



EUROPE BIOBANK WEEK CONGRESS 19-22 MAY 2026

ORAL PRESENTATIONS

Abstracts

Produced by the Europe Biobank Week Programme Committee and BBMRI-ERIC's
Department of Outreach, Education and Communications

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KN1: Prof. Joacim Rocklöv

How is climate change affecting infectious disease dynamics across Europe?

Authors:

Prof. Joacim Rocklöv, Head of Heidelberg Planetary Health Hub and Alexander von Humboldt Professor at Heidelberg University.

Topic: KN1: Keynote

Presenter Name: Prof. Joacim Rocklöv

Keywords: one health, climate change, infectious diseases

Climate change is reshaping the landscape of infectious diseases across Europe, with particularly profound implications for all climate-sensitive, especially arboviral diseases. This talk will highlight current evidence on how warming temperatures, shifting precipitation patterns and extreme events are influencing the emergence, transmission and geographic expansion of pathogens and vectors. Using concrete European examples, it will distinguish between what is well established and where critical uncertainties remain.

Beyond climate alone, the presentation will explore how interacting stressors—including biodiversity loss, land-use change and pollution—amplify or modify disease risks within a broader planetary health framework. Emphasis will be placed on advances in monitoring, modelling and early warning systems, as well as remaining gaps in surveillance and attribution.

By integrating perspectives from epidemiology, climate science and ecology, this talk aims to provide a forward-looking understanding of how multiple, intersecting crises are shaping infectious disease dynamics in Europe—but also

discuss how novel approaches to surveillance and prediction can help with more targeted and strategic responses.

KN2: Aneta Tyszkiewicz

From scientific excellence to industrial leadership: Strengthening Europe's attractiveness for research and innovation through the EU Biotech Act

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Topic: KN2: Keynote

Presenter Name: Aneta Tyszkiewicz

Keywords: biotech, biotech act, research and innovation, biotechnology, digital transformation

Europe stands at a pivotal moment in global biotechnology. While its scientific base remains strong, fragmentation, insufficient investment and regulatory complexity risk undermining its competitiveness.

The Biotech Act offers a unique opportunity to create a coherent, innovation-friendly ecosystem that enables research, development and manufacturing to scale in Europe. To deliver, it must combine effective incentives, a truly harmonised clinical trials system, regulatory simplification, strategic investment and a robust framework for data and AI.

With the right ambition, Europe can move beyond incremental change and position itself as

a global leader in biotechnology, ensuring faster patient access and long-term economic growth.

10A: Ethics Café

Health Data, EHDS and AI: What Could Possibly Go Wrong?

The European Health Data Space (EHDS) and the rapid uptake of Artificial Intelligence are transforming how health data from biobanks are accessed, reused and governed across Europe. For biobank professionals, this shift is not abstract — it directly affects data access procedures, secondary use decisions, collaborations and stakeholder relationships.

How does AI change the ethical landscape of health data reuse? What new responsibilities arise under EHDS for biobanks as data holders and facilitators? Where do transparency, engagement and societal expectations fit into evolving access frameworks?

Join the conversation to explore how biobanks can navigate AI-enabled data use while maintaining legitimacy, accountability and public confidence.

This session will be chaired by:

Assoc. Prof. Anto Čartolovni, PhD

Assoc. Prof. Anto Čartolovni, PhD is the new Head of the ELSI Department at BBMRI-ERIC, having recently joined from the European Research Council (ERC). An expert in bioethics, AI ethics and governance, he has extensive experience managing national and international projects focused on the ethical, legal and social

implications of digital transformation in healthcare.

Valentina Colcelli, PhD

Valentina Colcelli, PhD is a Senior Researcher at the Italian National Research Council (CNR). Her main research interests focus on the interaction of domestic and European law in shaping rights and interests and market regulation. She is also interested in a general reflection on personal and non-personal data beyond the EU legal system, internal market regulation, personal data protection, data circulation, legal and ethical issues in research and innovation activities and Artificial Intelligence and adequate judicial protection of biodiversity considering fundamental rights.

TRACK One: Biobanking without borders: Connecting biodiversity, medicine, and innovation

3A: Preserving biodiversity: Challenges and opportunities in non-human biobanking

OrganoZoo, CRB-Anim's new platform dedicated to organoids for domestic animals

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Topic: 3A: Preserving Biodiversity: Challenges and Opportunities in Non-human Biobanking

Presenter Name: Bertrand Pain

Keywords: BRC, Domestic animal, cryobanking, genetic resources, organoids

Organoids and complex 3D cell models are rapidly developing tools for studying embryonic and tissue development, assessing the toxicity of certain molecules, mimicking hostpathogen interactions, etc. This development also responds to the need for new predictive *in vitro* models that reduce animal testing and comply with the 3Rs recommendations, as promoted in the EuroFAANG INFRA-DEV project (<https://eurofaang.eu/in-vitro-models-hub-2/>).

Collections of cell samples – primary, adult and pluripotent stem cells – have been developed at CRB-Anim (the animal pillar of the RARE Infrastructure, <https://agrobrc-rare.org>) for a growing number of domestic animal species: cattle, pigs, horses, rabbits, poultry,

Considering this potential, French research institutions (INRAE, ANSES, CIRAD, INSERM...) have set up the OrganoZoo Platform, to make available to the community a whole range of organoids for tissues such as the intestine, lung, mammary gland, brain, etc. Using standard protocols, sometimes adapted and specific, the different organoids are now obtained, processed as needed and analyzed using imaging and omics approaches. Advances in the annotation of domestic animal genomes (<https://data.faang.org/>) provide a whole set of

markers and genes expressed specifically in these 3D structures. Among others, recent achievements by infecting bovine lung organoids with mycoplasmas, chicken skin equivalents with Marek's disease virus (MDV) and equine brain organoids with herpesvirus (EHV-1) demonstrate the value of these models in studies of host-pathogen interactions.

This new platform is open to European collaboration, particularly in the frame of the GenoPHEnix ESFRI proposal (<https://genophenix-ri.eu>).

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Marine cryopreservation across scales: from microbial communities to multicellular organisms

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Topic: 3A: Preserving Biodiversity: Challenges and Opportunities in Non-human Biobanking

Presenter Name: Michele Grego

Keywords: 16S/18S metabarcoding, Cryopreservation, Marine biobanking, Microbial communities

Cryopreservation is widely used in biological research and is now increasingly applied beyond single cells and simple cultures to include complex microbial communities and multicellular marine organisms.

At the Roscoff Culture Collection (RCC), one of the world's largest public collections of marine biological resources, cryopreservation is used to ensure long-term storage and access to marine biological samples. Over the past 15 years, the RCC has developed an integrated cryopreservation program and has successfully cryopreserved more than 4,000 of its approximately 10,000 strains, covering a wide range of taxa such as green algae, haptophytes, stramenopiles and cyanobacteria. Cryopreservation protocols have also been adapted for algal viruses, seaweeds (both gametophytes and sporophytes) and a variety of marine parasites that infect algae and invertebrates. More recently, these efforts have expanded to include the cryopreservation of marine invertebrate gametes and embryos.

In parallel, and within the framework of the MICROBE project (<https://www.microbeproject.eu/>), the RCC is developing novel approaches to cryopreserve

complex microbial communities from marine environmental samples. Unlike single-strain preservation, maintaining entire communities poses specific challenges relating to retaining taxonomic structure and functional diversity after revival. By using combinations of cryoprotective agents and optimised cell concentration protocols, we have developed methods that enable the cryopreservation of microbial communities from millimetric volumes of seawater. We assess community composition before and after cryopreservation using 16S and 18S rDNA amplicon sequencing, which allows us to evaluate the preservation of bacterial and eukaryotic diversity.

Together, these developments show how non-human biobanks support marine biodiversity preservation and long-term research access.

MIRRI.IT - A NATIONAL GATEWAY TO MICROBIAL BIODIVERSITY, SCIENTIFIC EXCELLENCE AND SUSTAINABLE INNOVATION

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Topic: 3A: Preserving Biodiversity: Challenges and Opportunities in Non-human Biobanking

Presenter Name: Rosario Musumeci

Keywords: Microbial biodiversity, bacteria, filamentous fungi, microalgae, microbiomes, viruses, yeasts

Introduction:

Microorganisms are the hidden engines of our planet: even though they are often reported only when they act as pathogens, their diversity

sustains life, shapes ecosystems, drives nutrient cycles, protects plants, enhances food production, and opens the door to new biotechnologies.

MIRRI-IT brings together the microbial expertise, resources, and facilities of Italy's research landscape to support science, industry, and society.

Material & methods:

MIRRI-IT is the Italian node of MIRRI-ERIC, the European Microbial Resource Research Infrastructure. The network includes 30 institutions, preserving, characterising and making accessible more than 100,000 microbial strains, including (cyano)bacteria, filamentous fungi, yeasts, microalgae, viruses and microbiomes from human clinical samples, as well as veterinary, plant, food and environmental sources.

All high-quality microbial resources are accompanied by metadata, standardised procedures, and a strong scientific and technological background that support research and biotechnological innovation, including diagnostics and industrial use, through growing expertise in culturomics, molecular/phenotypic characterisation, genomics, metagenomics, optimised long-term preservation and quality-control protocols.

Results:

MIRRI-IT harmonises and strengthens Italy's microbial biobanks through analytical/technological services, shared standards, interoperable procedures, quality assurance, advanced training courses, support for regulatory compliance (Nagoya,

biosafety/biosecurity) and a common access framework.

Discussion and conclusion:

All the researchers working in MIRRI.IT aim to strengthen Italy's microbial collections and research capacity, ensuring that microbial diversity is preserved, studied and translated into knowledge, tools and solutions capable of addressing today's health, environmental, societal, and economic challenges.

Moretti et al., 2024 - Treasures of Italian microbial culture collections: an overview of preserved biological resources, offered services and know-how, and management.

[Sustainability 2024, 16\(9\), 3777;](https://doi.org/10.3390/su16093777)
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5A: Building excellence: Developing skills for future biobanking

From Community Training to a European Learning Platform:

The Evolution of the BBMRI-ERIC Academy

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Topic: 5A: Building Excellence: Developing Skills for Future Biobanking

Presenter Name: Andrea Wutte

Keywords:

BBMRI-ERIC Academy, education, quality, training,

webinars **Introduction**

The health of humans, animals, plants, and ecosystems is closely linked. Delivering on the One Health paradigm requires technical professionals across biobanks who can connect science, infrastructure, and policy aspects. However, training for this workforce remains dispersed across different initiatives and countries, with limited visibility, coherence, and portability of skills.

Material and methods

BBMRI-ERIC is further developing its Academy through the stepwise implementation of a structured roadmap that builds on existing community expertise and training activities across National Nodes. Competence needs, role profiles, and practical training priorities identified in the EvolveBBMRI project together with practitioners form the basis for a competency-oriented, role-specific approach. Existing training offers were analysed, mapped, and gradually aligned within a common learning framework co-designed with the community.

Results

This process supports the consolidation of fragmented training efforts into modular, reusable learning assets and blended formats for the full spectrum of biobank professionals—from project managers and quality officers to technical staff handling samples and data, as well as researchers and data stewards. The BBMRI-ERIC Academy increases the visibility of training offers, enables clearer learning pathways across career

stages, and promotes recognition and transferability of skills through alignment with European frameworks, micro-credentials, and emerging digital identity mechanisms.

Discussion and conclusion

By progressively linking training offers with mobility opportunities and cross-domain exchange, the BBMRI-ERIC Academy is intended to foster collaboration across countries and disciplines. It is designed to contribute to greater coherence, sustainability, and future-ready capacity building for biobanking, biomedical research, health, and One Health across Europe.

From Sample Storage to the Motor of AI: The SUSA Living Lab Model for Future Skills

Authors:

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Topic: 5A: Building Excellence: Developing Skills for Future Biobanking

Presenter Name: Yulyana Kalesnik

Keywords: AI model, Living Lab, Precision medicine, SUSA, biomedicine, clinical data, skills building **Introduction**

Biobanking is transforming from sample storage to becoming the motor of AI and precision medicine. Hence, a significant skills gap arose in applying AI to real-world clinical data. This paper presents the SUSA project's "Living Lab" model. It is designed to train future employees capable of navigating the complex landscape between biobanking, medical informatics, and AI analytics.

