Balancing the benefits and risks of technologically enhanced communicable disease surveillance systems: A report on 4 community juries

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Parallel Session 1D, Grand Ballroom 6, November 19, 2019, 13:30 - 15:00

Abstract Title:
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Background
Outbreaks of Infectious disease cause serious health and social problems. New technologies –whole genome sequencing of pathogens (pathogenomics) and big data analytics – could limit outbreaks and save lives and resources, but social licence is lacking. Their routine use to capture more precise personal health information would be potentially intrusive and a threat to privacy.

Objectives
To elicit the views of well-informed citizens about acceptability and legitimacy of:
- using pathogenomics with deidentified personal data in public health *research*
- adding data-linkage and “smart” analytics to pathogenomics for routine public health *surveillance*

Method
4 citizens’ juries in metropolitan and regional NSW. 50 participants of diverse backgrounds, genders and ages were recruited by random-digit-dialing and social-media advertising. Juries were presented with, and able to question experts on, evidence supporting varied perspectives on potential benefits and risks of technologically-enhanced communicable disease research and/or surveillance.

Results
Almost all jurors supported using pathogemonics of routinely collected patient isolates, with de-identified data-linkage, for public health research. However operationalizing this, using artificial intelligence methods, for routine surveillance was highly contentious; three juries voted in favour and one against, by narrow

margins. Those against cited loss of privacy and lack of trust in governments to manage secure, effective systems.

Conclusions

An informed public would likely support use of pathogenomics with data-linkage for research. Combining them with artificial intelligence-based data analytics for routine surveillance would be controversial, despite potential public health benefits, because of lack of public trust. Private sector involvement or commercialisation of personal health data were unanimously rejected.