

DATA AND DEMOCRACY CPG

Minutes of the Welsh Senedd CPG meeting 19th February 2024

Present

Sarah Murphy MS (Chair), Brandon Renard, Mike Hedges MS, Nicholas Wall, Lizz Merrifield (Cardiff University), Dr Kevin Ashelford (Cardiff University), Dr Peter Giles (Cardiff University) Madeline Stone (Big Brother Watch), Kate Hopkins (BDUK), Adam Freedman (National AIDS Trust), James Baker (Open Rights Group), Sam Smith (MedConfidential)

1. Presentation – Accessing Cancer and Genomics Data in Wales

Lizz Merrifield gave a presentation on Accessing Cancer and Genomics Data in Wales, and the research her, Dr Kevin Ashelford and Dr Peter Giles had researched. The presentation focused on issues around patient concern around data sharing, issues around how data is shared for improving care and the mechanisms and processes for sharing data.

2. Presentation - on the AIDS trusts concerns around the Data Protection and Digital Information Bill and changing regulation of data.

Adam Freedman (Nation AIDS Trust) gave a presentation around the harms that arise when people's HIV status is shared without consent and the impact that can have on people who are HIV positive. Adam spoke about suggested amendments to the bill around the role of the ICO that would help to further protect people, and also raised concerns around how personal data was being redefined by the bill, and issues around transferring people's HIV status to different countries as part of international data transfers.

3. Presentation - from Sam Smith from MedConfidential

Sam Smith from MedConfidential gave a presentation on how health data is handled different in Wales compared to England. He spoke about how we could make it transparent in health apps how and when people's health records were accessed. That this would give assurances to patients it was being used safely for their benefit. He also spoke on the role of AI within health data.

4. Questions and Discussions

Following the presentations there were a series of questions and discussions around the case studies and presentations.