Material & methods

We established a strategic interface between the University of Lodz Biobank and the Regional Centre for Digital Medicine at the Copernicus Memorial Hospital. In this environment, trainees act as junior R&D staff. The methodology is based on Experiential Learning and high-performance green computing. Trainees develop and retrain AI models and federated learning algorithms. Subsequently, these models are stress-tested against realworld clinical data, hence addressing critical issues of AI and data interoperability.

Results

The "Living Lab" approach is a bridge between theoretical algorithms and clinical reality. Trainees validate AI algorithms for genomic data curation and phenotyping within trusted research environments. This collaboration produces tangible educational outcomes, which goes beyond sample management - it builds curated "AI-ready" datasets and reliable models compliant with EHDS standards.

Discussion and conclusion

SUSA demonstrates that embedding AI training in the interface between the University and the hospital-based "Living Lab" is essential for skills building. By exposing trainees to the practical challenges of AI deployment we ensure that trainees are equipped to drive the next generation of biomedicine.

From Gaps to Growth: Ensuring the Future of Biobank Training in Europe (Oral Presentation).

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*Topic: 5A: Building Excellence: Developing Skills for
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*Felgenhauer Keywords: Analysis of training gaps GAP,
Competency matrix, Training on biobanks.*

Introduction:

Evolve-BBMRI is a Horizon European project designed to accelerate biobanking digitalisation, foster sustainable practices and strengthen the One Health approach across research infrastructures. Within this framework, **we focused on developing a coordinated and future-ready training framework for biobank professionals.** A systematic comparison of existing training offers with current and emerging competence requirements has been performed to ensure that workforce development keeps pace with scientific, regulatory, and technological advances in biobanking.

Materials & Methods:

To assess the current training landscape, we surveyed BBMRI-ERIC nodes to compile their training programmes. Based on these data, we developed a biobank-specific **competency matrix structured** into four areas: **Research ecosystem; Biobank thinking and operations; Governance, ethics and quality management; Professional and interpersonal skills.** Participants were then recontacted to indicate which of these competency areas were covered by their training offers. A subsequent gap analysis identified underrepresented topics, and a workshop with academic training coordinators from nine European countries validated and contextualised the findings.

Results and Conclusions

Based on 62 self-reported training programmes from eight countries, the gap analysis identified **green and sustainable biobanking, interoperability and advanced analytics/AI, One-Health integration, and strategic-skills** such as funding and performance monitoring as underrepresented training topics within the BBMRI community. Additional training needs emerged in the workshop, including **pre-analytics** and **EHDS data governance**. Through a structured approach combining a competency matrix, training catalogue, gap analysis, and academic validation, **this project supports coordinated training pathways** within **BBMRI-ERIC** and **strengthens long-term staff capacity**, turning current gaps into **opportunities for growth, collaboration**, and a more **adaptable biobanking community**

Bridging the Gap: Transforming a Hospital Biobank into a Multidisciplinary Hub for the Clinical Research Spectrum

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Topic: 5A: Building Excellence: Developing Skills for Future Biobanking

Presenter Name: Edith Rubin

Keywords: Academic

Introduction: Since the 2008 Belgian regulatory shift, hospital-based biobanks have transitioned from passive repositories into active clinical facilitators. Our facility has navigated a unique institutional journey—moving from the Cancer Department to the Anatomopathology service and, finally, in 2021, to the SOHO Department. This abstract describes how we streamlined the pathway for investigators to move from hospital-based collection to advanced research applications.

Material & Methods: Since 2021, we have optimized our strategic partnership between the Biobank and the CTC to harmonize procurement with legal standards. In 2024, we extended this partnership to the academic biobank at Université catholique de Louvain (UCLouvain) to simplify organizational processes. To facilitate seamless electronic data and sample transfers, we are currently implementing a shared Laboratory Information Management System (LIMS).

Infrastructure upgrades include multi-array equipment and a digital request portal.

To drive the development of new treatments, we launched information sessions (concluding March 2026) regarding Advanced Therapy Medicinal Products (ATMPs).

Results: The SOHO integration expanded our research scope, and the transition to a shared LIMS is set to significantly reduce administrative burden and technical errors during transfers. Our partnerships have substantially lowered the bureaucratic hurdles required to initiate research and coordinate SOHO procurement.

Discussion and Conclusion: Our evolution proves that a hospital biobank's value lies in its role as a hub for the entire research spectrum. By integrating expertise (academic, pathology,..), shared digital infrastructure, and investigator information sessions, we have removed systemic barriers, effectively opening the door to the next generation of therapies directly within the clinical environment.

Improvement of biobank biospecimen packing and shipping by specific training efforts

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Keywords: Packing, proficiency test, shipping, webinar

The German Biobank Network (GBN) regularly conducts training and education sessions for its biobank members. Surveys are used to review the success of these sessions and appropriate proficiency test programs assess the implementation of the principles conveyed.

Here we present the results of an educational webinar about regulations, guidelines and best practices for the packing and shipping of biological samples. The webinar was followed by surveys, and a proficiency test.

The results of this proficiency test indicated better performance in packing and shipping among biobanks that participated in the webinar compared to those that did not.

These findings underscore the importance of targeted training programs in strengthening quality standards and promoting best practices in biobanking.

6a: Biobanks as local hubs: Interfaces and facilitators

Biobank as a platform for preventive healthcare and innovation

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Topic: 6A: Biobanks as Local Hubs: Interfaces and Facilitators

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Keywords: HIAAS, data-ecosystem, hub, innovation, interface, platform, prevention

Biobank as a Platform for Preventive Healthcare and Innovation

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Introduction

Biobanks are shifting from passive repositories to active hubs linking citizens, healthcare, research, and innovation. Helsinki Biobank is developing a secure, interoperable, GDPR-compliant platform that advances preventive healthcare and data-driven discovery. Leveraging Finland's nationwide electronic health records, population-scale biobanks, and genomic resources such as FinnGen, the platform creates seamless interfaces between participants, clinicians, industry, and translational research environments.

Methods

The platform supports three core functions: (1) citizen-facing services for personalised disease-risk prediction and preventive recommendations; (2) smart cohort formation and pre-screening tools that improve clinical trial

recruitment; and (3) integration of longitudinal biobank data with emerging healthcare innovations and digital services. These capabilities position the biobank as a connector between citizens, real-world clinical data, and population-level research assets. A pilot is being implemented within the Helsinki Biobank ecosystem and scaled nationally, with design adaptability for biobanks across Europe. The initiative also supports an EHDS-aligned “prevention-as-a-platform” model enabling interoperable, cross-border preventive services anchored in biobank infrastructures.

Results and Discussion

Results include integrated data flows combining participant-generated MyData, multi-omics risk modelling, ethical return of results, health-economic evaluation, and governance ensuring trust and scalability. Expected outcomes include reduced preventable morbidity, improved equity, and exportable services such as Health-Informatics-as-a-Service, validated biomarker algorithms, white-label portals, and secure data-ecosystem solutions. The platform positions Finland as a leader in ethical, scalable, biobank-enabled precision prevention.

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Empowering Biobanks as Local Hubs in a National Cancer Research Infrastructure

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Keywords: Biobank, Network, Oncology, Research Infrastructure, Translational

Biobanks are evolving from local repositories into active networks with the shared goal of connecting biological samples, clinical data, and research communities. While large multicenter research networks are highly effective in conducting scientific projects, the secondary use of biospecimens generated within these structures is often insufficiently addressed. The BioDataHub (BDH) supports principal investigators by enabling the sustainable provision and reuse of high-quality biospecimens for research.

Within the German Cancer Consortium (DKTK), BDH coordinates the identification, structuring, and operationalization of highly annotated oncological cohorts and biobank resources across multiple sites. Key activities include systematic cohort surveys, cohort-specific inventories, definition of minimal datasets and access conditions, and integration into national and European visibility platforms such as BBMRI-ERIC and federated exploration tools. Validation loops between IT teams and local biobanks ensure realistic assessment of sample availability. Complementary on-site training and governance development are conducted in collaboration with local sites and the National Center for Tumor Diseases (NCT).

This approach establishes biobanks as transparent access points that facilitate

interaction between researchers, clinicians, and IT infrastructures. Cohorts and jointly funded collections become searchable, comparable, and accessible across the network, while standardized workflows reduce barriers to sample and data reuse. Local biobanks are strengthened in their role as operational hubs, maintaining site-specific expertise while enabling cross-site collaboration. Numerous research projects have already been supported through structured biospecimen provision.

Positioning biobanks as active facilitators enhances their impact within translational research ecosystems. The BDH framework provides transferable strategies for multi-center research infrastructures aiming to improve collaboration, efficiency, and innovation.

The BBMRI-ERIC Negotiator: A Generic Platform for Federated Data, Sample and Service Access Management

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Keywords: Access Negotiation, Access Request, Data, Federation, Samples

Access to sensitive biomedical data and samples in federated research infrastructures requires transparent, traceable, and legally compliant processes. Additionally requesting access to services provided by Biobanks and Biomolecular research infrastructures is becoming more important to facilitate trans-national research cooperation. Historically, access procedures have been fragmented, project-specific, and difficult to

scale across networks and domains and beyond national provisioning.

The BBMRI-ERIC Negotiator [1] was initially developed to support access requests within the BBMRI-ERIC biobank network. It has since evolved into a generic, configurable platform for managing access to data and biological samples across heterogeneous federated infrastructures. The system supports structured access requests, multi-party review workflows, status tracking, and secure communication between requesters and collection and data holders and service providers. This is done while remaining agnostic to underlying data models and governance frameworks for specific needs of the research infrastructures and service providers.

The BBMRI-ERIC Negotiator [1] is now deployed beyond BBMRI-ERIC in multiple European research initiatives, including canSERV [2], EUCAIM [3], ISIDORE [4] and UNCAN.eu [5]. These deployments demonstrate its adaptability to diverse governance requirements, access policies, and organisational structures, while providing a consistent user experience for researchers and resource providers.

By decoupling access management from specific domains or infrastructures, the BBMRIERIC Negotiator enables scalable, reusable, and sustainable access support across federated health research ecosystems. Its adoption in multiple large-scale initiatives highlights its role as a shared European service for trustworthy access management.

The architecture of the BBMRI.at National Node Biobank Data Communication Platform

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*Keywords: automation, biobanks, data communication,
software architecture*

Introduction: As part of the BBMRI.at project we analyzed the current biobank IT landscape at Austrian BBMRI Node biobanks and the requirements for automated data transfer for current BBMRI-ERIC tools. Based on this analysis, we established architecture of BBMRI.at National Node Biobank Data Communication Platform (Biobank Hub), which is currently under development.

Methods: The proposed architecture was developed based on the analysis of requirements for both current biobank IT systems and BBMRI-ERIC tools (Directory, Negotiator and the Federated Platform). The analysis methodology combined qualitative data collection from a questionnaire, follow-up interviews, and workshops with structured comparative analysis.

Results: The Biobank Hub is designed as a centrally operated automation layer at the BBMRI.at National Node (Medical University of Innsbruck), responsible for: automated acquisition and harmonization of data from partner biobanks' LIMS / BIMS / HIS systems, validated preparation and delivery of Directory metadata and Negotiator interactions, coordination and quality assurance for Federated Platform (Locator) aggregates; and maintaining a single authoritative data model aligned with MIABIS.

The Hub makes use of the Health Data Research Hub infrastructure at the Medical University of

Innsbruck and builds upon the same data model originally used in the BBMRI.at Biobank Editor but focuses on automation rather than manual editing. The new Hub user interface provides monitoring and quality-assurance functions and will later form the basis of a unified interface framework towards an EHDS compliant infrastructure.

Discussion: The established architecture will serve as a basis for the implementation of the Biobank Hub software, ensuring interoperability and automated data exchange.

