

**34th EUROPEAN CONFERENCE
ON PHILOSOPHY OF MEDICINE AND HEALTH CARE
24 – 27 August 2022**

DIVERSITY AND BIOETHICS

PROGRAMME

Wednesday 24 August	VENUE: POLISH ACADEMY OF SCIENCES STASZIC PALACE, MIRROR HALL NOWY SWIAT 72
16.00-18.00	REGISTRATION
18.00-18.15	OPENING CEREMONY SPEAKERS: <i>PROF. ALOJZY NOWAK (UNIVERSITY OF WARSAW) – RECTOR OF THE UNIVERSITY OF WARSAW</i> <i>PROF. PETER KAKUK (CENTRAL EUROPEAN UNIVERSITY) – PRESIDENT OF THE ESPMH</i> <i>PROF. PAWEŁ ŁUKÓW (UNIVERSITY OF WARSAW) – DEAN OF THE FACULTY OF PHILOSOPHY; DIRECTOR OF THE CENTER FOR BIOETHICS & BIOLAW AT THE UNIVERSITY OF WARSAW</i>
18.15-19.45	PROF. MICHAEL GROSS (UNIVERSITY OF HAIFA, ISRAEL) TITLE: "WARTIME BIOETHICS, MILITARY NECESSITY AND INTERNATIONAL HUMANITARIAN LAW." <i>Chair: Prof. Paweł Łuków</i>
19:45	WELCOME RECEPTION

<p style="text-align: center;">PLENARY SESSION VENUE: POLISH ACADEMY OF SCIENCES, STASZIC PALACE, MIRROR HALL NOWY SWIAT 72</p>								
09.00-10.00	<p style="text-align: center;">PROF. JUDIT SANDOR (CENTRAL EUROPEAN UNIVERSITY, BUDAPEST, HUNGARY) TITLE: "WOMEN'S PERSPECTIVES IN BIOETHICS AND BIOPOLITICS" <i>Chair: Prof. Ana Borovecki</i></p>							
<p style="text-align: center;">PARALLEL SESSIONS VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING 3 KRAKOWSKIE PRZEDMIESCIE STREET</p>								
10.00-10.30	BREAK							
	<p>Session 1.1 Diversity and pluralism ROOM: 5 (Ground floor) <i>Chair: Johanna Ahola-Launonen</i></p>	<p>Session 1.2 Bioethics and democratic values ROOM: 4 (Ground floor) <i>Chair: Søren Holm</i></p>	<p>Session 1.3 Informed consent ROOM: 1 (Ground floor) <i>Chair: Frida Simonstein</i></p>	<p>Session 1.4 Moral pluralism and the value of human life & death ROOM: 109 (1st floor) <i>Chair: Joanna Rozynska</i></p>	<p>Session 1.5 E-medicine & e-health ROOM: 102 (1st floor) <i>Chair: Per-Anders Tengland</i></p>	<p>Session 1.6 Artificial intelligence ROOM: 108 (1st floor) <i>Chair: Mohammed Ghaly</i></p>	<p>Session 1.7 COVID ROOM: 209 (2nd floor) <i>Chair: Peter Šýkora</i></p>	<p>Session 1.8 Special seminar (See below) ROOM: 116 (1st floor)</p>
10.30-10.55	<p>Normative pluralism and rationality in medicine Wojciech Rutkiewicz</p>	<p>The empty place of knowledge. Why ethicists should be aware of becoming experts. Ignaas Devisch</p>	<p>Challenges in (shared) decision-making in gender affirmative medical care: an ethical analysis Karl Gerritse et al.</p>	<p>End of life decision-making in ICUs in Croatia what have we found so far? Ana Borovecki</p>	<p>Healing at a distance: Phenomenological perspective on the quality of the patient-health care provider relationship in teleconsultation Mara Grinfelde</p>	<p>AI as a third pillar in a future patient-physician relationship: the case of breast cancer screening Anto Čartolovni</p>	<p>What unique aspects has the COVID-19 pandemic presented in the realm of medical ethics? Wayne X Shandera</p>	
11.00-11.25	<p>Ethical Foundations for Biomedicine in Diverse Societies Mark Fedyk</p>	<p>How to design consent for research in democratic societies? Svenja Wiertz</p>	<p>Language as a barrier to informed consent and patient communications in healthcare Sylvester C. Chima</p>	<p>The legacy of eugenics in the post-war period in socialist countries Péter Kakuk</p>	<p>eHealth and Regional Inequalities Leon Rossmailer</p>	<p>Dynamic informed consent in medical AI applications Luka Poslon; Anto Čartolovni</p>	<p>Ethical Analysis of the Management of 2019-nCoV in Israel: Re-Mapping the Terrain Shlomit Zuckerman</p>	
11.30-11.55	<p>Intersectionality as a critical tool to account for diversity within mental health care – a systematic concept analysis Mirjam Faissner et al.</p>	<p>Deliberation Processes and Accountability Practices in Bioethics Vilhjalmur Arnason</p>	<p>Rights of patients and rights of others: how to (somewhat) ethically help when patients refuse to be patients? Jakub Zawila-Niedźwiecki</p>	<p>Ethical implications of DAMA: Cross-sectional survey of attitudes and intended behaviour among Lithuanian physicians Asta Cekanaukaite et al.</p>	<p>EHealth components and interpersonal relationships in health care – a paradigm shift? A scan for traces Julia Krumme; László Kovács; Linda Wienands</p>	<p>Artificial Intelligence (AI) and Islamic Ethics: The Moral Dilemmas of Humanoid Robots Mohammed Ghaly</p>	<p>"As if weights were hanging on my arms and legs" - Long-Term Effects of COVID-19 Infections in Children and Adolescents Marion Baldus, Daniel Vilser</p>	
12.00-12.25	<p>Does Complementary and Alternative Medicine correspond to ideals put forth in Medical Humanism? Ines Sophie Pietschmann; Marcel Mertz</p>	<p>Half a Century of Bioethics and Philosophy of Medicine. A Topic-Modeling Study Tomasz Żuradzki</p>				<p>In Defence of Robots in Care David Anthony Procházka</p>		
12.30-13.55	LUNCH							

