Training Ethical and Professionalism Aspects of Dealing with Health-Related Datasets

Date: 20-21 November 2025

Location: Academy for Music, Kongresni trg 6, 1000 Ljubljana

Agenda item	Time
Thursday 20 November 2025	
Registration	08:30-09:00
Welcome and opening chair (Damjana Rozman)	09:00-09:15
Framing Lecture: Igor Švab – *Why Ethics and Professionalism Matter in Health Data Use*	09:15-09:45
Participant Introductions & Expectations – Facilitated round-table	09:45-10:30
Coffe Break	10:30-11:00
Mini Lecture and discussion. Gerhard Fortwengel: *From Consent to Consequence: Rethinking Digital Ethics in Health Care and Research.*	11:00-12:00
Mini Lecture and discussion. Giovanni Spitale: *Ethical issues for data management in healthcare systems*	12:00-13:00
Lunch Break	13:00-14:30
Organisation into the working groups on chosen themes	14:30-15:00
Work in Groups on a chosen scenario	15:00-17:00
Reflections & Lightning Reports from the Groups	17:00-17:30
Group Dinner (self-paid): Ljubljančanka Restaurant (Knafljev podhod 2, 1000 Ljubljana)	19:00-21.00

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Agenda item	Time
Friday 21 November 2025	
Preparation of the groups for the presentations	08:30-09:30
Final Group Presentations (15 + 5 mins Q&A per group)	09:30-11:30
Wrap-up Discussion	11:30-12:00
Presentation of certificates & Departure	12:00-12:30
Farewell Lunch	12.30-13.30

Framing Lecture

Prof dr. Igor Švab: Why Ethics and Professionalism Matter in Health Data Use

The lecture offers a humanistic and educational framing of the workshop's theme from the perspective of a medical school dean and a family doctor. As the complexity and scale of health data continue to grow, ethics and professionalism remain essential across all areas of research. Drawing on decades of experience in patient care and medical education, the speaker will reflect on the responsibility of academic institutions not only to produce competent researchers, but to cultivate ethically grounded professionals. Participants will be invited to engage with these issues through the lens of clinical practice—where humility, curiosity, and a shared commitment to trust and social accountability must guide decisions we make.

Mini lecture

Prof. dr. Giovanni Spitale: Research with Health Data: Ethical Issues, Risk Mitigation, and Data Management Practices

Health data offers immense potential for advancing medical research, but it also raises pressing ethical questions. This lecture and the following workshop explore the complex landscape of working with health-related data, from informed consent and data anonymization to governance challenges and cross-border sharing. Participants will gain practical insights into identifying ethical risks, applying mitigation strategies, and implementing responsible data management practices. Designed for researchers and data stewards, this session bridges theory and practice to foster ethically sound research with health data.

Mini lecture

Prof. dr. Gerhard Fortwengel: From Consent to Consequence: Rethinking Digital Ethics in Health Care and Research.

Digital ethics in healthcare and research is reshaping how informed consent is understood and practiced. Technologies like AI, EHRs, and health apps offer new opportunities—but also raise ethical concerns. Digital platforms can enhance consent through multimedia, personalization, and traceability. However, they may oversimplify complex information or overwhelm patients. AI-driven decisions challenge transparency and accountability, making consent harder to validate. Patients often don't understand how algorithms influence diagnoses or treatments. Broad consent models allow future data use but reduce patient control and clarity. This can erode trust and compromise ethical standards in research. Digital exclusion and consent fatigue risk marginalizing vulnerable populations. Ethical design must prioritize clarity, transparency, and patient empowerment. Consent should evolve into a continuous, trust-based dialogue—not a one-time checkbox. Rethinking digital ethics means centering human values in every technological advance. In this brief introduction, we aim to present and summarize key questions, which will then be explored in more detail within working groups to encourage joint discussion and deeper analysis.

Themes for working groups

Prof. dr. Gerhard Fortwengel

1. *Consent vs. Comprehension: How Informed Is Informed Consent?*

Participants explore the gap between legal consent and actual understanding in digital health applications. Where does formal agreement end—and where does true patient education begin?

2. *Data Trails in Healthcare: Between Benefit and Surveillance*

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This group discusses how health data is collected via apps, wearables, and research. What ethical boundaries exist between innovation and individual rights?

3. Ethical Red Flags: What Would Make You Say No?

Participants discuss real-world scenarios where digital health solutions raise ethical concerns. Where do personal and societal boundaries begin to blur?

Prof. dr. Giovanni Spitale

1. Consent battle royale. In this hands-on game, small teams design an informed-consent form for a health-data study that is both actually understood by lay readers and usable under time pressure. Participants draft an informed consent form and a 5-item comprehension quiz, then A/B-swap with a neighboring team to test real comprehension without access to the form. They iterate once: cutting jargon, clarifying rights, and tightening specificity, before self-scoring on comprehension, readability, rights coverage, and brevity, with penalties for dark patterns and hidden risks. The session spotlights the consent–comprehension gap, forces trade-offs between completeness and clarity, and results in concrete, shareable artifacts (final consent, quiz, checklist). Ideal for researchers, ethics officers, and designers who want to pressure-test consent quality and leave with a blueprint for "plain-language by default."

2. Bad science — "How to ruin a study (so we learn why not)". A satirical reverse-engineering exercise on health-data ethics. Using a published social-listening study on Green Pass discourse, teams are challenged to design the worst possible study design and data management pipeline: ethically dubious, insecure, irreproducible. A "Badness Bingo" rubric scores poor consent/legal reasoning, over-collection, weak security, reckless sharing, endless retention, missing provenance, and zero accountability. By making mistakes deliberately, participants surface best practices by contrast: why group privacy and contextual integrity matter, where DPIAs, minimization, encryption, and deletion policies bite, and how transparent governance prevents real-world fiascos. Deliverables are the awful DMP, and scored bingo sheet, perfect fuel for a quick debrief on "how to do it right."

3. Open, but how much? Teams are given a health/AI research scenario and must decide how open to make the underlying data, code, and documentation, and then defend the choice. Using a tiered-openness canvas (open / controlled / closed), they weigh reuse benefits against dual-use risk, scalability of harm, and community impact from a third-bioethics lens (openness as instrumental, not absolute). The output is an Openness Justification Statement, a Redaction & Access Plan, and a Safeguards Pack. A self-scoring rubric rewards proportionality, stakeholder protection, and clarity, penalizing "open-by-default" dogma and hand-waving.

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