napwha national association of people with HIV australia

Patient Based Evidence:

Using qualitative research for PBAC/MSAC

Patient Voice Initiative

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Exploring the proposition:

Qualitative research can add to, enhance, be centrally positioned in representing patient experiences

- More than half the **HIV Futures 9** (2019) participants (56.6%) reported at least one experience of HIV-related stigma or discrimination in the past 12 months
- 38.0% reported that they had been treated differently by a healthcare worker due to their HIV in the past 12 months.

https://www.latrobe.edu.au/arcshs/publications/hiv-futures-publications

Meaningful involvement of people living with HIV in research

Barriers to meaningful involvement:

- HIV-related stigma
- health-related challenges
- lack of capacity to engage in research
- other issues taking priority
- mistrust of researchers

Factors that facilitate meaningful involvement:

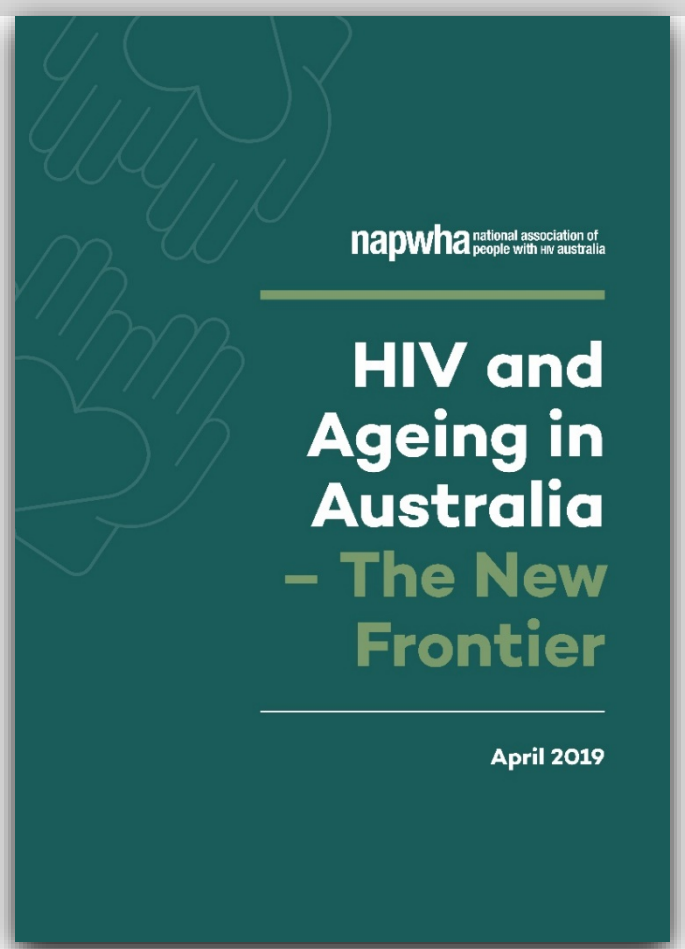
- research that values lived experience
- training and mentoring opportunities
- financial compensation
- trust-building
- accommodating to needs – e.g. health needs of PLHIV

Source: based on Travers et al. (2008)

Qualitative community-based research projects: What works best ?

- They are based on mutual respect and trust
- Partners express a commitment to long-term, sustainable relationships
- Methodological rigour and sound ethical practices are important
- Projects build on existing strengths of the community
- Flexibility and a longer-term vision are important

An emergent community need: People living longer and ageing with HIV



https://napwha.org.au/resources/

Partnerships work – Outputs and challenges

Our Outputs

- Co-constructing knowledges and collaborative process
- Peer reviewed research papers to meet the institutional demands – always include peers as co-authors, all undergo review by community.
- Reports for participants, that provide the 'bigger picture'
- Presentations that attempt to engage in a national conversation
- Examining more meaningful outputs that support community organisations

The University Of Queensland AUSTRALIA
Create change

Our Outputs : Challenges

- Meaningful outputs that support community organisations?
- Engaging those from smaller or more marginal groups
- How to tell different types of complex stories
- How we add value to the **national research** story?