Biobanks as Local Hubs: Interfaces and Facilitators – The Role of BBMRI.CZ in the Czech Republic

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*Topic: 6A: Biobanks as Local Hubs: Interfaces and
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Keywords: , BBMRI.CZ, local hub, national biobanks

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Biobanks increasingly function as local and national hubs that connect biological resources, data, expertise, and stakeholders across the biomedical research ecosystem. In the Czech Republic, this role is fulfilled by BBMRI.CZ, the national node of the Biobanking and Biomolecular Resources Research Infrastructure – European Research Infrastructure Consortium (BBMRI-ERIC). BBMRI.CZ integrates a network of hospital-based and research biobanks and provides a coordinated framework that facilitates access to high-quality biological samples and associated data for both national and international research.

As a local hub, BBMRI.CZ serves as an interface between clinical practice, academic research, and technological platforms. It supports the harmonization of biobanking processes, implementation of quality management systems, and adoption of common ethical, legal, and societal standards in line with European guidelines. Through centralized services, BBMRI.CZ simplifies communication between sample providers and users, increases transparency of available resources, and enhances interoperability with other European infrastructures.

BBMRI.CZ also acts as a facilitator of collaboration by fostering education, training, and knowledge exchange among biobank personnel, researchers, and clinicians. Its activities contribute to capacity building, sustainability of biobanks, and integration of biobanking into translational and personalized medicine initiatives. BBMRI.CZ strengthens the Czech Republic's participation in international research projects by enabling efficient cross-border access to samples and data.

In conclusion, BBMRI.CZ demonstrates how biobanks can operate as effective local hubs, bridging disciplines and institutions while aligning national biobanking activities with the broader European research landscape. Judita Kinkorová kinkorovaj@fnplzen.cz

8A: Unlocking health insights from donated human tissues

Building Humangenom Austria: The Interplay of Ethical, Data, and Governance Dimensions

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Topic: 8A: Unlocking Health Insights from Donated Human Tissues

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Keywords: ELSI, donation, genomics, governance

Humangenom Austria (HG-AT) is coordinated by the Medical University of Innsbruck and aims to accelerate the integration of clinical, genetic and genomic data into healthcare and research in Austria. By connecting Austrian academic institutions, medical centers, and national research initiatives, HG-AT is establishing a coordinated infrastructure for genome analysis that includes state-of-the-art sequencing pipelines, a national reference variant database, and a comprehensive network of sequencing platforms. Through three thematic use cases—(1) establishing a national cohort of fully genotyped Austrian residents, (2) creating a coordinated network for genomic rare disease diagnostics across Austria's six Centres for Medical Genetics, and (3) advancing genome sequencing in tumor diagnosis and treatment—HG-AT seeks to strengthen precision medicine, improve rare disease diagnostics, and enhance cancer care.

Beyond the establishment of sequencing infrastructures, computational capacities, and

integrated clinical databases, HG-AT's concept encompasses several foundational components, including a participatory communication platform designed to ensure transparency and the responsible return of results towards study participants. It builds on broad consent for secondary data use and the establishment of a cohort of participants who can be re-contacted for follow-up studies. Ultimately, this endeavor requires a robust governance framework for ethics, data management, and communication, as well as the capacity to address persistent structural gaps, in order to enable effective design, implementation, and sustained operation—particularly given the interdependent ethical, technological, and operational complexities.

The Netherlands Brain Bank: An open-access platform for brain tissue and integrated health data

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Keywords: Brain tissue, Data integration, Donor Program

Introduction – The Netherlands Brain Bank (NBB; www.brainbank.nl) is a professional brain biobank with extensive prospective donor programs that provides brain tissue for openaccess research worldwide.

Results – Annually, the NBB performs up to 150 autopsies with short post-mortem delays (mean 6.5 h) from donors who provided informed consent for the use of their brain tissue and clinical data for research. Since its establishment in 1985, the NBB has distributed tissue from more than 5,300 autopsies of donors with neurological and psychiatric disorders, as well as controls, to over 1,500 research projects worldwide, resulting in more than 140 scientific publications annually. The NBB currently has over 5,300 registered donors, including participants recruited through dedicated donor programs for multiple sclerosis (NBB-MS), psychiatric disorders (NBB-Psy), and myalgic encephalomyelitis/chronic fatigue syndrome (NBB-ME/CFS).

In 2022, the NBB initiated the Netherlands Neurogenetics Database, integrating detailed clinical, neuropathological, and genetic data from all donors. Medical record summaries and neuropathological assessments from over 3,000 donors have been transformed into standardized clinical signs, symptoms, and neuropathological traits using large language models. In parallel, the NBB is piloting artificial intelligence-based prediction models to support neuropathological assessments.

Conclusions – Through its long-standing donor programs, high-quality tissue collection, and innovative use of data integration and artificial intelligence, the NBB provides a unique and continuously evolving infrastructure that accelerates neuroscience research and advances the understanding of neurological and psychiatric diseases.

The "FMT in UC" microbe and host biorepository

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Topic: 8A: Unlocking Health Insights from Donated Human Tissues

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Keywords: Fecal Microbiota Transplantation

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Introduction

Fecal Microbiota Transplantation (FMT) is an efficient therapy for recurrent *Clostridioides difficile* infection, but also holds promise in the treatment of inflammatory bowel disease, like ulcerative colitis (UC) and other complaints. From an ecological perspective, FMT seeks to restore a homeostasis to a disturbed host-microbiome.

Methods

Our translational study group in Graz has gathered huge expertise in the treatment of patients experiencing therapy refractory chronic active UC, an end-stage disease condition, with repeated FMTs. Accompanying this study is a huge biorepository consisting of donor and recipient stools, gut biopsies of patients as well as other biospecimens (e.g. urine, plasma) for omics analyses.

Results

About 1/3 of these patients are experiencing remission of the disease, wherein other therapies are currently failing. Several molecular microbial (e.g. taxa associated with response) and host (e.g. mucosal transcriptome) features were identified which might explain the efficacy of this therapy.

Conclusion

This biorepository is used to investigate the principles governing healing induction in UC via FMT but also use this resource to identify and isolate beneficial microbes out of donor stools which can be exploited as biotherapies (i.e. "modern probiotics") in future.

References:

<https://doi.org/10.1016/j.xcrm>

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4387

Tissue Biobanking: Interface Requirements for High-Quality Support for Biomedical Research

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Topic: 8A: Unlocking Health Insights from Donated Human Tissues

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Keywords: Biobanking, Biosamples, ISO 20387, Interfaces, Quality management, Tissue processing

Human tissue biobanks are essential infrastructures for biomedical and translational research, particularly in precision medicine. The scientific validity and reproducibility of tissue-based research depend on consistently high-quality samples and data. However, heterogeneous organisational structures, non-standardised workflows, and fragmented IT systems impede efficient tissue management, ethical governance, and data integration. Harmonising interfaces between biobanks, pathology departments, clinical units, and researchers is therefore critical to ensuring responsible use and maximal research value of donated tissues.

This work is based on a systematic analysis of tissue biobanking workflows conducted by the Tissue Working Group of the German Biobank Network (GBN). Key interfaces were identified across sample selection, tissue processing, storage, distribution, and data management. Relevant national and international guidelines, including ISO 20387 and related standards, were reviewed. Challenges and best practice examples were collected from 13 academic biobank sites representing German university medical faculties.

Critical ethical, technical, and logistical interfaces were identified that determine tissue and data quality throughout the biobanking lifecycle. Minimum standards were defined for consent management, handling of residual diagnostic tissues, collaboration with Institutes of Pathology, documentation of pre-analytical variables, and secure data integration. Clearly defined responsibilities, harmonised procedures,

and interoperable digital infrastructures were shown to improve sample availability, regulatory compliance, and research reproducibility.

Standardising interfaces in tissue biobanking facilitates ethically sound governance, responsible data sharing and increased trust between donors, clinicians, and researchers. The recommendations presented provide practical guidance on implementing and documenting minimum standards, supporting sustainable biobanking infrastructures that advance biomedical research and deepen understanding of health and disease.

From Pathology to Precision Oncology: Patient-Derived Tumour and Normal Tissue Models as a Translational Interface

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Topic: 8A: Unlocking Health Insights from Donated Human Tissues

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Keywords: Three-dimensional patient-derived tissue models

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Introduction

Three-dimensional patient-derived tissue models are increasingly recognized as essential tools for bridging the gap between basic cancer research and clinical application. The Translational Tissue Engineering (TTE) group at the D&R Institute of Pathology, Medical University of Graz (BBMRI.at partner), focuses on the development of clinically relevant *ex vivo* models derived from fresh normal and tumour tissues. By integrating organoid technology with diagnostic pathology, we aim to recapitulate the architectural and functional complexity of human tissues to better understand tumour progression, metastasis, and therapy resistance.

Materials & Methods

Fresh surgical samples from normal and neoplastic tissue are processed immediately after surgical resection and pathological assessment. Tissue dissociation, three-dimensional organoid culture, and standardized quality control procedures are used. Tumour cells, stromal components, and matching normal cells obtained from patients are expanded and cryopreserved within the YouCell platform. Selected healthy cells are reprogrammed into induced pluripotent

stem cells (iPSCs) to create autologous comparative models. Tumor characterization included histopathology, immunohistochemistry, genomic profiling, and functional drug response assays.

Results

We successfully established paired tumour-normal models preserving histomorphology, key molecular signatures, and interpatient heterogeneity. Integration of stromal co-culture models enabled functional assessment of microenvironment-driven resistance mechanisms. The linkage of cell models with standardized patient anamnesis and a centralized database infrastructure allowed correlation of clinical parameters with experimental outcomes. Standardized workflows ensured reproducibility, high data quality, and long-term biobanking of patient-specific cell material.

Discussion/Conclusion

The combined TTE–YouCell platform provides a robust translational framework for mechanistic studies, preclinical drug testing, and personalized therapeutic strategies. By linking pathology-driven tissue acquisition with advanced 3D modelling and industry collaboration, we accelerate the transfer of innovative organoid technologies into precision oncology and clinical application.

11A: Inside the biobank – Organisational structures, strategies and success stories

Biobanking as a Catalyst for Precision Oncology and Health Equity in Sub-Saharan Africa

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Abstract ID: 689

Topic: 11A: Inside the Biobank: Organisational Structures, Strategies, and Success Stories

Presenter Name: Lina Winter

Keywords: Biobanking; precision oncology; global health; equity; sub-Saharan Africa

Background: Cancer incidence and mortality in sub-Saharan Africa (SSA) are expected to increase significantly over the coming decades. Although African populations have the highest genetic diversity worldwide, they remain

underrepresented in biomedical research. This gap limits biomarker discovery, constrains transferability of precision oncology approaches, and maintains global health inequities. To address these challenges, the Malian-German Network was established to promote equitable research in SSA. Methods: Based on a Delphi process involving 11 experts from three countries, we determined research-relevant foci of current biobanking in SSA and combined this with insights from a Malian-German biobanking partnership. The collaboration aims to harmonize biospecimen collection with a context-adapted shared minimal dataset, standardize preanalytical workflows, and allow ethically governed sample and data exchange. Results: Our analysis demonstrates that biobanking initiatives in SSA have expanded in recent years. Precision oncology was identified as a highly relevant research focus. However, biobanking continues to face structural challenges, including limited infrastructure, unstable funding, and heterogeneous regulatory frameworks. The Malian-German Network illustrates how equitable North-South collaboration can address these barriers by strengthening local expertise, harmonizing minimal datasets, and embedding biobanking within translational oncology research. Conclusion: Sustainable, locally governed biobanking infrastructures are fundamental to integrate African biospecimens and data into international research and clinical translation. Consequently, biobanking in SSA should be regarded as a strategic investment in precision oncology and global health rather than a purely technical service. Equitable biobanking partnerships are essential to close the North-South gap in cancer research and to enable precision oncology without borders.

Biobanking to complement the HANSE study for holistic lung cancer screening in northern Germany

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Abstract ID: 625

Topic: 11A: Inside the Biobank: Organisational Structures, Strategies, and Success Stories

Presenter Name: Gaede KI

ords: Biobanking, Clinical Study, HANSE Study, Oncology

Introduction

The HANSE study was designed as holistic lung cancer screening study in northern Germany to answer pressing questions for a successful implementation of an effective German lung cancer screening program.

