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Does inclusive data lead or follow data users?

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The questions!

Can researchers put diverse/inclusive gender/sexuality categories into studies before policy makers/donors/implementing partners are ready for it? Or, does research follow an enabling/receptive policy/practice environment?

- What role does research play in creating an enabling/receptive policy/practice environment?
- Is research a form of community activism or mechanism for influencing social change? (And, can also be rigorous, reliable research?)
- How does research lead policy and practice (what is the process)?
- How has research about gender and sexuality and LGBTQIA+ communities created an enabling or receptive policy and practice and environment?

The Australian Research Centre in Sex, Health and Society (ARCSHS)

Writing themselves in

Repeated cross sectional survey of LGBTQIA+ young people (14-21 years)

Four iterations: 1998, 2005, 2010, 2021

- Health and wellbeing
- Experiences of discrimination, harassment and violence at home, school, streets
- Positive experiences of sexuality and relationships

Private Lives

Repeated cross-sectional survey of LGBTQIA+ people in Australia

Three iterations: 2006, 2012, 2021

- Health and wellbeing
- Mental health
- Engagement with health services

HIV Futures

Periodic survey of people living with HIV in Australia.

Ten iterations: 1997-2021

- Health
- Financial security
- Relationships and sex
- Quality of life

LGBTQA+ community surveys

Writing Themselves In (1998 – 2021)

- First Australian survey of same-sex attracted young people
- Funded through HIV prevention funds, but drew attention to poor mental health and high rates of bullying, harassment, and violence against same-sex attracted young people.
- Has been cited in multiple policy documents, directly led to funding for national programs to support LGBTQA+ young people in schools

Private Lives (2006-2021)

- Drew attention to mental health issues, led to greater investment in dedicated mental health services for LGBTQA+ people.

Most recent iterations of both studies (2021) funded by state/territory governments who now want these data to inform mental health policy and service provision.

Research setting the policy agenda

- Surveys were organised with community input and so reflected the language used by community (e.g. in the 1990s it was 'same-sex attracted', now inclusive of non-binary and gender diverse people)
- Surveys seen by community as an opportunity to draw attention to need, have voices heard which meant high response rate and advocacy agencies using the research.
- Surveys reflected policy priorities in areas of HIV prevention, equity in health service delivery, mental health, school-based bullying – demonstrating the need to pay attention to gender and sexuality in these areas.
- Set the agenda for population-based studies (demonstrated how to ask about gender and sexuality, demonstrated the need to do this, trained researchers in how to do it)

ASHR 2: Sexual identity, attraction and

Identity, attraction and experience	Men			Women		
	ASHR1 (n=9723)	ASHR2 (n=8499)	OR (95% CI)	ASHR1 (n=9576)	ASHR2 (n=8740)	OR (95% CI)
Sexual identity^A						
Heterosexual	97.5	96.8	1	97.8	96.2	1
Homosexual	1.6	2.0	1.28 (0.98–1.68)	0.8	1.3	1.60 (1.12–2.27)
Bisexual	0.9	1.2	1.36 (0.87–2.14)	1.4	2.5	1.75 (1.32–2.32)
Sexual attraction						
Exclusively to other sex	93.0	92.3	1	86.5	83.7	1
Predominantly to other sex	4.5	4.8	1.08 (0.90–1.28)	11.1	12.9	1.21 (1.08–1.35)
Equally often to both sexes	0.6	0.4	0.80 (0.47–1.34)	1.0	1.6	1.75 (1.26–2.45)
Predominantly to same sex	1.1	1.0	0.96 (0.67–1.36)	0.6	1.0	1.66 (1.09–2.52)
Exclusively to same sex	0.6	1.2	1.84 (1.25–2.71)	0.2	0.5	2.16 (1.12–4.13)
No one	0.2	0.2	1.12 (0.47–2.65)	0.6	0.4	0.6 (0.34–1.07)
Sexual experience						
Exclusively with other sex	90.7	90.7	1	88.4	82.3	1
Predominantly with other sex	4.0	4.3	1.07 (0.89–1.28)	7.5	12.7	1.81 (1.60–2.05)
Equally often with both sexes	0.4	0.2	0.67 (0.34–1.33)	0.5	0.9	1.96 (1.22–3.13)
Predominantly with same sex	1.0	1.1	1.15 (0.81–1.62)	0.4	0.8	2.08 (1.34–3.23)
Exclusively with same sex	0.6	1.0	1.75 (1.15–2.68)	0.1	0.3	2.51 (1.06–5.97)
No one	3.3	2.6	0.78 (0.61–1.00)	3.1	3.0	1.04 (0.80–1.35)

^AUndecided, other and refused omitted from analysis (0.2% of total).

Richters Juliet, Altman Dennis, Badcock Paul B., Smith Anthony M. A., de Visser Richard O., Grulich Andrew E., Rissel Chris, Simpson Judy M. (2014) Sexual identity, sexual attraction and sexual experience: the Second Australian Study of Health and Relationships. *Sexual Health* **11**, 451-460.

Measuring quality of life (QoL) among people living with HIV (PLHIV)

- The focus of HIV prevention work internationally is the 90:90:90 (95:95:95) goals: diagnosis, treatment uptake, viral suppression.
- Community advocates calling for a 'fourth 90': QoL among PLHIV.
- How do we measure this in a meaningful way? (Relevant and specific to PLHIV and meaningful in relation to a goal of 90%)
- Policy tends to be based on what change is achievable and demonstrable.
- HIV Futures tasked with collecting data to inform progress in the Australian National HIV Strategy in relation to wellbeing and impact of discrimination/stigma
- We developed a QoL measure specific to PLHIV (PozQoI) and demonstrated to policy makers that we could collect meaningful data – this was picked up by advocacy agencies which led to QoL being included in the National Strategy.
- Example of research making policy feasible

A queer approach to research

Queer theory emphasises that research doesn't just reflect the social world in a neutral way, but it influences how we understand the social world.

Research plays a role in creating reality – the ways people and issues are understood, the issues that 'matter'.

To this end, research is always leading policy and researchers have a political responsibility to understand the impact of their research.

That said, it is not always possible politically to introduce new ways of talking about sex and gender in research, and it can undermine the quality of research if participants don't understand or refuse to respond.

So it is likely researchers will need to engage in the politics of this – advocating a position, breaking new ground.

Either way, researchers and research plays a role in creating the enabling/receptive environment.

Thank you

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