’ in NZ
- Lock hospitals in Australia

Ethical considerations: symbolic aspects of vulnerability

- Fricker (1980) - epistemic injustice
  - Both patients (denial of knowledge) and
  - Staff, in particular (but not only) allied health, nursing, and ancillary staff
- Bourdieu - symbolic violence (terminology)
- Monique Lanoix - the citizen in question (even ethics is problematic)

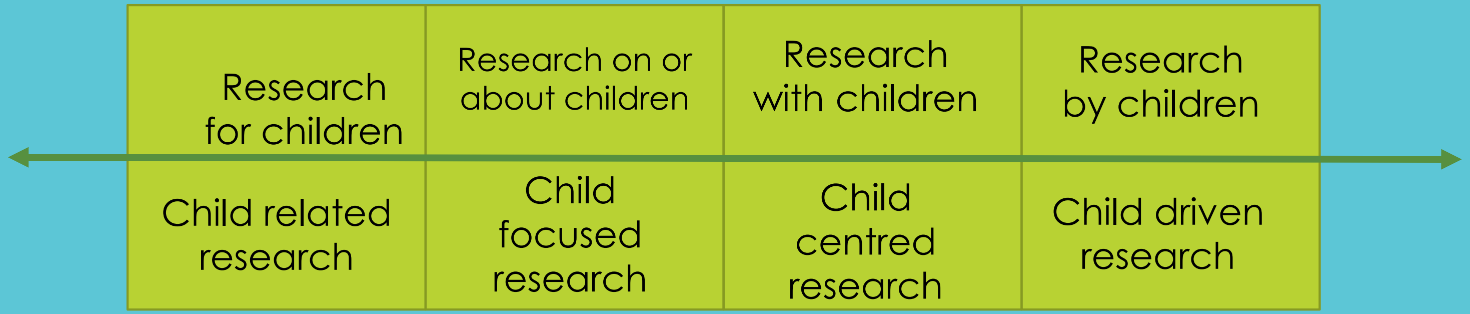
WHAT YOU CAN DO

What you can do

- Research with, rather than on/about, including co-design
  - Keep the principle of “nothing about us, without us”
- Remember - Ann Phoenix’s “normalised absence, pathologized presence”
- Remember intersectionality
- Avoid tokenism
- Remember your research (whether your include or exclude vulnerable groups) has consequences for those groups and society as a whole

Examine the continuum of research

Continuum of engagement of children (or any group) in research



Research for children	Research on or about children	Research with children	Research by children
Child related research	Child focused research	Child centred research	Child driven research

Rationale for co-design of research

The potential use, influence and impact of health research is seldom fully realised. This stubborn problem has caused burgeoning global interest in research aiming to address the implementation 'gap' and factors inhibiting the uptake of scientific evidence.

Scholars and practitioners have questioned the nature of evidence used and required for healthcare, highlighting the complex ways in which knowledge is formed, shared and modified in practice and policy. This has led to rapid expansion, expertise and innovation in the field of knowledge mobilisation and funding for experimentation into the effectiveness of different knowledge mobilisation models.

One approach gaining prominence involves stakeholders (e.g. researchers, practitioners, service users, policy-makers, managers and carers) in the co-production, and application, of knowledge for practice, policy and research (frequently termed integrated knowledge translation in Canada). Its popularity stems largely from its potential to address dilemmas inherent in the implementation of knowledge generated using more reductionist methods.

One example of benefits of co-design – involvement of children and youth with disabilities in research

Potential positive aspects of involvement on children and youth

- *Increased confidence*
- *Increased self-esteem*
- *Gaining new skills and experiences*
- *Greater responsibility and independence*
- *Opportunity to socialize with peers*
- *Enhanced knowledge of and access to decision making*
- *Being empowered*
- *Positive changes in expectations of being involved*
- *An opportunity to share frustrations and appreciations*
- *Knowing that their views and opinions are respected and valued*
- *Knowing that they can make a difference*
- *Knowing that their efforts may help other young people*

Potential positive aspects of involvement on research

- *Improved appropriateness and quality of research*
- *Prioritization of research questions that are relevant and important to DCYP*
- *More age appropriate and accessible recruitment and advertising materials*
- *Study protocols and interventions that are more acceptable to other DCYP*
- *Greater credibility and interest in studies*
- *Posive contribuon to data collecon, especially when DCYP interview others in their peer group*
- *A unique perspective during data analysis, particularly on data collected from other young people*
- *Successful contribution to interview transcript coding*

Bailey, S., Boddy, K., Briscoe, S., & Morris, C. (2015). Involving disabled children and young people as partners in research: a systematic review. *Child: care, health & development, 41*(4), 505-514., pg 511.

One example

- Morrison et al (2013) report on *a one year service improvement project to identify areas in a particular hospital setting that could be improved, and to explore possible solutions*
- *During this project, a design team used participatory design methods to enable older patients and staff representatives to work together to drive improvements. The approach used provided ways to give voice to the patients' perspectives about attending the outpatients' clinic, and facilitating them to take part in designing solutions.*
- *Members … visited older people in their homes and recorded their experience of their last visit to hospital and any other stories they wanted to share. These were transcribed and shared with the design team to provide a starting point for creating emotional maps, which are visual representations that highlight aspects of patient experience. In this case, the emotion maps showed the sequence of touch points through time horizontally, and illustrated the positive and negative emotions of the patient's experience of a visit to outpatients, or of a 'day in the life' of a health professional against a vertical axis*
- *Two groups, one of patients and carers (public participants) and one of health professionals, worked separately during a half-day session to create their own maps. The public participants' session began with people retelling their stories, which prompted further stories and discussion. Participants and facilitators then wrote incidents and emotional keywords drawn from the patients' stories, onto 'post-it' notes which were placed on the map below the touchpoint they were associated with. The post-it notes were positioned vertically with strong positive emotions at the top, and strong negative emotions towards the bottom. For example, one post-it note which said, "slept in chair and clothes waiting for morning ambulance," was placed under the touchpoint, getting to hospital, with an arrow to the word anxiety. The health professionals' session was similar, but focused on 'a day in the life.'*

Four elements that supported co-design

- They established and maintained an appropriate vocabulary that retains patient priorities rather than organisational ones in discussions.
- They gave permissive cues for patients to participate.
- Their physical properties, in this case persistence (of the emotional map) and size (of groups), actively encouraged equal participation.
- They scaffolded interactions with experts, to enable meaningful participation in complex health service design activities.

While an ethic of justice proceeds from the premise of equality - that everyone should be treated the same - an ethic of care rests on the premise of nonviolence - that no one should be hurt.

My proposal for the qualitative research mascot

The Kea