Material and Methods

Former and current smokers aged 55–79 years were assessed for their lung cancer risk by the NELSON and PLCO_{M2012} risk scores (1). 5192 high-risk participants whereas 7100 low-risk participants serve as controls. All participants will be followed-up for up to 10 years at the MHH, the LungenClinic Grosshansdorf and the UKSH, Campus Lübeck. All sites are part of the DZL. Funding: DZL, Astra Zeneca and Fritz Behrens Stiftung.

Results

Although the primary purpose of this study is to implement an effective German lung cancer radiological screening program, complementing this with biobanking offers unique opportunities to identify biomarkers for early detection of lung cancer in blood, as well as supporting research projects at the DZL. To this end, BMB Nord and the HUB, both funded by the DZL, offered HANSE participants the DLZ Broad Consent. So far SOP-based blood samples from baseline, after 1 and 4 years are now available to science upon request.

Conclusion

The HANSE study rich data set (clinical and socioeconomic parameters, low-dose chest CT

imaging) combined with supplementary biobanking, provides invaluable resources for future research. This project demonstrates how cooperation between clinics, study centers and biobanks can provide a platform for outstanding research. To date, nine research projects have been supported through this platform.

References

(1) Vogel-Claussen J et al, Rofo. 2022. doi: 10.1055/a-1853-8291.

Flexibility in Biobanking: Balancing Collections on Demand and Retrospective Use

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Abstract ID: 605

Topic: 11A: Inside the Biobank: Organisational Structures, Strategies, and Success Stories

Presenter Name: Monika Valjan

Keywords: clinical research, flexible, innovative, on demand, retrospective, samples

Introduction

Biobanking has evolved from a static model of sample collection and storage into a dynamic framework that addresses specific research needs. We compare two distinct biobanking projects and their respective options, the innovative "Biobanking on Demand" approach utilized in the DIOPTRA project (<https://dioptra-project.eu/>) and the retrospective sample collection from the Multiplex project. This comparison aims to highlight the advancements and challenges in biobanking methodologies, particularly in relation to specific research requirements and sample availability.

Material & Methods

We compared Biobanking on Demand, as seen in the DIOPTRA project and the retrospective use of samples from the Multiplex project. The Multiplex initiative involved 399 breast cancer patients, resulting in 3528 FFPE blocks, supported by extensive clinical and pathological data. For the DIOPTRA project, so far 55 fresh frozen tissue samples and 120 serum and plasma samples have been provided.

Results

The DIOPTRA project underscored the necessity for flexible sample availability, while the Multiplex project demonstrated successful integration of retrospective sample retrieval and use to enhance research outcomes. Collaborative efforts with Biobank Graz (BBMRI.at partner) played a key role in both projects.

Discussion and Conclusion

This work advocates for biobanks to adopt a flexible structure that accommodates both

immediate and retrospective research needs. By balancing these approaches, biobanks can significantly enhance their utility in clinical research, ultimately facilitating advancements in personalized medicine.

Accredited, but Resilient? Leading an ISO 20387 Biobank through ISO 22301 Integration in Uncertain Times

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Abstract ID: 634

Topic: 11A: Inside the Biobank: Organisational Structures, Strategies, and Success Stories

Presenter Name: Agnieszka Matera-Witkiewicz

Keywords: ISO 20387, ISO 22301, business continuity, integration, leadership, quality, resilience, security

Introduction:The current geopolitical landscape, marked by conflicts, economic instability, cyber threats, and global health crises, challenges organizational stability worldwide. Biobanks as critical infrastructures for biomedical research and healthcare, are particularly vulnerable to operational instability, which can compromise sample integrity, data reliability and public trust. While ISO 20387 accreditation ensures quality, competences, and governance it doesn't fully address continuity plan facing external disruptions.

Materials and Methods:Systematic review of biobank management, ISO20387 implementation reports, and ISO22301 business continuity frameworks was conducted. Integration strategies were analyzed by mapping ISO 22301 requirements into existing ISO20387 processes, assessing governance alignment, risk management practices, documentation overlap, and staff training programs.

Results:The analysis revealed that ISO 22301 can be efficiently integrated into ISO 20387 accredited biobanks by leveraging existing quality management systems, aligning leadership roles, and using shared risk and audit frameworks. Key success factors include structured continuity planning, scenario-based exercises, and embedding recovery objectives into routine operational procedures. Integrated systems improve preparedness for supply chain failures, IT outages, and emergency scenarios, while maintaining accreditation compliance.

Conclusions:Integration enhances biobank resilience without duplicating processes. Organizations benefit from a unified approach combining quality, compliance, and continuity, allowing leaders to maintain operational functionality under uncertainty. This offers a practical model for other biobanks aiming to strengthen regulatory adherence and operational robustness.

This work is supported by Grant from the Medical Research Agency ABM.D250.24.001.

1.ISO 20387:2018 Biotechnology—Biobanking—General requirements for biobanking.

2.ISO 22301:2019 Security and resilience— Business continuity management systemsRequirements.

3.Sampers, I.etal., *Biobank Resilience and Risk Management in the 21st Century*, Biopreservation and Biobanking, 2021

Time to First Use of Biobank Samples: A Retrospective Analysis of Collection Types and Sample Materials in a Hospital-Based Biobank

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Topic: 11A: Inside the Biobank: Organisational Structures, Strategies, and Success Stories

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Keywords: aliquot patterns, biobank utilization, prospective biobanking, sample management, storage time

Introduction: Biobanks collect biological material prospectively without detailed knowledge of future research needs. The relationship between collection strategy and actual utilization remains poorly documented, yet understanding usage patterns is critical for resource allocation and planning.

Material & Methods: Retrospective analysis of metadata for all submissions (patient sample set per timepoint) deposited in pre-pandemic 2019 (n=13,666 from 56 collections) at BBMRI.at partner MedUni Wien Biobank. Time from storage to first request, stratified by sample type (serum, citrate plasma, lithium heparin plasma, EDTA whole blood, DNA/whole blood, urine, faeces, CSF, PAXgene, punctate) and collection type (prospective collections/cohorts vs. dedicated studies), were analyzed. Utilization rates were calculated as percentage of deposited submissions accessed per collection.

Results: Of 56 collections, 31 (55%) supported research projects with 3,466 submissions accessed. Among utilized collections, 21/35 were prospective cohorts and 9/21 were dedicated studies. Utilization rates varied substantially (median 54.2%, Q1-Q3: 25.2-93.1%, range 1.2-100%). Median time to first use was 926 days

(Q1-Q3: 438-1,5730, range: 2-2,514). Faeces showed fastest utilization (132 days median). Aliquot requests per submission varied by material: for all materials except for citrate (median 2 aliquots) and lithium heparin plasma (5), a median of one aliquot per sample was distributed. Serum was most frequently requested (24/31 projects). Six material types showed no demand: buffy coat, ccfDNA, double-centrifuged citrate plasma, and saliva.

Discussion and Conclusion: Within 6-7 years, 55% of collections were accessed with a median submission utilization of 54.2%. Material-specific patterns in timing and aliquot requirements provide evidence-based guidance for optimizing collection protocols and resource allocation.

TRACK Two: Ethics, regulation and digital innovation: Navigating the future of biobanking

3B: The EHDS unveiled: Latest developments and national perspectives EHDS and secondary use of data from biobanks – Czech perspective

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Topic: 3B: The EHDS Unveiled: Latest Developments and National Perspectives

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Keywords: European Health Data Space, biobank data, secondary use

Regulation (EU) 2025/327 on the European Health Data Space (EHDS) came into force in March 2025. The ambitious aim of EHDS is to establish, from March 2029, a transparent and secure process for secondary use of electronic health data within the EU, based on authorization issued by Health Data Access Body (HDAB) at request of eligible entity.

One of key principles introduced by EHDS is opt-out. Under this principle, secondary use of personal electronic health data is possible unless the data subject has expressed their objection. Although EHDS does not regulate the use of samples, regulation will certainly have an impact on biobanking, especially in view of anticipated growth of storing genetic and omics data obtained from samples or whole slide images data.

We would like to focus on possible influence of EHDS on biobanking. Does EHDS bring more opportunities or threats? Could EHDS opt-out system erode current system where samples and data are largely used for research based on and in compliance with donor's consent? What role can biobanks play in EHDS governance?

Member states may introduce stricter measures and additional safeguards for secondary use of certain sensitive data including biobank, genetic or omics data. These may include opt-in principle, obligatory approval of biobank or ethics committee. Should member states introduce such measures or should they refrain as they could lead to renewed legal fragmentation within EU? In our presentation we will focus on above-mentioned topics as well as on related legal

environment in Czech Republic and interplay with other EU laws.

Dutch law on (human) biological material

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*Topic: 3B: The EHDS Unveiled: Latest Developments and
National Perspectives*

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*Keywords: consent register, human biological material,
secondary use*

There is lack of awareness among the Dutch public that human (residual) biological material can be preserved for research and innovation. The current regulatory system appears to be inadequate in practice; regulations regarding the storage and use of biological material are spread across various laws and regulations.

In 2021, the first version of the now proposed law was submitted to Parliament by the Ministry of Health, Welfare and Sport. For research a distinction was made between extra collection of biological material, i.e. biobanking, and secondary use. These initial regulations regarding the collection, management and provision of biological material for (consented) biobanking closely resemble current practice as developed with and by the Dutch biobank community. However, these regulations lacked concreteness and coherence regarding secondary use of biological material. The collaborating representatives of national stakeholders have

sent a letter to Members of Parliament containing their greatest concerns with suggestions for adaptations. This resulted in 2024 in a second note of changes by the Ministry whereby the adapted proposed law is more aligned with stakeholders concerns and the European Health Data Space (EHDS).

The proposed law will be introduced in the Netherlands at the same time as the EHDS. In the meantime, the national stakeholders continue to discuss with the Ministry and Members of Parliament the need to work on integrated sectoral legislation and regulations and the establishment of a national consent register. Furthermore, the discussion focuses on consent and individual unexpected clinical findings plus the handling of long-living cell lines and organoids.

The CANDLE project -the 'what' and 'how' in developing the EHDS-compliant UNCAN.eu network of national cancer data nodes in member states across Europe

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*Topic: 3B: The EHDS Unveiled: Latest Developments and
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Presenter Name: Lifang Liu

*Keywords: CANDLE, EHDS, Nation Cancer Data Nodes,
Secondary data use*

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Introduction

The CANDLE project^[1] addresses fragmentation and variable data quality in cancer data infrastructures across Europe, which limits effective secondary use of health data for research, innovation, and policy. Regarding the European Health Data Space (EHDS), CANDLE aims to strengthen national and cross-border capacity for high-quality, interoperable, and FAIR cancer data. CANDLE is fundamental in the establishment of the **UNCAN.eu network of national cancer data nodes**.

Methods (the ‘how’)

CANDLE involves over 20 member states across Europe, six European Research Infrastructures and key EU-funded projects to deliver synergized digital assessments supporting the national oncology community, in a way serving as “super use cases” for secondary data use under the EHDS. CANDLE develops common operating principles, standards, and self-evaluation tools, supported by pilot use cases for NCDNs across participating countries. Work packages focus on capturing users’ needs, defining quality and interoperability requirements, implementing functional data infrastructure alignment with EHDS requirements, and reuse of existing European and national standards.

Results (the ‘what’)

CANDLE co-develops models tailored to the needs of the national oncology research community. Key outputs include a structured overview of national cancer data ecosystems, shared quality and interoperability frameworks, and practical tools to support implementation nationally. Pilot activities demonstrate improved consistency in data description, governance processes, and readiness for secondary data use.

CANDLE also delivers guidance for national coordination and integration with EHDS services.

Future perspectives

Results of CANDLE highlight the importance of national coordination mechanisms to reduce fragmentation and ensure sustainable alignment with EHDS, ultimately enabling the strong network of cancer data nodes in the UNCAN.eu federate research platform.