Thursday
25 August
(morning)

SPECIAL SEMINAR
VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING
3 KRAKOWSKIE PRZEDMIESCIE STREET

Session 1.8
ROOM: 116 (1st floor)

**Special seminar:
The ethics of ethical consultation with biotech and pharmaceutical companies**

Chairs: Jeremy Sugarman & Christoph Rehmann-Sutter

Topic: Along with the growth of the field of bioethics, some biotech and pharmaceutical companies have engaged those with bioethics expertise. This can include ad hoc consultations as well as more sustained involvement, such as bioethics advisory boards comprised of academics from different disciplines, including philosophy, law, the social sciences, and theology. While seeking the authentic advice of bioethicists to help analyze and address ethical issues is commendable, the practice can raise complex ethical challenges for bioethicists such as:

- What conflicts of interests and obligation arise in this work? How can they be appropriately managed?
- What mechanisms can be used to ensure integrity of the process?
- Are bioethics consultants or advisory boards “fig leaves” that veil economic interests?
- What should be the public role of bioethics consultants and advisory panels?
- What is the role and moral responsibilities of industrial leaders (such as chief medical officers, heads of research) in regard to bioethics experts?
- Is there “good practice” or a workplace ethics for bioethics consultants?

10.30-12.25

This special seminar shall describe and discuss these kinds of questions. Given the immense power and influence that industry and industry based biomedical R&D has for healthcare, it is essential to critically and constructively talk about the role of bioethics counseling in industry, and about professional responsibilities of bioethicists who do such work. The seminar consists of five 15 minutes input talks followed by questions, and an open roundtable where the audience can participate.

