

Transforming Consumer Engagement: Health system resilience & the COVID-19 pandemic

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Video Message from Dr Anthony Brown



Study aims

- To document the accounts of **consumer engagement** among consumer representatives in the NSW health system during COVID-19
- Analyse these events through the concept of **health systems resilience**

Study strengths & limitations

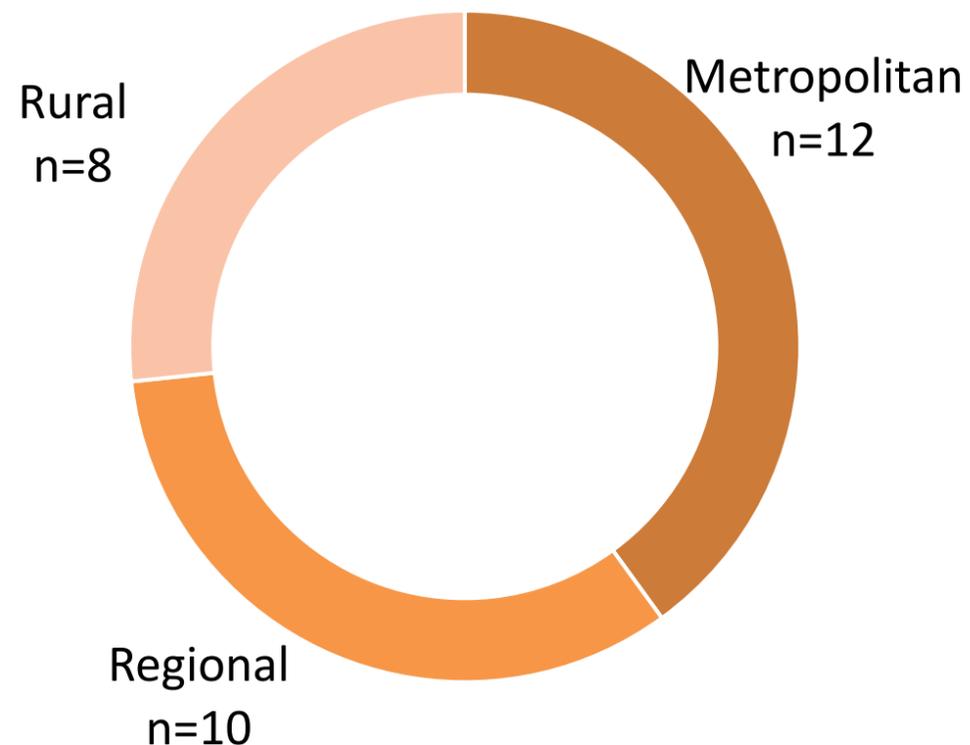
- Collaborative & co-researched study methodology, involving researchers and consumer representatives; Supported by Advisory Group
- Limited to the earlier period of the pandemic in 2020/2021; two cohorts interviewed in two time periods
- Study participants not intended to be a generalizable sample of all consumer reps in NSW

Research design

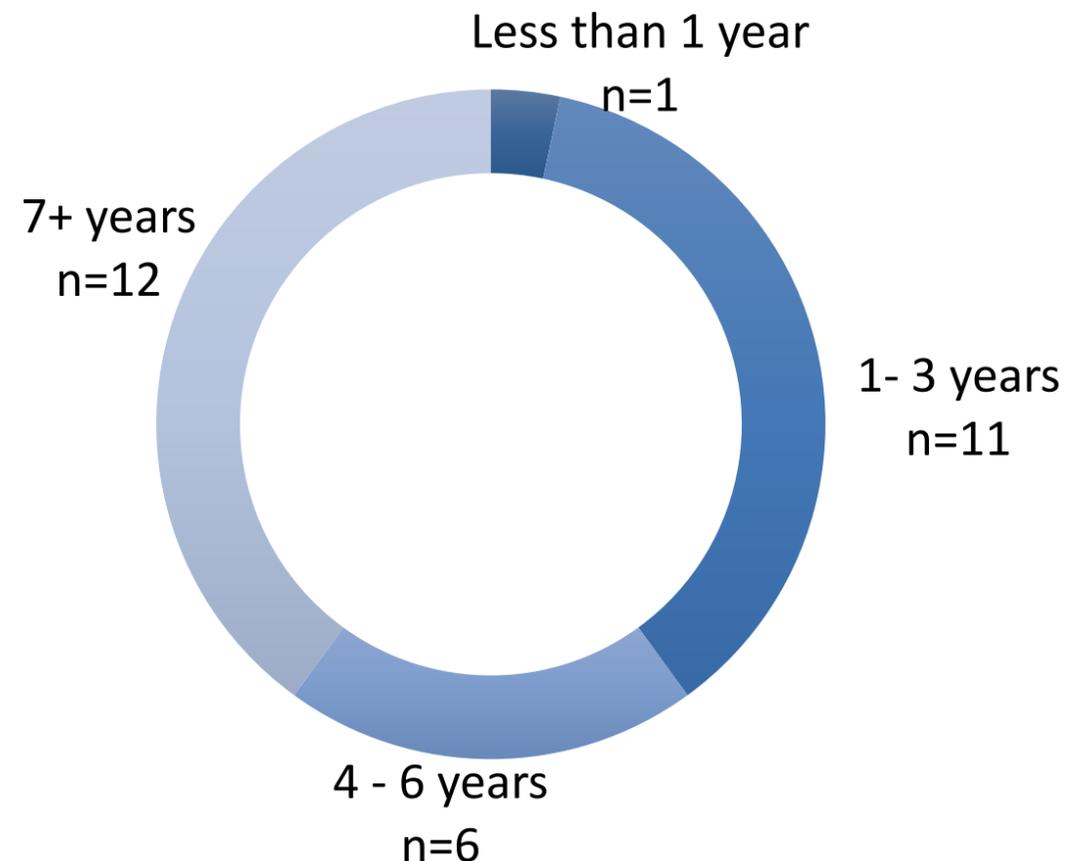
- Qualitative in-depth interviews with 30 health consumer representatives: 2 cohorts from diverse communities across NSW
- Cohort A: n=14, interviewed Oct.- Dec. 2020, experienced consumer representatives working together in HCNSW Leaders Taskforce ; Cohort B: n=16, interviewed Apr.- Jun. 2020, outside of Leaders Taskforce, purposively drawing participants from rural and regional area