The University Of Queensland AUSTRALIA
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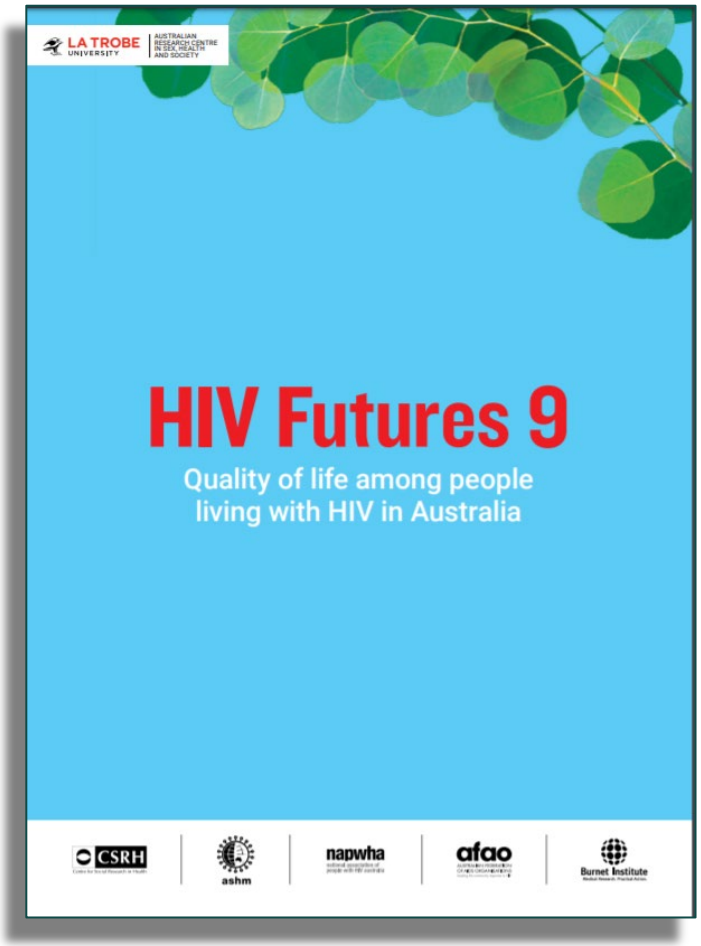
Community Advisory Boards and Co-investigator models



Research article | Open Access | Published: 20 April 2018

Development and validation of PozQoL: a scale to assess quality of life of PLHIV

Graham Brown, Gosia Mikołajczak, Anthony Lyons, Jennifer Power, Fraser Drummond, Aaron Cogle, Brent Allan, Craig Cooper & Simon O'Connor

BMC Public Health **18**, Article number: 527 (2018) | Cite this article

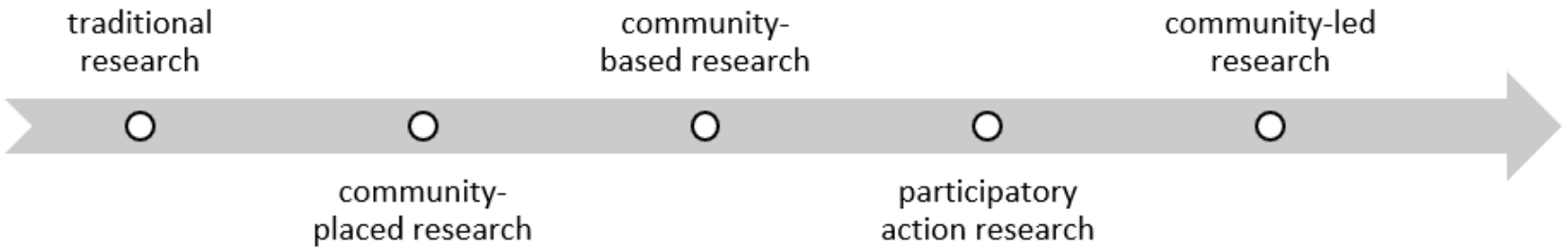
2703 Accesses | **6** Citations | **32** Altmetric | Metrics