Contributions

- Nancy King (Department of Social Sciences & Health Policy and Wake Forest Institute for Regenerative Medicine, Wake Forest School of Medicine, USA):
“Bioethics in Pharma: Lap Dog, Show Dog, or Service Dog?”
- Emilia Kaczmarek (Department of Ethics, Faculty of Philosophy, Warsaw University, Poland):
“Should you only do it for free? Why it does matter who pays for an ethics consultation”
- Eugenijus Gefenas (Centre for Health Ethics, Law and History, Faculty of Medicine, Vilnius University, Lithuania):
“A “Figleaf” Phenomenon and How to Deal with it”
- Jeremy Sugarman (Berman Institute of Bioethics, Department of Medicine, and Department of Health Policy and Management, Johns Hopkins University, USA):
“Bioethics Engagement with Industry: A Reality Test with Consequences”
- Christoph Rehmann-Sutter (Institute of History of Medicine and Science Studies, Lübeck University, Germany):
“Moral reasons in favour of bioethics consultation for pharmaceutical companies”

Thursday 25 August (afternoon)				
PARALLEL SESSIONS VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING 3 KRAKOWSKIE PRZEDMIESCIE STREET				
	Session 2.1 Epistemic injustice ROOM: 4 (Ground floor) <i>Chair: Vilhjalmur Arnason</i>	Session 2.2 Global bioethics ROOM: 5 (Ground floor) <i>Chair: Péter Kakuk</i>	Session 2.3 Right-to-try and compassionate use ROOM: 108 (1 ST floor) <i>Chair: Shlomit Zuckerman</i>	Session 2.4 New frontiers in medicine ROOM: 116 (1 ST floor) <i>Chair: John Lizza</i>
14.00-14.25	Epistemic in/justice in patient participation Marjolein de Boer	Global Bioethics: "Back to the Future"? Renzo Pegoraro	A critical evaluation of the 'right to try' approach to the early access to medicines problem Soren Holm	Ethical Advertising and Moral Bioenhancement Sarah Carter-Walshaw
14.30-14.55	Precision medicine from the margins: standpoint epistemology and risks of epistemic injustice in precision medicine Daan Kenis	Human genome editing: between universalism and particularism Julia Stanek	What's wrong with life-saving drug lottery? Joanna Rozynska	Philosophical Aspects of Biomimetics in Medicine Cristina Richie; Martí Verdaguer Mallorquí
15.00-15.25	Epistemic Injustice and Informed Consent in Psychiatry Joanna Smolenski	Strengthening Global Human Research Protection Programs Elyse Summers; Michelle Feige		Research on ageing. 120 as 20? Frida Simonstein
15.30-16.00	BREAK			
	Session 3.1 Sex and gender ROOM: 5 (Ground floor) <i>Chair: Joanna Smolenski</i>	Session 3.2 Cultural diversity and concepts of health, disease, and illness ROOM: 4 (Ground floor) <i>Chair: Ignaas Devisch</i>	Session 3.3 Personality, mental health and well-being ROOM: 108 (1 ST floor) <i>Chair: Gerrit Kimsma</i>	Session 3.4 Empirical bioethics ROOM: 116 (1 ST floor) <i>Chair: Ana Borovecki</i>
16.00-16.25	A principled ethical approach to intersex paediatric surgeries Kevin Behrens	Ethnical and Cultural Factors and their Influence on Chronic Diseases in Italy: Bioethical Perspectives Matteo Zanetti	Recasting 'self-care' as a physician's ethical practice Pacifico Eric Eusebio Calderon	How do citizens experience vulnerability in genomics? Chloé Mayeur; Wannes Van Hoof; Heidi Mertes
16.30-16.55	The sex binary as a perceptive act Christoph Rehmman-Sutter	Difficulties in drawing the line – A Foucauldian view on diagnosis Antonia Sahn	Personality discrimination and hiring? Is it permissible to prefer extroverts over introverts? Joona Räsänen	Professional and emotional care of a patient in physiotherapists' opinion¹ Alicja Przyłuska-Fiszler et al.
17.00-17.25	Moral Challenges in Transgender Care: A Thematic Analysis Based on a Focused Ethnography Karl Gerritse et al.			
18.00-19.30	GUIDED WALKING TOUR: WARSAW OLD TOWN MEETING POINT: WARSAW UNIVERSITY MAIN ENTRANCE GATE			