Years active as Consumer Representative

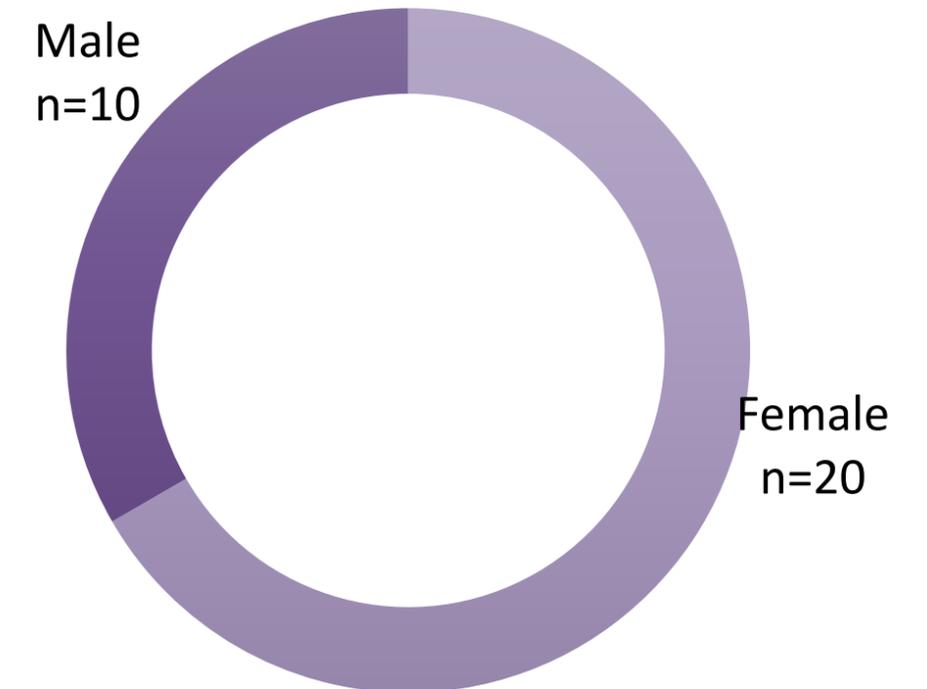
Residential Area



Representative



Gender



Study background

The Sydney Morning Herald

First published 1831 No. 56,833

INDEPENDENT. ALWAYS.

Friday, December 6, 2019 \$3.40 (inc GST)

Sydney chokes as state burns

Lucy Cormack

As Sydney held its breath yester-

Heartbreak for small coastal communities



NEWS UPDATE
LOCKDOWN
IN FORCE
EXPOSURE
SITES GROW

9
NEWS

CROSSROADS
HOTEL
BISTRO



Theme #1: 'Brittleness' & 'Resilience' of Consumer Engagement in the healthcare system

