

2nd ELSI Conference 2026 (Thursday 19th November 2026, Cardiff, UK)

DRAFT PROGRAMME

DATE Thursday 19 November 2026

LOCATION Glamorgan Building, Cardiff University, UK, CF10 3WT

UMBRELLA THEME

Mainstreaming Ethics Alongside Genomics in Rare Disease Research and Clinical Practice

[Register your place to attend this event here](#)

Draft Programme — Subject to Change | [ELSI Node Information](#)

TIME	SESSION / ACTIVITY	SPEAKER / DETAILS
09:00–09:30 30 mins	Arrival, Registration & Coffee	Registration, arrivals and coffee
09:30–09:35 5 mins	Welcome	Prof. Angus Clarke Cardiff University • Warm welcome and landscape setting for the 2nd ELSI Conference
09:35–09:50 15 mins	Manchester Node Progress and Updates	Dr Ramona Moldovan The University of Manchester • Overview of the ELSI Node as a whole • Improving Clinical Trials for Rare Conditions
09:50–10:05 15 mins	Oxford Node Progress and Updates	Dr Susie Weller The University of Oxford Genome testing but no molecular diagnosis: SWAN syndrome experiences
PERSPECTIVES ON MAINSTREAMING 10:05–11:15		
10:05–10:35 30 mins	PPIE Perspective from Genomics Partnership Wales	Session Speaker TBC: Patient perspectives and lived experience insights • Supporting Patients Beyond Diagnosis • PPIE Demonstrating Impact of Patient Involvement • Getting the balance right between enthusiasm and realism, optimism and caution. No room for hype.
10:35–10:55 20 mins	Mainstreaming in Wales	Dr Joanne Thomas Genomics Researcher and Registered Nurse, The University of South Wales Presentation Title: Mainstreaming genomics: where are we going, and how do we get there?
10:55–11:15 20 mins	A Perspective from Sheffield	Dr Alisdair McNeill Senior Clinical Lecturer in Neurogenetics, The University of Sheffield Presentation Title: Challenges of mainstreaming genome sequencing for adult neurodegenerative disease
11:15–11:30 15 mins	Coffee Break	Refreshments and networking

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TALKING GENOMICS — KEYNOTE SPEAKER PRESENTATIONS 60 mins total 20 mins per keynote speaker		
11:30–13:15 105 mins (30 mins presentation per keynote speaker plus 15 mins discussion)	Talking Genomics Keynote Speaker Presentations	Prof. Adam Hedgecoe Director of Wales Institute of Social and Economic Research and Data (WISERD) Presentation Title: ‘Professional decision making around ambiguous genomic results’ Dr Janneke Kuiper Postdoctoral Fellow, Centre for Sociological Research, KU Leuven, Belgium Presentation Title: ‘Shaping genomic care: navigating the complexities of genomic diagnostics in practice’ Dr Celine Lewis Principal Research Fellow in Genomics, UCL Great Ormond Street Institute of Child Health Presentation Title: ‘Consenting and returning results for whole genome sequencing: What do these conversations look like in a clinical setting?’
13:15–14.00 45 mins	Lunch	Lunch and Networking
14.00–14:15 15 mins	How to Approach Clinical Training	Presentation of Cardiff Node Project findings Dr Shane Doheny and Prof. Angus Clarke
14:15–15:45 90 mins	Needs for Mainstreaming Specialties Workshop	External Workshop Chair: Prof. Marcus Longley <i>Topics and themes to likely touch on but are not limited to:</i> • Orientation to training • What further voices should we be listening to? (A focus on PPIE) • How to support the mainstreaming of genomics by the Specialty Training Committees across the range of specialties? • A European dimension?
15:45–15:50	Thank You and Closing Remarks	Delivered by Prof. Angus Clarke
ELSI Conference Close		
<i>Mid-Afternoon pre-SAB coffee break and relocation to SAB meeting room location (15:50 – 16:00)</i>		
ELSI SCIENTIFIC ADVISORY BOARD – Attendance only required for ELSI SAB Members		
16:00–17:00 60 mins	ELSI Scientific Advisory Board (SAB) — Hybrid meeting enabling attendance from ELSI SAB members unable to travel to Cardiff	Hybrid meeting facilitating both online and in-person ELSI SAB attendance. <i>Topics and themes to likely touch on but are not limited to:</i> • Specialty Clinical Training Needs? • Avenues to policy change and changes to clinical guidance • SAB engagement, strategic feedback, discussion and recommendations

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