<p style="text-align: center;">Friday 26 August (morning)</p> <p style="text-align: center;">PLENARY SESSION VENUE: POLISH ACADEMY OF SCIENCES, STASZIC PALACE, MIRROR HALL NOWY SWIAT 72</p>							
09.00-10.00	<p>PROF. UDO SCHUKLENK (QUEEN'S UNIVERSITY, ONTARIO, CANADA) TITLE: "RETHINKING CONSCIENTIOUS OBJECTION AND MEDICAL PROFESSIONALISM: NEGATIVE VS POSITIVE CLAIMS" <i>Chair: Prof. Eugenijus Gefenas</i></p>						
<p style="text-align: center;">PARALLEL SESSIONS VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING 3 KRAKOWSKIE PRZEDMIESCIE STREET</p>							
10.00-10.30	BREAK						
	<p>Session 4.1 Research ethics ROOM: 108 (1st floor) <i>Chair: Sylvester C. Chima</i></p>	<p>Session 4.2 Diversity in bioethics ROOM: 102 (1st floor) <i>Chair: Cristian Timmermann</i></p>	<p>Session 4.3 Doctor-patient relationship ROOM: 1 (ground floor) <i>Chair: Stephan Sahn</i></p>	<p>Session 4.4 Reproductive medicine ROOM: 209 (2nd floor) <i>Chair: Antonia Sahn</i></p>	<p>Session 4.5 Big data on health and data mining ROOM: 4 (Ground floor) <i>Chair: Udo Schuklenk</i></p>	<p>Session 4.6 Disease, illness & health ROOM: 5 (Ground floor) <i>Chair: Nathan Emmerich</i></p>	<p>Session 4.7</p> <p>Special seminar (See below)</p> <p>ROOM: 116 (1st floor)</p>
10.30-10.55	<p>Trachea transplants and the regulation of unproven methods in clinical innovation Gardar Amason</p>	<p>The price of the diversity of bioethics Daniela Cutas</p>	<p>Doctor-patient relationship and its evolution: ethical implication of modern technologies Aistė Bartkienė, Margarita Poškutė Rytis Virbalis</p>	<p>Single mother by choice – a contested account of parenthood Stefanie Weigold</p>	<p>Open Data Policy and Biobank Research – Some Implications for Informed Consent Emmi Kaaya</p>	<p>Autonomy in Politics and in the Definitions of Health and Disease Andrew Spear</p>	
11.00-11.25	<p>The Ethical Challenges of Governing Biobanking for Genetic Research in India Manjulika Vaz</p>	<p>Is There a Moral Imperative to Pursue Ethnic/Cultural Diversity Among American Health Care Ethicists and Academic Ethicists? Amy M. VanDyke</p>	<p>The Patient Life Empowerment Approach Brenda Bogaert</p>	<p>Applying the Dual-Interest Theory: Another Argument in Favor of Pregnant Women's Autonomy Emma Moormann</p>	<p>Informed consent: is it still a fundamental principle of human research? Eugenijus Gefenas, V. Lukaseviciene, J. Lekstutiene</p>	<p>Normative Metaphysics and the Definition of Death John Lizza</p>	
11.30-11.55	<p>Ethicists into the lab – once again? How to conceive of a sound practice turn for bioethics Anja Pichl</p>	<p>Moral Knowledge and the Good of Medicine in Diverse Global Contexts Timothy Mosteller</p>	<p>Meaning of being. About closeness in the treatment process from a law and psychology perspective Agnieszka Bielska-Brodziak; Marlena Drapalska Grochowicz</p>	<p>A bioethical policy debate concerning the recent 'surrogate mother' case in Russia. Roman Tarabrin</p>	<p>Responsibility and moral diversity in IT-based decision support systems Wenke Liedtke; Martin Langanke</p>	<p>Disagreement on death and what to do about it? Ivars Neiders</p>	
12.00-12.25			<p>The specter of paternalism haunts the shared decision making Yi-Ting Kuo; Ya-Ping Lin</p>	<p>"It is highly unlikely that your child is healthy" Marion Baldus</p>		<p>Precision health/ ethical ambiguity. How much cancer can we afford to prevent? Leonard Fleck</p>	
12.30-13.55	LUNCH						

