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Priorities for future research: the community adding value to linked data research

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Introduction

Whilst there is limited published information on the benefits of engaging the public in linked data research, our presentation will add to international knowledge about the benefits of involving the community in a priority setting exercise for future research areas in a new linkage project.

Objectives and Approach

We'll co-present with a consumer about our experiences of the community having a role in linked data research over the past 20-years. Community members have provided input into: research projects; feedback to government agencies; submissions to federal/state governments; issues about access to data; and priorities for research.

In 2017 community members prioritised broad research areas for a new project involving cross-agency linkage, investigating pathways to wellbeing and social-outcomes across the life-course to improve outcomes and identify cost-efficiencies. Community members completed a survey to rank the broad themes and then attended a workshop to discuss the themes and identify gaps or new ideas.

Results

Following the workshop all suggestions made on the day were themed into broad areas and then circulated to the attendees to rank in order of importance. These community activities identified the top ten priorities, as shown below, as being the most important areas for future research:

1. Aboriginal Health and Wellbeing
2. Children in Care
3. Disability
4. Education
5. Families

6. Health
7. Homelessness
8. Refugees
9. Alcohol and other drugs
10. Fetal Alcohol Spectrum Disorders

The community input has provided valuable insights about 'what is important to them' and informed the development of the proposal for this new cross-agency project. It also had a positive impact on the community member's perception of, and support for, this potential new research.

Conclusion/Implications

The 20 years' experience gained by the WA Consumer and Community Health Research Network in Western Australia has led to the development of a range of methods for involving the community in linked data research. These methods enable us to clearly demonstrate benefits and value of consumer and community involvement.