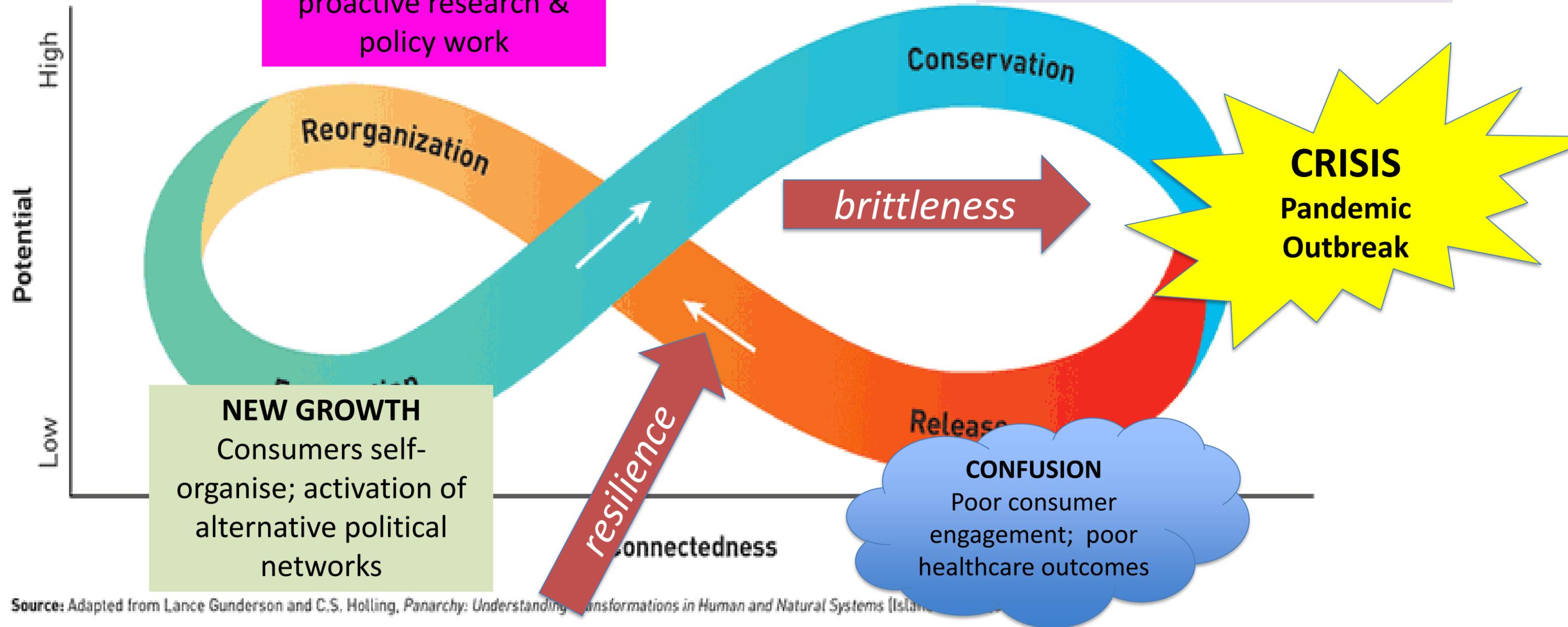
- Pause in consumer engagement during lockdown:
 - An 'understandable' 'command-and-control' systems approach to the pandemic coupled with health system under strain meant consumer engagement was de-prioritized by many managers and policy makers
 - But the expectation of re-activating engagement did not occur => *this suggests consumer engagement is actually 'brittle'*.
- Proactive self-organization and consumer-led responses:
 - In response, consumer networks and consumer-led research & community actions flourished => *(see theme 2) source of 'resilience'*

Health system & consumer engagement during COVID-19: Patriarchy & Resilience

The adaptive cycle

An infinity loop is a model of how systems evolve and create spaces for new growth in both

STABILITY; REDUCED FLEXIBILITY:
Top-down Consumer engagement becoming routinised but lacked innovation



Theme #2: 'COVID silver lining': outcomes and impact of consumer-led engagement

- Response to lack of engagement & poor care outcomes and patient experience during the pandemic
- Initiating consumer-led research and publications, e.g.
 - Visitation Policy Paper
 - Telehealth Research
- Forming new networks, building confidence & motivation, taking ownership
 - Reimagining, resetting new ways of working (e.g. online, with people outside of previous networks)
 - Consumers were the ones maintaining consumer engagement => *i.e. they were the source of health system resilience*

[The research project gave] us information that we can **speak with more confidence** to when we're engaging within the system, in terms of the **weight of evidence**, because we can see that a group of people have actually **contributed to that conversation** or position statement or policy statement, and we're very clear about what that actually means for us as health consumers within the system (A02)

