

Appendix 3: Expert witness presentation and guiding question

Expert witness presentations (20-25 minutes each):

1. General Practice in Australia: (i) an overview of the general practice context in Australia, (ii) what is in a GP record, and (iii) how information is recorded in a GP record.
(Position blinded), (University blinded)
2. Using the Data in General Practice Records: (i) who uses general practice data and, (ii) what general practice data is used for.
(Position blinded), (University blinded)
3. Linking Health Records: (i) what is data linkage (ii) how does data linkage happen (iii) what data can be shared, and (iv) examples of data linkage.
(Position blinded), (Organisation blinded, University blinded)
4. General Practice Data Sharing Example (Lumos): (i) what is Lumos (ii) what types of data does Lumos collect (iii) general practice participation in Lumos (iv) privacy and ethics in Lumos.
(Position blinded), (Organisation blinded)
5. Ethical Issues in Sharing General Practice Data: (i) ethical principles in sharing personal health information (ii) benefits and harms (iii) bias and fairness, and (iv) ethical clearance for research projects.
(Position blinded), (University blinded) & (Position blinded), (Organisation blinded)
(Melbourne Jury only)
6. Legal Considerations, Regulations and Consent: (i) confidentiality (ii) privacy legislation, and (iii) consent.
(Position blinded), (University blinded)
7. Community Views: (i) results from a national survey
(Position blinded), (University blinded)
8. Community and Health Consumers Views on Sharing GP Data: (i) community and consumer concerns, and (ii) Consumer and Community Involvement (CCI)
(Position blinded) (Sydney) & (Position blinded) (Melbourne), (Organisation blinded)

Guiding questions for the jurors:

1. Who should have direct access to general practice data when used for research?
2. Who should oversee and make decisions about sharing general practice data?
3. Do certain types of general practice data need more protection than others?
4. Should there be penalties applied if those who use general practice data break the rules or misuse the data?
5. Who should pay the costs associated with sharing general practice data?
6. How should general practice patients be told about the way in which their general practice data are collected and shared? And how much should they be told?
7. Should there be a requirement that research findings be released to general practice patients or to the Australian community?