Friday
26 August
(morning)

SPECIAL SEMINAR
VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING
3 KRAKOWSKIE PRZEDMIEŚCIE STREET

Session 4.7
ROOM: 116 (1st floor)

Special seminar: Equal access to healthcare in Europe

Chairs: Paweł Łuków & Florian Steger

Topic: The seminar is linked to the ongoing project HERA: Public Spaces. Culture and Integration in Europe (2019–2022) – “Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe.” The project is financially supported by the HERA Joint Research Programme (www.heranet.info) under HERA Public Spaces: Culture and Integration in Europe Programme (Hera.2.029) which is co-funded by the German Federal Ministry of Education and Research (BMBF); National Science Centre, Poland (Project No. 2018/28/Z/HS1/00554); Croatian Academy of Sciences and Arts; Slovenian Ministry of Education, Science and Sport and European Commission through Horizon 2020 (grant agreement No 769478).

Healthcare as a public space can be conceived of as a space of integration and equity. Equal access to healthcare is crucial for modern democracies, particularly when healthcare is perceived as a social service, which can contribute significantly to fairness and equal opportunity. Equality in healthcare is even more demanding in the context of the growing diversity of contemporary European societies. Diverse health needs are a constant challenge to anti-discrimination policies and activities.

Although the European Union’s Charter of Fundamental Rights guarantees the right to healthcare, healthcare appears to be a space of contradictions and confrontations, combining various elements of both integration and exclusion. One reason is that the principles of equal treatment and non-discrimination have been adopted fragmentarily in the European Union; the other reason is that healthcare remains mainly within the competencies of the Member States.

Adopting the comparative and interdisciplinary approach, we will examine anti-discriminatory policies, regulations and practices in the context of healthcare in Europe. We will pay particular attention to the ways in which anti-discrimination measures in healthcare are designed, adopted, and implemented, as well as to the ways in which they are neglected, ignored or even openly opposed.

During this seminar, we will ask the following questions: What are ethical, cultural, and normative aspects of integration and exclusion within the healthcare sector? How social diversity issues in the context of access to healthcare are regulated on the European and national level? Are aspects of racial, ethnic, cultural, religious, gender or sexual orientation associated with disparities in healthcare systems? How deep are these disparities? What ethical problems for healthcare professionals and patients are raised by the phenomenon of social diversity? How are these issues resolved in everyday healthcare practice? How can these problems be addressed and ameliorated?

10.30-12.25

Contributions

- Florian Steger (Institute of the History, Philosophy and Ethics of Medicine, Ulm University, Germany):
“EU Research Project „Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe”
- Paweł Łuków (Center for Bioethics and Biolaw, Institute of Philosophy, University of Warsaw, Poland):
“Accessibility of healthcare services as a relational concept”
- Marcin Orzechowski (Institute of the History, Philosophy and Ethics of Medicine, Ulm University, Germany):
“Social diversity as a challenge – Equal access to healthcare from the German perspective”
- Katarzyna Bielińska (Center for Bioethics and Biolaw, Institute of Philosophy, University of Warsaw, Poland):
“Access to healthcare for diverse patients: National peculiarities in Poland”
- Anna Chowaniec (Center for Bioethics and Biolaw, Institute of Philosophy, University of Warsaw, Poland):
“‘Diversity competency’ in Polish hospitals internal regulations. Are the EU and Polish guidelines on equal access to healthcare implemented into the hospitals’ policies?”
- Ivana Tutić Grokša (Department of Social Sciences and Medical Humanities, Faculty of Medicine, University of Rijeka, Croatia):
“Access to healthcare of minority groups in Croatia - comparison of legal regulations and practices ”