References

1. The CANDLE project receives funding from the European Union’s Horizon Europe program, project number 101214368

^[1] The CANDLE project receives funding from the European Union’s Horizon Europe program, project number 101214368

Preparing a national infrastructure for EHDS implementation: the Dutch approach

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Keywords: DCAT-AP, EHDS, HDAB, HealthDCAT, metadata, national catalogue, secondary use

BBMRI.nl as the Dutch node of BBMRI-ERIC, operates within Health-RI, national organization that is part of the consortium implementing the European Health Data Space (EHDS) in the Netherlands. Recently, Health-RI has developed key components in preparation for the EHDS, including a National Catalogue, a metadata model based on DCAT-AP and HealthDCAT-AP, and a request tool. Several targeted activities were undertaken to prepare for EHDS with a specific focus on biobank integration. These included a national HDAB-NL pilot, expansion of the metadata model, and exploration of approaches for mapping complex datasets, such as biobank data, to ensure rich, interoperable metadata.

In 2025, Health-RI officially released metadata model version 2, incorporating DCAT-AP NL and HealthDCAT-AP (draft version). Using this model, datasets from six out of seven Dutch academic medical centres were onboarded into the National Catalogue, alongside metadata from other major stakeholders such as the Netherlands Cancer Registry and the Netherlands Institute for Health Services Research. In parallel, a working group of data holders addressed the challenge of describing complex datasets, resulting in mappings to the v2 model and identifying requirements for model extension. Additionally, the HDAB-NL pilot end-to-end tested key EHDS processes, including metadata onboarding, data requesting, request handling, and data access via a secure processing environment. Substantial progress was made toward EHDS implementation and integration of complex data sources such as biobanks. Future work will focus on onboarding biobank data at scale, expanding the metadata model to meet

domain-specific needs, and establishing a fully operational national EHDS infrastructure.

5B: AI-enhanced biobank research: Integrating, analysing and advancing biomedical discovery

From Fragmentation to Findability: A Federated Service Finder for Research in Switzerland

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Topic: 5B: AI-Enhanced Biobank Research: Integrating, Analysing, and Advancing Biomedical Discovery

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Keywords: Biobanking infrastructure, Federated search, Research support services, Service discovery

Introduction

Hosted by the Swiss Academy of Medical Sciences (SAMS) on behalf of the State Secretariat for Education, Research and Innovation (SERI), the national Coordination Platform Clinical Research (CPCR) aims to strengthen institutional collaboration among key stakeholders in Swiss health and clinical research. CPCR supports joint initiatives and tool development to increase transparency, improve coordination, and optimize the use of resources in a highly fragmented research landscape.

Within this context, the CPCR Service Finder was developed to address persistent challenges faced

by researchers in identifying relevant support services across national research infrastructures.

Materials and Methods

Swiss Biobanking, the national BBMRI node, was mandated as technical lead for the development of the CPCR Service Finder. The tool implements a federated discovery approach combining AI-supported free-text search with contextual filters to help users identify services aligned with their research needs. As service descriptions are maintained independently by participating organizations, ensuring fair, transparent, and balanced ranking was a core design requirement. Safeguards were implemented to prevent optimization-driven bias and ensure equitable visibility across providers.

Results

User testing confirmed the robustness, usefulness, and perceived fairness of the Service Finder. The tool supports researchers, study coordinators, data managers, and biobank professionals at different stages of research projects, and feedback encouraged expansion of scope and onboarding of additional national service providers.

Discussion

This work demonstrates how federated search can enhance transparency and equitable access to services in complex European research ecosystems, while providing a reusable foundation for broader research resource discovery.

A Paradigm Shift in Disease Understanding: Leveraging Multi-Omics and Biobank Network Japan for Personalized Prevention

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Topic: 5B: AI-Enhanced Biobank Research: Integrating, Analysing, and Advancing Biomedical Discovery

Presenter Name: Soichi Ogishima

Keywords: Biobank cross-search system, Biobank network, Deep phenotyping, Disease redefinition,

Genomic medicine, Metadata standardization, Molecular mechanisms, Multi-omics data, Pathology trajectories, Personalized medicine

In Japan, the government has drawn up a health and medical strategy for genomic medicine as the national growth strategy, and research and development to realize genomic medicine utilizing biobanks is being promoted. We developed a network of 14 major biobanks and a

system for utilizing biospecimens and data that will facilitate research and development of genomic medicine in Japan. We then developed a biobank cross search system on biospecimen and data stored in our biobank network. Research institutions can find biospecimens and data they need for their research and development. To implement a crosssearch service for biospecimens and data, we standardized the metadata of biospecimen and data. Now our biobank network stores 1,900,000 biospecimen and 330,000 data provided by 700,000 donors. We also setup the web-based coordination system of fast access to biospecimen and data to meet the requests by academic/commercial users. Our biobank network provides essential infrastructures for different types of health research including basic medical science to accelerate progress towards personalized medicine. The paradigm of genomic medicine requires a fundamental shift in disease understanding, moving from traditional anatomy-based clinical phenotypes to classifications rooted in molecular mechanisms. We developed a methodology focusing on redefining disease concepts by analyzing pathology trajectories over time. By leveraging multi-omics data and comprehensive deep phenotyping, we enable the profiling of holistic disease states that account for comorbidities. This approach facilitates the transition from symptom-based observations to a mechanism-based understanding of disease, paving the way for precise diagnosis, drug repositioning, and personalized prevention.

6B: Secure, fair and smart: Best practices for biobank data integration

Negotiating Trust

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Topic: 6B: Secure, Fair and Smart: Best Practices for Biobank Data Integration

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Keywords: governance, innovation, potentiality, practice, trust

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Historically positioned at the intersection of healthcare and biomedical research, biobanks have evolved from relatively stable repositories of samples and associated data into complex, distributed, internationally connected infrastructures for large-scale data integration, reuse, and analysis. Throughout these transformations, biobanks have always depended on public trust, grounded in solid governance practices, regulatory compliance, public engagement as well as the potentiality of R&D. National health data strategies encourage AI-enabled biobanking, open data access, and the linkage with electronic health records to improve efficiency in patient care and support personalized medicine. At the same time, these transformations intensify concerns related to fairness, data governance, value distribution, and the risks of bias, exclusion, or discrimination embedded in datadriven systems.

Trust in data-driven biobanking is neither uniform nor guaranteed, but constantly negotiated across stakeholders, including policymakers, patient advocacy groups, researchers, and biobank professionals. While frameworks such as the FAIR

principles, for example, support technical trustworthiness, they are insufficient to address questions of fair access, accountability, and legitimacy, which depend on institutional practices. By examining tensions between efficiency, innovation, equity, and privacy, this talk will show why trust must be understood as an ongoing practice of governance rather than a purely technical achievement.

References

Mayrhofer MT. About the new significance and the contingent meaning of biological material and data in biobanks. *Hist Philos Life Sci.* (2013) 35:449–67.

Mayrhofer, MT. How the world of biobanking is changing with artificial intelligence, *Frontiers in Digital Health* (2025), Volume 7.

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Building a National Genomic Data Repository: Ethics and Governance by Design

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Topic: 6B: Secure, Fair and Smart: Best Practices for Biobank Data Integration

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Keywords: ELSI, federated data analysis, genomic data, governance, repository

Introduction

Genomic data repositories enable data reuse and federated research while raising important ethical and legal considerations due to the sensitivity of genomic information. Protecting donor rights, ensuring regulatory compliance, and maintaining public trust require governance frameworks that are embedded into repository design. We present an ethics-by-design approach for a national genomic data repository establishment that supports secure, transparent, and responsible federated data sharing.

Methods

The policy framework was developed through several rounds of moderated discussions involving key stakeholders: data producer, repository architect, data specialists, legal expert, and bioethicist. The bioethical perspective guided the alignment of legal and technical requirements with core ethical principles, including autonomy, proportionality, accountability, transparency, and ongoing oversight. The design of the Data Access Committee (DAC) and access procedures were informed by biobank operations and published literature.

Results

A three-level policy framework was established governing data deposition, access, and secondary use. For each level of the framework, standardized policy documents were drafted. The first policy defines the relationship between data producers and the repository. The second establishes the mandate, composition, and responsibilities of the DAC. The third specifies eligibility criteria for data access and outlines the technical and procedural implementation of approved requests.

Discussion and Conclusion

Integrating ethical governance and transparent operating conditions into repository workflows from the outset supports responsible innovation, strengthens stakeholder trust, and enables secure federated sharing of genomic data.

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A Cryptographic Framework for Secure Biobank Data Collaboration

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*Topic: 6B: Secure, Fair and Smart: Best Practices for
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Presenter Name: Ortner Philipp

Keywords: bio-

cybersecurity, biomedical data, data exchange, secure

biobank Introduction

As biobanks transition toward full datafication, the secure management of sensitive biomedical data across the BBMRI-ERIC network presents a critical challenge. While seamless data access is essential for medical innovation, robust cybersecurity measures are required to prevent privacy violations, data manipulation, and the loss of irreplaceable resources.

Material and Methods

The research conducted within EvolveBBMRI introduces a comprehensive cryptographic framework for the information-theoretic protection of sensitive biomedical data and secure inter-institutional exchange among BBMRI.at (Medical University of Graz), BBMRI.it, BBMRI.cy, and BBMRI-ERIC. The proposed solution utilizes Shamir's Secret Sharing, a cryptographic secret sharing scheme, within a distributed multi-cloud architecture to fragment data into cryptographic shares with a predefined reconstruction threshold. This approach effectively eliminates single points of failure. Even if a specific geographic node or cloud provider is compromised, the underlying data remains inaccessible to unauthorized actors.

To validate the cryptographic framework across international infrastructures, a custom Command-Line Interface (CLI) module was developed to measure key metrics including latency, throughput, and error rates in real time using a predefined test dataset. Comprehensive statistical analysis, including percentile distributions, confirms the system's reliability and reproducibility across diverse network conditions.

Results

Overall, the cryptographic framework provides a resilient foundation for secure, scalable data exchange within BBMRI-ERIC and beyond. The performance results demonstrate efficient data transfer and validate the system's practical viability for real-world deployment. **Conclusion**

This cryptographic framework ensures that sensitive biomedical data remains protected while still being accessible for vital scientific research.

From Local Management to Federated Networks: Resource Optimization and ETL Automation Using "a-smallfire", BBMRI-ERIC Federated Platform and eBiobank

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Keywords: Biobanking, ETL Automation, Federated Networks, GDPR, HL7 FHIR, Interoperability, MIABIS

Introduction

Modern biobanking strives to balance donor privacy with data exchange. The challenge is transforming heterogeneous datasets into HL7 FHIR® standards while ensuring GDPR compliance. We integrated the internal eBiobank system with the BBMRI-ERIC Federated Platform via a Bridgehead node to automate data flow.

Material & methods

We implemented a two-stage architecture. First, eBiobank (LIMS) assigns pseudonyms to securely link samples with data. For ETL, the Python-based "a-small-fire" toolkit was selected for its flexibility in custom mapping. Data was normalized to the MIABIS model, converted into FHIR JSON bundles, and shared via the Bridgehead node using Sampil.Beam middleware.

Results

The automated flow to the Blaze FHIR Store was validated, including quality control verifying inventory against records. The implementation ensures strict data residency; sensitive data remains local, and only anonymized, aggregated query results are shared.

Discussion and conclusion

"a-small-fire" enabled full automation and asset reorganization, optimizing transparency and sample storage. Open-source FHIR standards allow biobanks to securely join Big Data ecosystems, accelerating discovery and enabling sustainable development.

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From Data Discovery to Federated Analysis: Supporting the Research Journey

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Topic: 6B: Secure, Fair and Smart: Best Practices for Biobank Data Integration

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Keywords: Biobanks, Data catalogue, Federated data analysis, Metadata

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Introduction

Biobanks and cohort studies provide indispensable resources for health research. However, (multi-center) data and sample request

and access while keeping full access control with sample/data holders is not easy. In recent years, the MOLGENIS team therefore developed reusable infrastructure, in close collaboration with and for large infrastructures such as BBMRI-ERIC, and large multi-center studies, such as LifeCycle, EOSC4Cancer and large biobanks such as Lifelines. Here we report on a particular demonstrator, developed in BBMRI-ERIC lead 'Integrate Large Medical Cohorts' project (INTEGRATE-LMEDC).

