

Workshop: Demonstrating the Impact of Genomic Data Sharing

October 2018

This workshop, open to the full community, will begin with a presentation of preliminary data from the Your DNA, Your Say survey, a patient perspective from the HIV community where data sharing has been well developed, and three short presentations to kick off a 30 minute group discussion to crowdsource good news stories demonstrating the impact of genomic data sharing.

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CHAIRS

- **Anna Middleton** (Head of Society + Ethics Research, Wellcome)
- **Kathryn North** (Director, Murdoch Childrens Research Center; Director, Australian Genomics)

AGENDA (1.5 hours)

1. **Introduction** (10 mins): Kathryn North
2. **Expectations of Our Audience — Your DNA, Your Say preliminary data** (10 mins): Anna Middleton
3. **Patient Perspective** (10 mins): David Haerry, Secretary General, Swiss Academic Foundation on Education in Infectious Diseases (SAFE-ID)
4. **Good News Stories:**
 - a. **DECIPHER** (10 mins): Julia Foreman, Wellcome
 - b. **Australian Genomics** (10 mins): Clara Gaff, Executive Director, Melbourne Genomics; workforce/education co-lead, Australian Genomics
 - c. **BabySeq/MedSeq** (Robert Green, 10 mins)
 - d. **UPD** (10 mins): Nicola Perrin, Head of Data for Science and Health priority, Wellcome
5. **Group Discussion: Crowdsourcing the Good News Library** (20 mins)