**Friday
26 August
(afternoon)**

PARALLEL SESSIONS
VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING
3 KRAKOWSKIE PRZEDMIESCIE STREET

	Session 5.1 Ethics/bioethics committees ROOM: 1 (Ground floor) <i>Chair: Oliver Feeney</i>	Session 5.2 Conscientious objection in medicine ROOM: 4 (Ground floor) <i>Chair: Emily E. Anderson</i>	Session 5.3 Diversity and justice in healthcare ROOM: 108 (1 ST floor) <i>Chair: Eugenijus Gefenas</i>	Session 5.4 Public health surveillance technologies ROOM: 209 (2 ND floor) <i>Chair: Michal Wieczorek</i>	Session 5.5 Medical decisions at the end of life ROOM: 5 (Ground floor) <i>Chair: Gerrit Kimsma</i>	
14.00-14.25	Diversity in the ethics committee for the protection of animals used for scientific purposes Joanna Wysocka-Andrusiewicz	Accounting for the Referral Requirement: Conscientious Objection and the Idea of a Morally Permissible Moral Mistake. Nathan Emmerich	Diversity of men who have sex with men (MSM) as ethical problem and potential in new strategies of HIV prophylaxis Mathias Wirth	Medical confidentiality, communicable diseases, and public health: the case of HIV positive sex workers Maria Damanaki	Moral diversity and the ethics of assisted dying Stephan Sahn	Session 5.6 Special seminar (See below) ROOM: 116 (1 ST floor)
14.30-14.55	Ethics/bioethics committees Leopoldo Sardonà	Conscientious objection in healthcare, moral complicity, and the duty to refer: Taking reasonable pluralism seriously Ruth Denkhaus	Do States Have a Moral Duty to Participate in Addressing the Global Challenge of Antibiotic Resistance? Lovro Savic	GEN-Ethics: What do Norwegian women think of utilising genetic testing as part of breast cancer screening? Rigmor Katrine Johansen	Travelling to die: Views, attitudes and end-of-life preferences of Israelis considering receiving aid-in-dying in Switzerland Daniel Sperling	
15.00-15.25	The role of clinical ethic committees in Italy on end-of-life matters and beyond Carlo Chiurco	Why conscience based refusals to provide patient care ought not to be accommodated Udo Schuklenk	Diagnosis as a moral dilemma: case of autism spectrum disorder. Marie Sommier	The need for an ethical framework for health data reuse and its purposes Marlies Saelaert	Experiences and attitudes of medical professionals on treatment of end-of-life patients in intensive care units in the Republic of Croatia Diana Spoljar	
15.30-15.55		Conscientious objection in the profession of pharmacist. A survey of pharmacists' opinions on the conscience clause in Poland Justyna Czekajewska, Dominik Langer, Ewa Baum	(Too much) technological optimism (or pessimism) constructs simplistic theoretical foundations Johanna Ahola-Launonen	Participant Recruitment and Engagement - Fostering Inclusivity and Diversity in the Obesity and its hidden tragedy of commons Cristian Timmermann	End-of-life Options in Humans and Animals: A Comparison Gerald Neitzke; Peter Kunzmann; Kirsten Persson; Johanna Risse; Felicitas Selter	
16.00-16.25					Religion & End-of-Life Healthcare: Accommodating Differing Values, Norms and Ontologies Aasim I. Padela	
16.30-17.00	BREAK					
17.00-18.00	ESPMH GENERAL ASSEMBLY ROOM: 116; 1 ST floor					
19.00-23.00	CONFERENCE DINER ALEGLORIA RESTAURANT TRZECZ KRZYZY SQUARE 3					

Friday
26 August
(afternoon)

SPECIAL SEMINAR
VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING
3 KRAKOWSKIE PRZEDMIESCIE STREET

Session 5.6
ROOM: 116 (1st floor)

Special seminar: Participant Recruitment and Engagement - Fostering Inclusivity and Diversity in the *All of Us* Research Program

