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Out of the mouths of researchers: experiences of involvement

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Objective

The presentation will:

- Increase awareness of a range of methods that researchers can use to involve patients and the public (consumers and community members) in linked data research.
- Promote shared learning of how these methods have been successfully implemented
- Provide insights from researchers, consumers and community members about their experiences of using these methods

Approach

The University of Western Australia School of Population Health and Telethon Kids Institute established a Consumer and Community Involvement Program (the Program) in 1998 in response to community concerns about linked data research.

Since its inception, the Program has developed a range of strategies, systems and methods to successfully involve consumers and community members in a variety of research projects. These include projects ranging from student and individual projects to large multi-million dollar programs of research.

A key role of the Program has been to increase skills and capacity for researchers at both organisations. In order to do this a series of training workshops were developed in collaboration with a UK consumer advocate. The training workshops cover the foundations and principles, as well as guidance on the implementation of consumer and community involvement in research.

In 2015 - 2016, an online training course was developed to support the needs of researchers using linked data, who were unable to access face-to-face training and to maximise the focus of face to face training on the implementation of consumer involvement. As part of the development of the online training course a series of interviews were recorded with researchers,

consumers and community sharing their experiences of consumer and community involvement.

Results

A wealth of material was collected during the interviews that will be used to enable researchers to learn from their peers conducting linked data research:

- Researchers experiences of involving consumers and community members in their linked data research
- The benefits of involving consumers and community members in research and tips for how to do this
- Consumers and community members experiences of being involved in linked data research
- Consumer and community involvement in a range of topics including: child protection and health, cardiology and health services research
- Researchers experiences of involvement throughout the research process
- The impact of consumer and community involvement on the research

Conclusion

This presentation will promote shared learning of good practice models of consumer and community involvement to the international linked data research community.

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