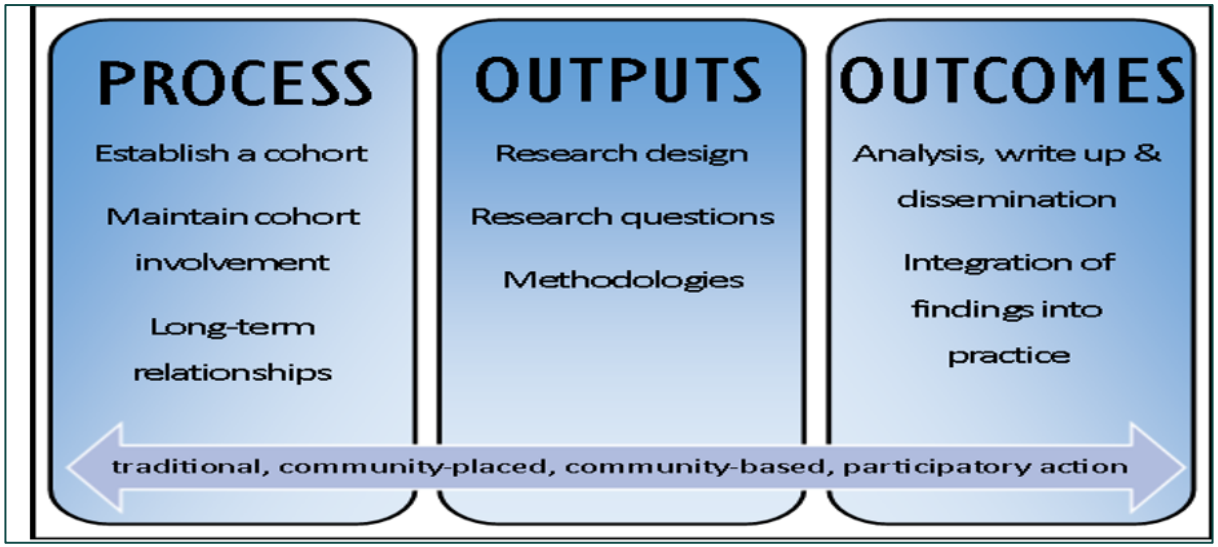
Abstract

Background

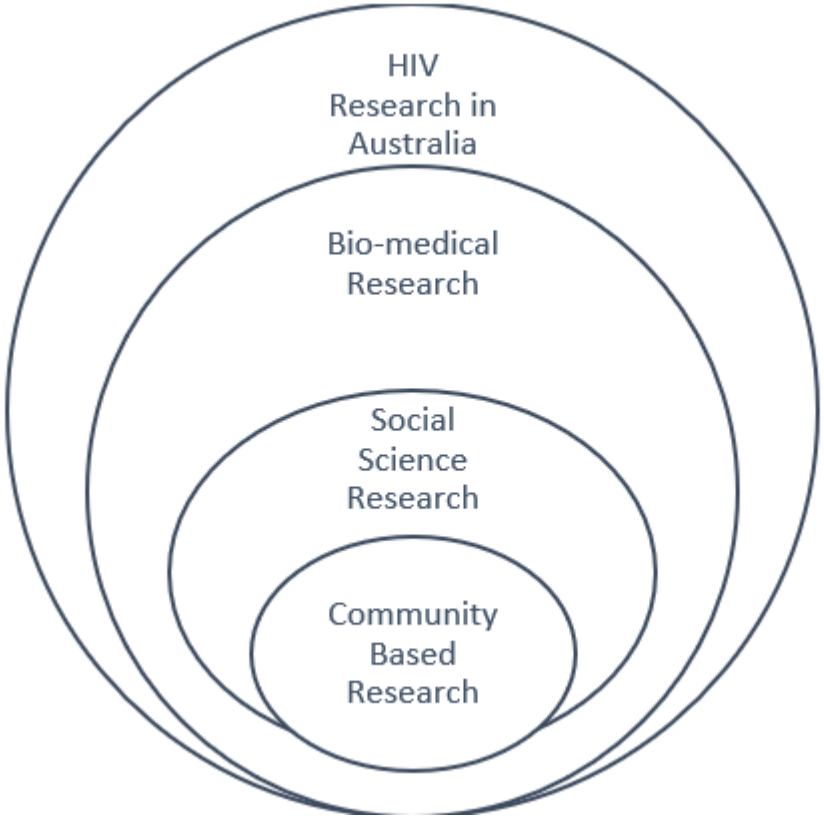
Advances in medical treatment for HIV are driving major changes in HIV policy and practice, including the encouragement of intake and adherence to HIV antiretroviral treatment (ART) by people living with HIV (PLHIV) for both personal and public health benefits. However, there is increasing recognition that achieving these goals will require a concurrent focus on the broader psychological and social wellbeing of PLHIV. Increasingly calls are being been made to incorporate a stronger focus on quality of life (QoL) of PLHIV into HIV prevention policy.