Chair: Subhashini Chandrasekharan

Topic: The *All of Us* Research Program (AoU), is a large federal longitudinal cohort program designed to be ethically robust and inclusive of the United States national population. AoU hopes to collect genomic, biological, environmental, and lifestyle longitudinal data and biospecimens from one million or more people living in the United States. The scientific resources of AoU will reflect the socioeconomic and demographic (race, ethnicity, gender, age etc.) diversity of the U.S. population. AoU aims especially, to include historically underrepresented groups and communities, and to have the large and heterogeneous data base be open and accessible to a wide array of researchers and data users. This raises familiar ELSI concerns about the potential for harm to individuals, groups, and communities, especially those who have faced systemic discrimination and historical research abuses. It also presents new challenges and opportunities for meaningful and sustained community engagement, which is needed to build trust, set expectations, and prevent harm to participants and communities in precision medicine research. As core values, the program has promised broad access to its resources for research and to simultaneously uphold the privacy and security of participants. Enabling and managing access to these resources for a wide range of researchers (including citizen scientists) at national scale, while ensuring responsible use, presents competing tensions and ELSI challenges both familiar and new.

This session will provide an exploration of goals, progress, and challenges faced by AoU examined through the lenses of experiences of program/consortium partners and NIH staff. Panelists will discuss how ELSI considerations are being addressed in design, policy, and operations of the program. They will describe strategies used for facilitating trusting relationships with diverse participant populations; ensuring appropriate communication of population-specific risks/benefits, implications, and limitations in consent and other materials; and approaching bidirectional data sharing with participants in responsible, culturally competent ways. Panelists will share AoU approaches and experiences with participant and community engagement and feedback, integrating participants in AoU governance, challenges faced, and needs going forward. The panelists will also detail how considerations of equitable and transparent access, protecting participant privacy, and reducing potential harm to individuals, groups, and communities are being integrated in developing and implementing data access and use policies; processes to monitor data use behaviors and review and adjudicate data use agreement violations, including potentially stigmatizing research; and developing policies and governance structures for biospecimen access and use, respectively. The following moderated open discussion will focus on approaches needed to integrate ELSI research and stakeholders' feedback for anticipating and addressing concerns in an ongoing way as technology and policy continue to evolve, policy and legal issues surrounding inclusion of diverse and vulnerable participants at national scale, addressing considerations of justice, and stakeholder expectations of equitable access to outcomes of precision medicine research.

14.00-16.25

Session Aims

- Understand AoU challenges and experiences in recruiting populations underrepresented in biomedical research and approaches for participant and community engagement
- Understand data and biospecimen access and use policies of AoU and their ELSI implications.
- Understand AoU processes for monitoring resource use, reviewing, and adjudicating user agreement violations, and approaches needed to prevent harm to participants, groups and communities
- Evaluate and anticipate ELSI considerations for sustaining trust-based relations with participants, groups and communities in precision medicine broadly, and specifically for AoU
- Identify, anticipate and evaluate ELSI issues focusing on group and community perspectives of benefit and harm and enabling fair and beneficial use for betterment of all

Session Details: Each speaker will make a 15-minute presentation followed by 20 minutes Q&A session for all speakers together. Next the panel will have a moderated discussion for 45 minutes with the audience. The last 15 minutes will be used to collect questions and surface ELSI issues for *All of Us* to consider in the near horizon from the audience.

Contributions

- Sonya Jooma (Participant Priorities Lead, Policy Office, The *All of Us* Research Program, National Institutes of Health, USA):
"Participant Recruitment and Engagement - Fostering Inclusivity and Diversity in the *All of Us* Research Program"
- Katherine Blizinsky (Director, Policy Office, The *All of Us* Research Program, National Institutes of Health, USA):
"Data Access and Use Policies in *All of Us*: Balancing Tensions between Broad Access and Protecting Privacy in "Big Data" Research"
- Subhashini Chandrasekharan (Ethical, Legal, and Social Implications Lead, Policy Office, The *All of Us* Research Program, National Institutes of Health, USA):
"Biospecimen Access and Data Use Monitoring: Preventing Harm to Individuals and Communities"
- Jessica Reusch (Genomics Lead, Policy Office, The *All of Us* Research Program, National Institutes of Health, USA):
"Informed Consent for the *All of Us* Research Program: Experiences and Challenges at National Scale"