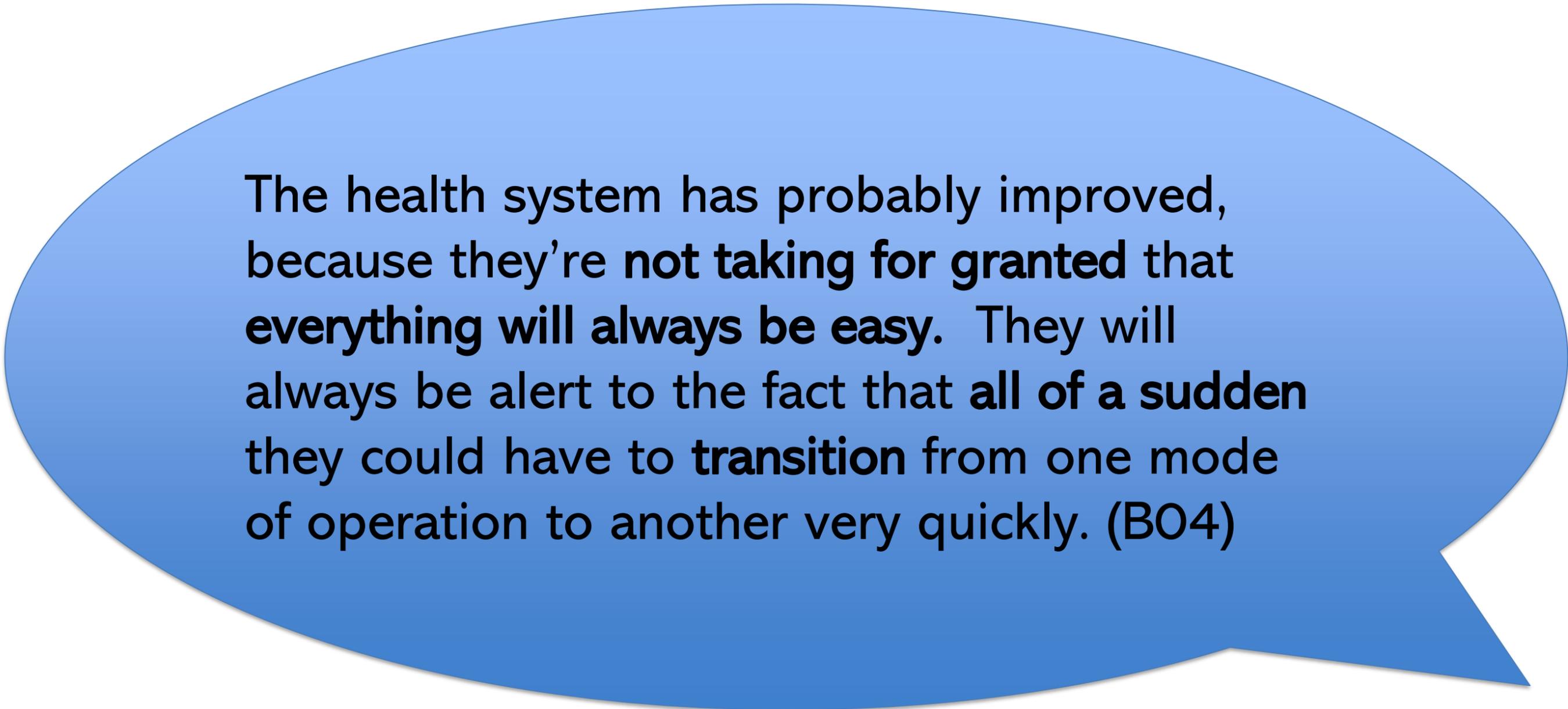
Theme#3: “It wasn’t all roses and sunshine” – disconnections and lack of capacity in certain communities

- Some communities and consumer representatives did not identify the need to self-organise or lead engagement with the health system
 - E.g. Partnership with health services already strong;
 - consumer networks with each other already established
- Some did not have the opportunity, capacity, or community connections or support to do so

For us consumer representatives in [a CALD community], what make it more difficult is **the inability for us to reach the greater number** of people in our community. Many people **do not actually know that this role exists** and what it does, they don't have this information. And even if so, the reluctance of some of them to meet us because of their concerns about COVID. **And because of COVID, the number of people using the health facilities has decreased.** So they don't have any ways of raising issues about the health services. (B07)

What we learnt

- Experience of the pandemic exposed the brittleness of pre-existing consumer engagement processes; Re-organization, proactivity and self-organization of consumer representatives sustained the engagement and proved innovative & adaptive
- While this was not always the case among our research participants/communities, there were other similar experiences and observations elsewhere & outside of NSW and internationally



The health system has probably improved, because they're **not taking for granted** that **everything will always be easy**. They will always be alert to the fact that **all of a sudden** they could have to **transition** from one mode of operation to another very quickly. (B04)

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Read the open access paper:

Shih, P., Hallam, L., Clay-Williams, R., Carter, S. M., & Brown, A. (2022). Reimagining consumer involvement: Resilient system indicators in the COVID-19 pandemic response in New South Wales, Australia. *Health Expectations*.

<https://onlinelibrary.wiley.com/doi/pdf/10.1111/hex.13556>