Material & methods used to obtain and analyse the data

We integrated the existing MOLGENIS Catalogue, BBMRI-ERIC Directory, BBMRI-ERIC Negotiator, and MOLGENIS DataShield-Armadillo. MOLGENIS catalogue unites and sustains previously parallel cataloguing efforts into one extensible catalogue platform including open access EU health data catalogue. BBMRI-ERIC directory, also built on MOLGENIS, does the same for BBMRI samples. Negotiator enables access negotiation to more than 600 biobanks from the BBMRI-ERIC Directory and other discovery services. DataSHIELD enables federated analysis—where data is analyzed remotely without sharing individual-level data by sharing only model parameters or summary statistics which are not disclosive.

Results or findings from your work

We describe a user journey where:

- I. The researcher finds data in [MOLGENIScatalogue.org](https://molgeniscatalogue.org)
- II. Follow links to BBMRI-ERIC Directory finding also samples

III. Initiates access requests through the BBMRI-ERIC Negotiator.

IV. Once data access is obtained and legal permissions are in place, the researcher begins set-up of Armadillo DataSHIELD servers.

V. Perform federated analysis using DataShield.

Discussion and conclusion that will help others in their work

We present a concept for facilitating the researcher's journey from data discovery, data access negotiation and federated data analysis that can be copied by other consortia.

References

- Swertz & Gini (2022), <https://doi.org/10.1055/s-0042-1742522>
- Holub et al. (2016), <https://doi.org/10.1089/bio.2016.0088>
- Reihs et al (2022), <https://doi.org/10.1089/bio.2020.0144>
- Cadman et al (2024), <https://doi.org/10.1093/bioinformatics/btae726>

8B: Balancing ethics and innovation: ELSI in biobanking

The Seattle Principles: Promoting a Harmonized Ethical Framework for Banking and Secondary Research Use of Human Biospecimens and Associated Data

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Topic: 8B: Balancing Ethics and Innovation: ELSI in Biobanking

Presenter Name: Mark Barnes

Keywords: , biobanking, ethical, legal and policy framework, secondary use of biospecimens

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Introduction:

Large, representative and well-characterized biospecimen collections are essential for advancing scientific research and developing therapies that will serve diverse populations. Exchange of biospecimens internationally is essential for obtaining this goal. Yet, significant obstacles exist,¹ including the absence of harmonized legal, ethical and policy frameworks governing such sharing and the secondary use of biospecimens.

Methods:

A series of virtual and in-person discussions including a wide range of stakeholders were held at meetings of the International Society for Biological and Environmental Repositories, Public Responsibility for Medicine in Research, and the 2024 UN General Assembly Science Summit. The goal was to identify and elaborate a set of principles that could provide a basis for greater harmonization of policies globally regarding sharing and secondary use of human biospecimens, as well as guiding ethical practice in this area.

Results:

The following principles were defined: Transparency to Participants, Respect for Consent of Participants, Respect for the Scope of Consent, Respect for Withdrawal of Consent for Future Research, Safeguarding the Welfare of Specific Communities, Human and Community Welfare Protection, Participant Privacy, Specific Consideration of Genetic/Genomic Research, Returning Research Results, and Governance and Oversight. These principles will be further elaborated and their implementation discussed

during this presentation. A publication is currently in press.² **Conclusions:**

Our hope is that these principles can support the creation of a unified, ethics-based international framework that will enable important global research benefiting diverse populations, while at the same time promoting rigorous ethical standards for human biospecimen research.

References:

Schmid A, Bledsoe M. International Regulatory Harmonization: One World for Human Health. *Biopreservation and Biobanking*. 2025;23(3):163-164. doi:10.1089/bio.2025.0102

Barnes, M, Bledsoe, M, Kusonose, M. et. al. "Towards an International Ethical Framework for Banking and Secondary Research Use of Human Biospecimens and Associated Data: The Seattle Principles", *J Law Med and Ethics*, 2026 (in press).

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An Ethical Engagement Model for Biobanking in LowResource, Culturally Diverse Settings: Lessons from Pakistan

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Topic: 8B: Balancing Ethics and Innovation: ELSI in Biobanking

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Keywords: Cultural Sensitivity, Informed Consent, Multilingual Consent, Public Trust

Introduction

Biospecimen donation is often hindered by fears of misuse, religious concerns, and uncertainty about data sharing and confidentiality. Cultural norms, gender roles, multilingual populations, and variable literacy further challenge informed consent. This study presents a culturally adapted ethical engagement framework to enhance participant trust and consent quality in a hospital-based biorepository.

Materials and Methods

A multi-component strategy was implemented at the IHHN Biorepository, including: multilingual written consent (Urdu, English) and audio explanations in Punjabi, Pashto, Sindhi, Balochi, Saraiki, and Persian; a standardized culturally sensitive consent checklist; regular staff training on ethical and cultural competence; monthly reflective feedback sessions; participant awareness sessions; and an ongoing qualitative study of participant perceptions. Interview and staff feedback data were thematically analyzed to identify barriers.

Results

Multilingual and audio-supported tools enhanced comprehension among low-literacy participants. Staff reported greater confidence and consistency in consent delivery. Participants expressed reduced fear of misuse, better understanding of confidentiality, and increased willingness to participate. Family involvement, respectful communication, and privacy assurance were key trust factors.

Discussion and Conclusion

This framework demonstrates that culturally adapted, language-inclusive consent processes combined with continuous staff training and quality monitoring can substantially strengthen trust in biobanking within diverse populations. This scalable model supports ethical recruitment and sustainable biobanking in LMIC settings and aligns with international ethical standards.

References

1. ISBER Best Practices: Recommendations for Repositories, 5th Edition.
2. CIOMS International Ethical Guidelines for Health-related Research

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BBMRI Consent to Biobanking Governance Over time and in the real world through a Standard-Based Digital Approach

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Topic: 8B: Balancing Ethics and Innovation: ELSI in Biobanking

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Keywords: DUC/CCE, FHIR HL7, IT integration, biobank participant, consent to governance, dynamic information, next-generation biobanking, transparency, trustworthy

Next-generation biobanking, evolving technologies, and One Health are challenging old ELSI standards, marking shifts in consent and governance. They stress the need for dynamic information and participation, framing this change within a responsible ecosystem, emphasising trust, transparency, and participatory governance. Clarifying the role of research biobanks, especially BBMRI, as custodians and guarantors is crucial, with reputation and accessibility being key to trustworthiness.

BBMRI.it recently tested the biobanking governance participatory consent prototype in realworld settings. Developed by BBMRI.it, funded by the EU Next Generation Initiative, it includes:

a. “bIOpartecipo BBMRI”, a participant app offering a two-way digital pseudonymised interface for participants to update preferences and to opt out to new research, while the biobank shares news, results, and access to samples/data in a traceable way; b. the biobank public page, with ELSI/governance tools and an updated protocols/disclosures list, positively evaluated by the access committee; c. integration of sample data with ELSI Metadata expressed by the Common Condition of use Elements (CCE) terminology; d. a Consent Profile based on the HL7 FHIR standard and software components supporting interoperability with the BBMRI Federated Platform and EHDS.

In four biobanking settings—population, cardiology, oncology, and rare disease—participants, professionals, and three BIMS companies collaborated with biobanks to verify app usability (“biObanco BBMRI” for professionals, “biOpartecipo BBMRI” for participants). Biobanks assessed the digital flow’s functionality and sustainability across the apps, BIMS, the Federated Platform, and European Data Spaces in a demo environment. The software is opensource, while the apps are available on Android and iOS.

Casa, S., Ellul, B. (2024). How-To Guide: Next Generation Biobanking/Biobanking with the Next Generation (V 1.0). Zenodo.

<https://doi.org/10.5281/zenodo.11400120>

Thompson, R., Lyle, K., Samuel, G. *et al.* The research relationship: participant perspectives on consent in biobanking. *BMC Med Ethics* **26**, 47 (2025).

<https://doi.org/10.1186/s12910-025-01199-0>

Samuel, G., Hardcastle, F., & Lucassen, A. (2025).

Technologies Do Not Build Trust, People Do: A Critical Response to Promises of Trust in Biobanking Through Blockchain and Generative AI. *The American Journal of Bioethics*, 25(4), 130–132.

<https://doi.org/10.1080/15265161.2025.2470646>

Beyond the algorithm: Trustworthy AI and the role of biobanking infrastructures in pathology and imaging

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Keywords: Artificial Intelligence; Biobanks; Public Attitudes; Pathology; Healthcare Data

Background: Artificial intelligence (AI) has advanced in healthcare, with pathology emerging as an area to improve cancer diagnosis and

management. Many AI systems are developed using datasets, including pathology images and tissue samples from biobanks. While these tools could increase diagnostic efficiency and accuracy, their use depends on public support for AI-assisted diagnosis and for using healthcare data and biobanked tissue for algorithm development.

Aim: To examine UK public awareness of and attitudes toward AI in pathology research and practice.

Methods: A nationally representative, cross-sectional online survey of 1,518 UK adults was conducted. The survey contained 30 closed and two open questions, plus sociodemographic data and previous cancer experience. Quantitative data were analysed using descriptive and inferential statistics, and qualitative responses using thematic analysis.

Results: Awareness of AI in pathology was low, with only 24% reporting moderate awareness. Most respondents did not support cancer (60%) or biomarker (46%) diagnoses made solely by AI. However, 97% supported diagnoses made by a pathologist assisted by AI. Support was higher among men (OR 1.34), those with greater awareness (OR 1.25), trust in data security and privacy (OR 1.04), and more positive beliefs about AI (OR 1.27), while perceiving more risks reduced support (OR 0.80). Qualitative themes emphasised keeping a human in the loop, robust governance of data and biobanked tissue, and evidence of benefit.

Conclusions: Despite low awareness, the public showed conditional support for AI in pathology, though concerns remain among women, and about commercial access to healthcare data.

Limits of Commercialisation in Biobanking and the European Health Data Space: Towards Harmonised Participant Protection

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Topic: 8B: Balancing Ethics and Innovation: ELSI in Biobanking

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Keywords: Biobanking, Commercialisation, European Health Data Space (EHDS), Participant protection, Secondary use of health data

Introduction

The development of biobanking and the growing use of health data and biological material for research have intensified debates on the limits of commercialisation. The European Health Data Space (EHDS) aims to expand secondary data access, including for commercial use, raising questions about compatibility with traditional bioethical and legal constraints, particularly the prohibition of financial gain from the human body and participant control.

Material & methods

The study is based on doctrinal and comparative legal analysis. It includes a conceptual examination of commercialisation in the context of biological material and health data and a review of legal and bioethical literature. The analysis covers selected national approaches to the commercial use of biological samples and health data and assesses the regulatory framework proposed under the EHDS, focusing on the opt-out model and its compatibility with the Convention on Human Rights and Biomedicine (Oviedo Convention).

Results

The analysis shows the lack of a uniform legal definition of commercialisation and diversity in regulatory approaches. While many jurisdictions allow commercial use of research results or data, stricter limits apply to biological material. The EHDS may expand access to health data for commercial actors while reducing individual control. Opt-out mechanisms may not provide sufficient protection where awareness of potential commercial use is limited. The findings reveal inconsistencies in the protection of health data and related pseudonymised biological material, highlighting tension between traditional restrictions and the EHDS data access model.

Discussion and conclusion

The results highlight the need to clarify the concept of commercialisation in biobanking and develop clearer standards for informing participants about potential commercial uses. While the opt-out model may improve data availability, it should be complemented by stronger transparency and information obligations to ensure compliance with the Oviedo Convention and maintain public trust. Greater coherence and harmonisation are needed between rules governing secondary use of health data within the EHDS and those applicable to related pseudonymised biological material.

References:

Corradi, A., Bonizzi, G., Sajjadi, E., et al. (2025). The regulatory landscape of biobanks in Europe: From accreditation to intellectual property. *Current Genomics*, 26(1), 15–23.