<p>Saturday 27 August (morning)</p> <p style="text-align: center;">PLENARY SESSION VENUE: POLISH ACADEMY OF SCIENCES, STASZIC PALACE, MIRROR HALL NOWY SWIAT 72</p>					
09.00-10.00	<p style="text-align: center;">PROF. HANS VAN DELDEN (UTRECHT UNIVERSITY, THE NETHERLANDS) TITLE: “DIVERSITY AND PERSON-CENTERED CARE: NATURAL ALLIES BUT NOT WITHOUT BLIND SPOTS” <i>Chair: Prof. Bert Gordijn</i></p>				
<p style="text-align: center;">PARALLEL SESSIONS VENUE: UNIVERSITY OF WARSAW, FACULTY OF PHILOSOPHY BUILDING 3 KRAKOWSKIE PRZEDMIESCIE STREET</p>					
10.00-10.30	BREAK				
	<p>Session 6.1 Autonomy, dementia, and informed consent ROOM: 5 (Ground floor) <i>Chair: Ruth Denkhaus</i></p>	<p>Session 6.2 Ethical theory & access to healthcare ROOM: 1 (Ground floor) <i>Chair: Daniel Sperling</i></p>	<p>Session 6.3 Wearables in healthcare & m-health ROOM: 108 (1ST floor) <i>Chair: Gardar Arnason</i></p>	<p>Session 6.4 Citizen science, participatory research & public engagement ROOM: 4 (Ground floor) <i>Chair: Amy VanDyke</i></p>	<p>Session 6.5 Organ Transplantation and organoids ROOM: 116 (1ST floor) <i>Chair: Pacifico Eric Eusebio Calderon</i></p>
10.30-10.55	<p>Operationalizing authenticity – matching treatments with patients or fitting patients to treatments? Jasper Debrabander</p>	<p>The Suffering of the Many Outweighs the Suffering of the Few or the One. Steven Firth</p>	<p>Self-tracking and personalisation in healthcare Michał Wiczorek</p>	<p>Increasing participation of diverse public stakeholders in biomedical research oversight Emily E. Anderson</p>	<p>Fairness, Transparency and Responsibility in Organ Allocation Soren Holm</p>
11.00-11.25	<p>Relational autonomy in the light of hope in end-of-life care Marta Szabat</p>	<p>Beyond biopolitics: the importance of the later work of Foucault to understand care practices of healthcare workers caring for undocumented migrants. Dirk Lafaut</p>	<p>On the moral reasons for problematizing the dominance of pregnancy-related mHealth (despite, or because of, the promise of better neonatal outcomes) Seppe Segers</p>	<p>Public engagement on Germline Genome Editing: decreasing or replicating wider polarisation in society? Oliver Feeney</p>	<p>The Transplant Patient, Personal Identity, and a Good Life Paweł Łuków</p>
11.30-11.55	<p>Intersectionality and autonomy in bioethics: in search for diversity and convergence Michiel De Proost</p>		<p>Diversity of ethical perspectives in medicine 4.0 – A project report Bettina Schmietow; Georg Lindinger</p>	<p>Power and ethics in qualitative health (promotion) research Per-Anders Tengland</p>	<p>The conceptual shift from altruism to reciprocity is needed for ethical justification of kidney exchange programs Peter Sýkora</p>
12.00-12.25	<p>Ethics and dementia: Between quality of life and life expectancy Gila Yakov; Rachel Nissanholtz-Gannot; Inbal Halevi Hochwald</p>			<p>Engaging uninformed or misinformed publics: Hearing every voice Wannes Van Hoof; Heidi Mertes; Chloé Mayeur</p>	<p>Conflicts between patient wishes and health practitioner duties: the case of transplant tourism into China David Matas</p>
12.30-12.55	<p>Empowered by technology? Reflections on the changing dementia care ethos by means of monitoring and assistive technologies Silke Schickanz; Johannes Welsch; J Perry</p>			<p>The race for public trust: is public engagement the solution? Louise Mathieu; Wannes Van Hoof</p>	
13.00-13.30	<p>CLOSING SESSION ROOM: 116 (1ST floor)</p>				