Continuum approach to research involvement





The conundrum of research hierarchies



A research justice approach – Who gets observed and why?

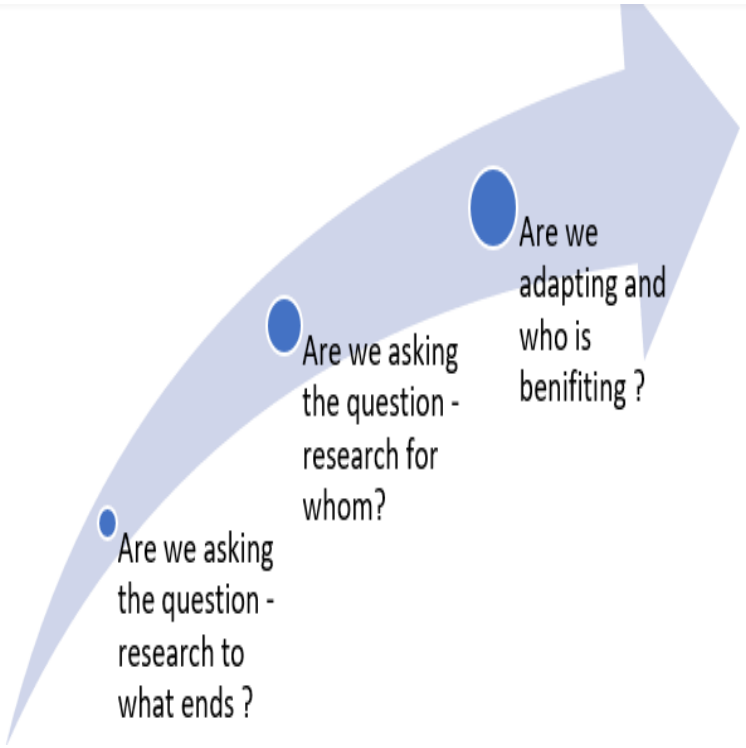
BREAKING EVENTS

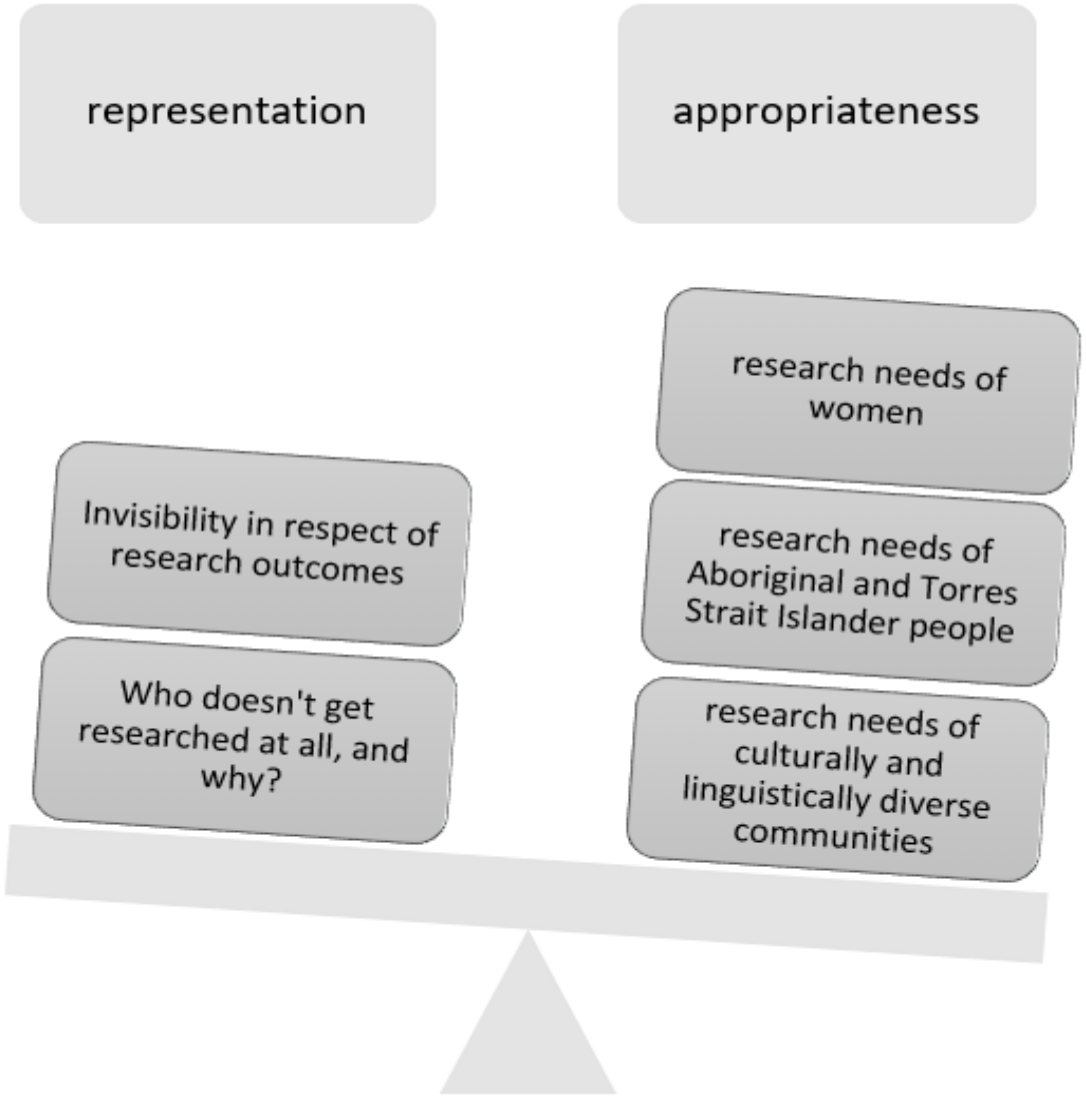
Mardi Gras explains those large cameras creeping out revellers