Donia, J. and Marelli, L. (2025). Anticipating ethical and social dimensions of the European

Health Data Space: A rapid systematic review. *Health Policy*, 162, 105443.

Kosta, E., Papakonstantinou, V., Slokenberga, S., Staunton, C. and Tzovaras, B.G. (2025). Secondary use of health data in the European Health Data Space: Legal and ethical challenges. *Computer Law & Security Review*, 55, 105942.

Mitchell, C., Waldby, C. and Kerridge, I. (2017). Commercialisation, consent and communication in biobanking. In: Mitchell, C., Waldby, C. and Kerridge, I. (eds.), *The Biobank Governance Toolkit*. Springer.

Pawlikowska, J., Pawlikowski, J. and Krekora-Zajac, D. (2023). Biobanking of human biological material and the principle of noncommercialisation of the human body and its parts. *Bioethics*, 37(4), 356–365.

11B: Pediatric biobanking

Novel Strategy in Broad Consent-based Paediatric Biobanking: Re-Information instead of Re-Consent when Minors attain Majority.

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Abstract ID: 470

Topic: 11B: Paediatric Biobanking

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Keywords:

Biobanking, Broad

Consent, Minors,

Re-consent, Re-

information.

Background: Many paediatric departments/networks collect biosamples of children using a disease-specific consent. However, collection of biosamples from minors based on a “broad consent” (BC) would foster medical research in paediatrics. In 2018, the Association of German Medical ECs (A-GMECs) developed a framework for an age-adapted mastertemplate “for the broad use of biosamples & data donated by diseased children”, recommending re-consent of minors when they reach majority. In addition to the consent by the legal guardians, minors are asked to give their assent. Under the 2018-scheme they had to confirm the parent’s decision later-on by re-consenting. However, research on the legal practice and prevailing case law in Germany concluded that there is no strict legal requirement of re-consent.

Methods/Results: Therefore, in 2023/2024, the A-GMECs adapted its recommendations establishing the principle of **re-information** instead of **re-consent**. The formerly treating physicians/hospitals must re-contact the parents in order to re-inform the minors attaining majority. The actual information and BC are sent to the former donor using the current address of

the parents giving her/him the possibility to withdraw BC, implying deletion of donated data and remaining biosamples. If the donor does not react, the parent's consent remains valid; if she/he signs and returns the updated BC, former data/samples may be used and new data/samples gained.

Conclusion: The novel principle of re-informing rather than re-consenting facilitates handling of data & biosamples gained from minors under a BC; at the same time it preserves the individual rights of the formerly minor when attaining majority.

The Swedish Childhood Tumor Biobank - A national omics and tissue research resource for pediatric cancers

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Abstract ID: 607

Topic: 11B: Paediatric Biobanking

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Keywords: biobank, genomics, pediatric cancer, precision medicine

Introduction:

In Sweden, around 350 children are diagnosed with cancer annually. Despite an 85% survival rate, cancer remains a leading cause of childhood death. Survivors often suffer treatment-related sequelae, underscoring the need for deeper biological insights to improve survival and quality of life. The Swedish Childhood Tumor Biobank (Barntumörbanken, BTB) enhances understanding of pediatric solid tumors by providing infrastructure, biological samples, and molecular/genomic data for research.

Material & Methods:

BTB collaborates with the six university hospitals treating pediatric cancer nationwide. Fresh frozen tumors, blood samples, CSF, viable tumor cells, digital pathology slides and parental blood are collected. BTB registers, processes, and stores samples with linked clinical information, and performs whole genome and transcriptome sequencing, proteomics and methylation profiling. BTB partners with SciLifeLab for comprehensive molecular characterization and developing bioinformatic pipelines. Internal variant databases and data portals support secure data organization, traceability, and visualization.

Results:

Over 2600 cases are registered and 60,000 samples collected./prepared. About 1600 cases have been genomically characterized, with BTB managing the resulting data, including for the Genomic Medicine Sweden Childhood Cancer study. BTB has shared samples and data with over 20 approved research projects, governed by

medicolegal review and specific access agreements. BTB also supports clinical studies with logistics, regulatory guidance, and data interpretation.

Conclusions:

BTB systematically collects specimens and informed consent from over 90% of Swedish pediatric patients with solid tumors, generating high-quality molecular data. Continued use of these samples and omics datasets in approved studies is expected to improve future clinical care for children with cancer.

Communication and Ethical Challenges in Pediatric Cohort-Based Biobanking: Lessons from the Birth and Three Generation Cohort in Japan

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Abstract ID: 667

Topic: 11B: Paediatric Biobanking

Presenter Name: Fuji Nagami

Keywords: birth cohort, ethics, multi generation, pediatrics

Tracking changes in children's developmental trajectories is critically important in medical research. However, collecting biospecimens and data from minors presents substantial challenges, particularly with respect to communication and ethics. The Tohoku Medical Megabank Project includes a unique initiative known as the Birth and Three-Generation Cohort.

In this project, pregnant women were recruited through obstetric facilities across the prefecture, and participation was extended to their children, older siblings, partners, and both sets of parents. Through this approach, we have established a large-scale biobank comprising more than 20,000

families and over 70,000 participants. Participants are followed through written and electronic communications, as well as in-person visits approximately every five years, during which biospecimens are collected. Genomic and metabolomic analyses are conducted using these biospecimens.

Over the course of conducting long-term follow-up of children as part of a cohort study, while simultaneously maintaining the biobank and performing analytical research, a wide range of issues have arisen. These include operational challenges, such as limitations on blood draw volumes, as well as issues that have at times required legal consideration.

In this presentation, we focus primarily on the communication and ethical challenges encountered over more than a decade of experience. These include issues related to proxy consent, situations involving multiple stakeholders, and questions surrounding the use and secondary use of biospecimens and information. By organizing and presenting diverse experienced cases, we aim to share insights gained from these and to discuss future perspectives for pediatric cohort-based biobanking.

VIVO Biobank – Supporting Translational Research in Paediatric Cancers Linked to Innovative Clinical Trials

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Abstract ID: 715

Topic: 11B: Paediatric Biobanking

Presenter Name: Eszter Tuboly

Keywords: Paediatric and Young Adult Cancer; Clinical Trials; Translational Research; Genomic Biomarkers; Risk Stratification; Neuroblastoma; Acute Lymphoblastic Leukaemia, Pediatric Biobanking

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Introduction

VIVO Biobank is the UK's National Biobank dedicated to collecting and storing various biological samples and associated data from children and young people (CYP) across the full spectrum of cancer diagnoses. The initiative is a collaboration between the Universities of Newcastle, Bristol and York, fully funded by Cancer Research UK and Blood Cancer UK.

Methods

VIVO Biobank is open to all CYP with cancer treated at participating UK centres. It supports prospective sample collection for numerous clinical trials and enables the use of surplus trial material for secondary research. In addition, VIVO curates legacy clinical trial samples, providing a uniquely valuable resource with comprehensive clinical annotation and longterm outcome data.

Results

Research using clinical trial samples collected by VIVO Biobank has been instrumental in changing patient treatment.

Case study 1 – UKALL2003 trial

UKALL2003 was a UK-wide clinical trial for children with acute lymphoblastic leukaemia and the first to systematically bank bone marrow via VIVO Biobank. Leveraging these samples, a series of inter-related projects identified, characterised and evaluated several genetic biomarkers including *iAMP21*, UKALL copy number alteration (CNA) profile, *EBF1::PDGFRB*. In addition, research using samples from UKALL2003 led to the redefinition of refractory disease and the concept of genotype-specific MRD thresholds. These research findings led to the development of a novel integrated risk classification algorithm which has been adopted by the international ALLTogether01.

Case study 2 – High Risk Neuroblastoma 1 (HRNBL1 trial)

Investigation into *ALK* genetic modifications in high-risk neuroblastoma patients recruited onto the SIOPEN HR-NBL1 trial revealed that particular alterations, such as clonal mutations and amplifications, are associated with worse survival outcomes. This was a large international European study and VIVO Biobank provided samples for UK patients. As a result of this research patients with *ALK* alterations will be randomised to receive an *ALK* inhibitor (Lorlatinib) in addition to standard treatment in an upcoming amendment to the SIOPEN HR-NBL2 trial.

Conclusion

Both of these international research projects highlight the importance of VIVO Biobank in supporting centralised sample collection for clinical trials facilitating access to samples to support research that has changed treatment for CYP with cancer in the UK and all around the world.

References:

Nature 508:98 (2014), *J.Clin Oncol.* 31:2289 (2013), *Blood* 124(9): 1434 (2014), *Blood* 127(18): 2214 (2016), *J Clin Oncol* 35(6): 660 (2017). *J Clin Oncol* 36(1): 34 (2018), *Blood Adv* 3(2): 148 (2019), *Br J Haematol* 191(5): 844 (2020), *Blood.* 137(13):1835 (2021)

J.Clin Oncol. (2021) 39(30), 3377;. *Clin. Cancer Res.*(2023) 29(7):1317

Broad consent in paediatric biobanking – A review of current practise in 10 European countries

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Keywords: broad consent, paediatric biobanking,

secondary use of paediatric data and biosamples for medical research

Introduction

Precision medicine and translation are central aims of current medical research, requiring both the collection and extensive use of medical data and biosamples. For adults, broad consent has become a standard legal basis for the secondary use of data and biosamples from the healthcare context in many countries. In terms of its ethical, legal and practical implications, however, broad consent for paediatric biobanking differs substantially from its adult counterpart. These differences need to be addressed to ensure a legally and ethically acceptable secondary use of paediatric data and biosamples for medical research.

Methods

A lively debate held at the 'Ethics Café' of the European Biobank Week 2025 prompted an international review of the paediatric consent practices for biobanking. Based upon current national and international legislation as well as expert reports provided to us, we compared the respective legal and ethical framework in 10 European countries.

Results

The review focused on specific aspects of paediatric consent, namely (i) the possible reporting of incidental findings, (ii) the procedures upon reaching age of majority, particularly in cases of non-response after re-contact, and (iii) the appropriate integration of minors into the consent process (e.g. by a right to veto the parental decision at a certain age).

Abstract ID: 654

Topic: 11B: Paediatric Biobanking

Presenter Name: Gesine Richter

Conclusion

Against the backdrop of the increasing need for comprehensive data and biosamples for paediatric medical research, particularly in Europe, our review aims to contribute to establishing a valid legal and ethical basis for the secondary use of both in the context of paediatric biobanking.

Track three: Fit-for-purpose biobanking: Enhancing sample quality from collection to analysis

3C: Biobank advanced technologies: Challenges, opportunities and solutions

Implementing e-Consent to Digitise Biobank Recruitment Across a Multi-Hospital Consortium

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Topic: 3C: Biobank Advanced Technologies: Challenges, Opportunities and Solutions
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Keywords: digitization, e-consent, engagement, multicentre

Background:

Paper-based consent remains the predominant approach in research and biobanking. The Victorian Cancer Biobank (VCB) obtains consent from approximately 1,000 participants annually across its hospital network. However, paper-based consent processes are inefficient, resource-intensive, and environmentally unsustainable, limiting VCB's ability to scale participant outreach. To address this, VCB initiated implementation of an electronic consent (e-consent) system to digitise workflows, eliminate paper use, and expand remote participation capability.

Methods:

e-Consent implementation included system design, user acceptance testing (UAT), ethical approvals, and a staged rollout. Healthcare consumers played a central role as co-design partners and UAT participants. UAT incorporated structured qualitative and quantitative interviews to evaluate usability and acceptability. The project also required meeting IT and cybersecurity requirements across all partnering hospitals to ensure secure management of participant information.

Results and Discussion:

A customised e-consent module was developed within VCB's biobanking platform (OpenSpecimen), featuring:

- End-to-end digital consent workflows
- Optimised Participant Information and
- Consent Forms (PICF) for multiple devices
-

Participant-centred pathways for in-person and remote consent

A standardised yet customisable PICF (including hospital branding and governance needs)

- Personalised pre-filled and autosaved PICFs enabling efficient review and electronic signing

Key challenges included navigating multisite ethical and governance approvals and undertaking substantial system customisation to enhance staff and consumer experience.

