

HeRC Patient and Public Involvement Forum

Meeting 14 October 2016

Agenda Item 4

INTERNATIONAL POPULATION DATA LINKAGE CONFERENCE

LINKING DATA- IMPROVING LIVES

Reflections and Main Points- Angela Ruddock

Pre Conference Workshop

This pre-conference workshop was a pretty good exercise in how to involve the public - through the media - in data, although it was clear how data can be manipulated by the national press to sensationalise and distort information in a bad way! Examples (bad ones) are the MMR vaccine and how many members of the public were dissuaded from taking up the vaccine because of distorted information which led to an increase in the diseases in infants rising as a result.

It was lesson in how difficult it can be to present health data in a way that is understandable, interesting and 'sexy' without being sensational or misleading.

Full Conference Programme

There was a choice of 260 presentations over the 3 days, of which I attended about 23. They ranged in countries from Brazil, Canada, the Netherlands, Australia, as well as England, Scotland and Wales.

I think it is important to state from the outset that **the conference was focussed** in the majority of presentations I attended, **on the benefits of linking data and how linked data** can be beneficial in providing a range of not just specific health and medical improvements but also - when linked with social and economic data - **can provide general improvements to well-being at a community level.**

I was particularly interested in the presentations which focussed on the links between health issues in minority ethnic communities in Canada and Australia. Examples included teenage pregnancy in Canada (Manitoba), in an adverse environment and how they are strongly influenced by the behaviour of their elder sisters rather than their mothers within the family.

Other examples included the position of first nation groups in Canada and the effects of socio-economic factors on these communities and the association of severe parental mental illness with lower school readiness in their offspring.

Public Housing and the quality of the environment provided was linked with respiratory infections, the prevalence of campylobacter infections was also another example.

In a small number of presentations, the focus was how the public can be assured of the anonymity of data in order to provide and promote confidence amongst the public in agreeing to the sharing of data- the need to develop protocols, policies and procedures that ensure organisations are able to co-ordinate their systems and data holistically.

Data matters and it is important to raise the issue of linked data between and with separate organisations in order to provide a 3 dimensional picture of their communities and how what may appear to be different and unconnected factors contribute to the health and well-being of communities, particularly those from deprived and low socio-economic backgrounds.

Overall, I was tremendously impressed with the quality of the presentations I heard. In some cases the presentations were clearly aimed at fellow researchers and needed some plain English rewrites but I recognise that the presentations were not aimed at lay attendees like me but to fellow researchers.

It was fantastic 3 days and I enjoyed the camaraderie and networking

Angela Ruddock

HeRC Public Forum (H@PPI) Member