JORDAN HIRST 6 MONTHS AGO

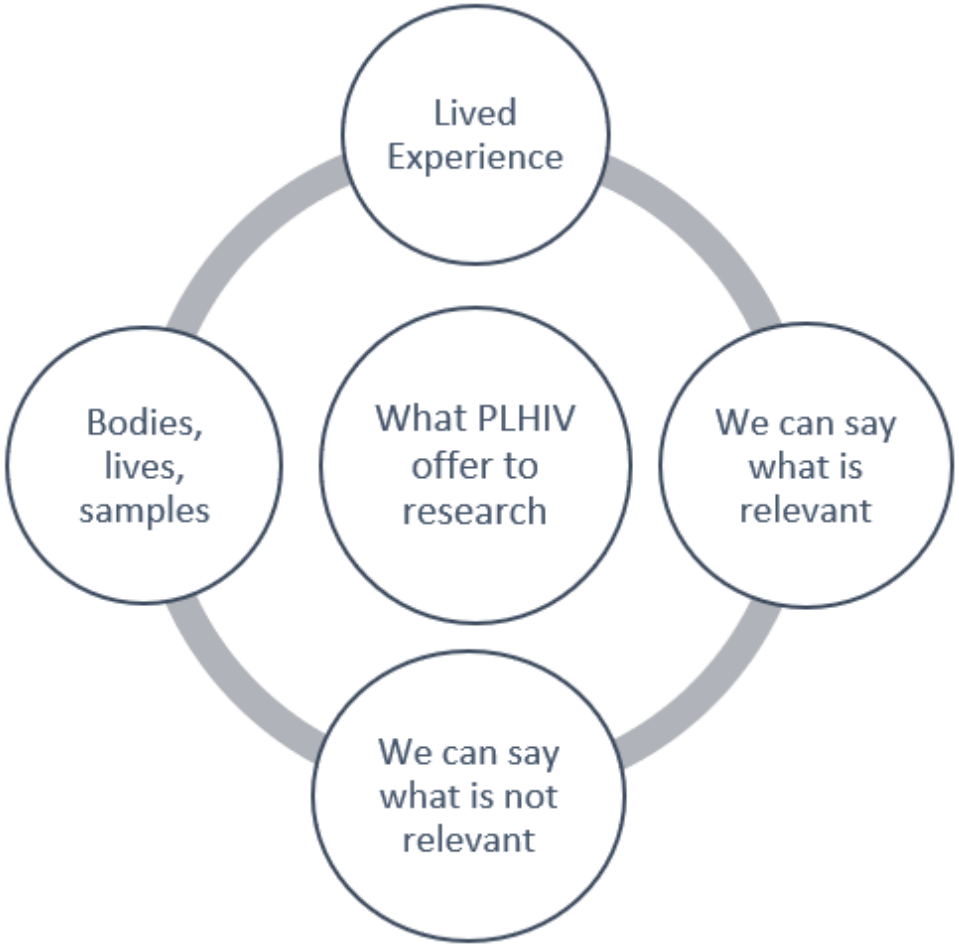
Photo: @cckatoo/Twitter

Sydney Gay and Lesbian Mardi Gras has responded to privacy concerns after nondescript cameras counted revellers entering Fair Day last weekend.




representation
appropriateness
Invisibility in respect of research outcomes
Who doesn't get researched at all, and why?
research needs of women
research needs of Aboriginal and Torres Strait Islander people
research needs of culturally and linguistically diverse communities

Contributions of HIV positive people to research



Not so random principles...

Valued knowledge is that which can be acted upon to make lives better for people living with HIV.

Knowledge is co-created and co-owned.

Research questions are relevant and timely: responding to today's questions, not yesterday's.

PLHIV are involved in research governance at all levels of the process: research agenda-setting, not only responding.

Not so random principles... continued

Science privileges the unambiguous, but lives are often messier than that.
Ambiguity: we need to live with it.

The health literacy of PLHIV has been honed over many decades and communities have shown that they can and do act on information when it is seen as credible.

Autonomy: people are not consumers, or subjects. The knowledge that is generated is for people.

Understanding how we want to communicate the position of the community is a mechanism to also generate that community. This also requires a balance between representing general interests on the one hand and having an individual perspective on the other.

Not so random principles... continued

Research participation creates new leaders that contribute to the advocacy effort. What structure or structures would help to deliver on that? Access points, referral points, community liaison not just organisational liaison

Developing science literacy

Science literacy includes developing more nuanced understandings of concepts such as ‘needs’, and that this is different to talking about ‘my needs’

The ideal is for willing participants to be more informed and engaged as research partners, as opposed to being only consumers of research outputs.