The e-consent system is now live at Monash Health as a pilot prior to broader rollout.

Conclusion:

A purpose-built e-consent system can streamline consent processes, improve consent and data management as well as participant experience, and increase capacity for remote recruitment.

Enhancing Pre-analytical Standardization and Biobanking Efficiency through Automation: The BioCor Biobank Experience

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Topic: 3C: Biobank Advanced Technologies: Challenges, Opportunities and Solutions
Presenter Name: Renna Laura Valentina
Keywords: automation, biobanks, procedures, standardization

Introduction: Biobanks play a pivotal role in translational research by providing long-term access to high-quality samples and robust associated data. A critical quality determinant is the pre-analytical phase, where handling and processing strongly influence integrity, standardization, and reproducibility. From receipt through cryopreservation, standardized procedures are essential to preserve biological functionality. Increasing volumes and stringent traceability requirements pose operational challenges, as manual workflows are time-consuming and prone to operator-dependent variability. To address these, automation has emerged as a key strategy to improve efficiency and compliance with quality standards. At BioCor Biobank, automated, traceable workflows have been implemented across preanalytical and processing phases to ensure standardized, high-quality samples for translational research.

Materials and Methods: Automated liquid aliquoting was performed using air-displacement technology to ensure precise, contamination-free dispensing and uniform volumes. Peripheral blood mononuclear cells (PBMCs) were isolated via automated magnetic separation, enabling standardized purification while minimizing mechanical and thermal stress. PBMC quality was assessed by flow cytometry and cryopreserved using a controlled-rate freezing protocol to minimize thermal stress and maximize post-thaw recovery. Sample tracking was managed through a QR-code-based system, providing real-time digital mapping and inventory control. **Results and Conclusion:** Automated, traceable workflows, including handling, PBMC separation, aliquoting, cryopreservation and digital inventory, significantly improve efficiency, standardize quality, reduce variability and maintain high PBMC viability. These processes ensure long-term availability of reproducible

samples, strengthening resources for advanced translational research.

Designing a Future Proof Automated Storage Facility:

Implementation Pathways, Technical Challenges and Optimization Strategies

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Topic: 3C: Biobank Advanced Technologies: Challenges, Opportunities and Solutions

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Keywords: Automated Biobanking, Energy-Efficient Biobanking, High-Capacity Sample Repository

Introduction

The increasing demand for high-quality biospecimens creates favorable conditions for implementing automated and energy-efficient storage infrastructures. To prepare a biobank for future scientific needs, an automation program was initiated following funding approval in 2020, with the first samples entering the new system in 2025. The project involved defining labware formats, sample volumes, and technical requirements for automated storage at -80°C and in the gas phase of liquid nitrogen (LN_2). This work outlines how the transformation was executed, highlights key challenges encountered, and presents practical solutions that supported successful implementation.

Materials & Methods

Automated storage systems (capacity >5 million samples at -80°C) and LN_2 gas-phase units (capacity >200,000 samples) equipped with robotic handling and barcode-based identification were implemented. System selection focused on storage density, LIMS interoperability, sustainability targets, and standardized labware compatibility. Application programming interfaces enabled real-time communication with the institutional LIMS. Redundant cooling units and emergency power supplies ensured operational continuity. Infrastructural upgrades—including insulation, ventilation, and spatial restructuring—were required to meet the technical demands of automated systems.

Results

Automation reduced manual handling and error rates while enabling high-throughput processing. The system architecture provides substantial space savings and supports greening goals through energy-efficient cooling. Automated picking accelerated retrieval times and minimized handling variability. Integrated backup systems further strengthened operational resilience.

Discussion & Conclusion

The multi-year transition demonstrates the importance of early system and labware decisions, robust infrastructure planning, and LIMS integration. The resulting automated -80°C and LN_2 repository provides a scalable, sustainable, and future-proof model for biobanks.

Automation in Rehabilitation Biobanking: Enhancing Longitudinal Sample Quality through Integrated Liquid Handling and Digital Traceability

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Topic: 3C: Biobank Advanced Technologies: Challenges, Opportunities and Solutions

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Keywords: Integrated Liquid Handling, Liquid Traceability, Longitudinal Sample Quality

Introduction

Rehabilitation research increasingly depends on longitudinal biological sampling integrated with functional and clinical data. In patients with neurological, cardiometabolic, and chronic disabling conditions, reproducible pre-analytical processing is essential to preserve long-term sample value. Our multi-site IRCCS biobank was established to support translational rehabilitation research through structured governance, digital traceability, and laboratory automation.

Materials and Methods

A Fluent® automated liquid handling workstation was implemented to standardize blood fraction processing and aliquoting across multiple sites. Automation was integrated within harmonized SOPs aligned with ISO 20387 principles, digital tracking, and risk-based workflow redesign. The system performed standardized plasma and serum aliquoting with automated tip management, ensuring precise volume dispensing and consistent preanalytical conditions. This reduced manual handling, minimized cross-contamination risk, and limited

operator-dependent variability in longitudinal collections.

Results

Automation improved aliquoting consistency and reduced variability across operators and timepoints. Digital integration strengthened traceability between biological samples and associated clinical and functional data. Throughput increased while maintaining quality control checkpoints, enabling scalable recruitment and sustainable management of rehabilitation cohorts.

Discussion and Conclusion

Automation in rehabilitation biobanking enhances efficiency and scientific reliability. Integrating liquid handling technology within a quality-driven governance and digital framework improved robustness, reproducibility, and long-term value of biological resources supporting translational rehabilitation research and future biomarker discovery.

Transforming biobank operations through integrated digital systems and efficient researcher – biobank interfaces

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Keywords: KPI monitoring, digital biobanking, paperless, researcher-biobank interface, workflow efficiency

Introduction

To reduce email- and paper-driven workflows, the Central Biobank of Erasmus MC aimed to create an efficient digital interface between researchers and the Central Biobank.

Material & methods

We implemented one digital workflow for sample acquisition, processing, registration, storage and issuance by linking our Electronic Health Record System, Laboratory Information Management System (LIMS) and Biobank Information Management System (BIMS). Other biobank processes were integrated into existing institutional systems already familiar to researchers.

Results

Our integrated digital sample journey results in a paperless and traceable workflow that reduces workload and human error while enabling the monitoring of key performance indicators. Study-specific details and sample requests are managed in the Study Management System, which also supports multi-level issuance approval. Researchers prepare sample requests directly in the BIMS, while practical operational requests - such as sample transport, storage submissions, data corrections, and consent withdrawals - are handled via forms in the hospital portal. Researchers fill in digital forms with required fields with defined data specifications and receive standard replies containing answers to frequently asked questions, eliminating back and forth emailing. Additionally, a web-based BIMS portal is being implemented for direct digital registration at external collection sites.

Discussion and conclusion

This integrated approach reduces staff workload, enhances data traceability, and enables robust analysis of turnaround times and service volumes.

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Lyophilization: a Sustainable Alternative to Conventional Extracellular Vesicles Freezing

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Topic: 3C: Biobank Advanced Technologies: Challenges, Opportunities and Solutions

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Keywords: Lyophilization; extracellular vesicle; exosome; biomarker; biospecimen science; biobanking

The preservation of biological samples is critical for biomedical research, biobanks, and hospitals, particularly in the field of exosomes, whose growing interest as biomarkers and therapeutic tools requires storage methods that ensure their stability and integrity. Traditionally, freezing has been the most commonly used method for exosome preservation; however, it presents logistical limitations, high energy costs, and dependence on specialized infrastructure. In this

context, lyophilization emerges as an innovative, more sustainable, and efficient alternative.

This study compares the performance of freezing and lyophilization (300K solutions SL) as methods for the exosome conservation isolated from plasma. Plasma was stored using both methods for periods of 1 and 6 months to evaluate sample stability in short- and medium-term. For lyophilization, a 300K Solutions S³ (Sample Stabilization System) and 300K plasma-serum stabilization vials were used. Exosomes were purified by differential ultracentrifugation. Characterization was performed using nanoparticle tracking analysis (NTA) to determine size and concentration, flow cytometry for the detection of exosome-associated tetraspanin markers (CD9 and CD63), and electron microscopy to assess morphology and integrity.

The results indicate that lyophilization preserves the physical, structural, and molecular characteristics of exosomes comparably to freezing at both short- and medium-term storage. Our findings suggest that lyophilization constitutes a viable alternative for exosome storage, offering advantages in terms of long-term stability and sustainability. This approach could facilitate biobank management and expand the potential use of exosomes in research and clinical applications.

Study supported by grants PT23/00083 ISCIII, Madrid, Spain and DISRUPT GA 101099663 – Pathfinder Open Funded by the European Union

5C: Tools and processes for quality implementation and use cases

Flow Cytometry–Based Quality Assessment of Serum and Plasma for Biobanking

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Topic: 5C: Tools and Processes for Quality Implementation and Use Cases

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Keywords: Flow cytometry Quality

Introduction: Pre-analytical variability, hemolysis, and cryopreservation represent major challenges in the use of serum and plasma samples for biobanking and downstream analyses. These factors can affect sample integrity and compromise the reliability of biomarker and cytokine measurements. The implementation of objective, standardized, and reproducible quality control (QC) strategies is therefore essential to ensure high-quality biospecimens. Flow cytometry offers a multiparametric and quantitative approach for evaluating sample quality both before and after cryopreservation. **Materials and Methods:** Serum and plasma samples were processed at the BioCor Biobank according to internal Standard Operating Procedures. Phenotypic characterization was performed by flow cytometry using antibodies against CD41a, CD45, CD235a, CD71, and the nuclear dye DRAQ5.

Hemolysis was assessed spectrophotometrically by measuring absorbance at 414 and 385 nm and further evaluated through direct detection of red blood cell (RBC) fragments within the platelet-size range. Cytokine expression was analyzed using the MACSPlex Cytokine Kit to assess the impact of pre-analytical variables. All analyses were performed before and after cryopreservation at $-80\text{ }^{\circ}\text{C}$. **Results:** Flow cytometry accurately discriminated serum from plasma samples based on platelet content (AUC=1; $p<0.0001$), both before and after cryopreservation. Controlled hemolysis experiments confirmed a strong correlation between visual hemolysis, RBC fragment detection, and absorbancebased measurements ($r=0.97$; $p<0.0001$). Cytokine analysis revealed inter-sample variability after long-term cryopreservation, underscoring the importance of QC monitoring. **Conclusions:** Flow cytometry is a robust and reproducible QC tool for serum and plasma biobanking, enabling objective hemolysis assessment, sample-type discrimination, and informed selection of high-quality samples for long-term storage.

Closing the Gap: Proficiency Tests Identify Cryotube Sealing Deficits Across Biobanks

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Keywords: , Proficiency test, cryotubes, pre-analytical variability

Background: Proficiency tests (PTs) are established tools for external quality assessment and increasingly used in biobanking to assess critical core processes and detect preanalytical

deviations, including long-term storage of aliquots in cryotubes. Reliable sealing is essential for biospecimen integrity; insufficient closure can cause evaporative losses and ingress of O₂/CO₂/H₂O, thereby promoting oxidation, acidification, dilution, and hydrolysis—effects that may be exacerbated in dehumidified storage systems.

Methods: Cryotube closure was assessed. In PT1 (24 national biobanks), closure was documented only photographically. In PT2 (27 national/international biobanks), a quantitative approach was implemented on dry ice. Tube height was measured and heatmaps were used to visualize site-specific height deviations consistent with insufficiently closed tubes. For external screw-cap cryotubes without a gasket, cap–tube gap width was measured using a feeler gauge. Scatterplots (tube height vs. gap width) were used to illustrate outliers.

Results: In PT1, insufficiently closed tubes were observed in 8/24 biobanks; three sites had > five deficient closures, indicating a systematic issue, but confirmation was limited by image-only documentation. PT2 revealed within-site variability in cryotube height. Overall, 13/27 biobanks exhibited insufficiently closed cryotubes, with five sites showing more than four deficient closures. Repeated findings at selected sites pointed to persistent procedural shortcomings.

Conclusions: Tube-height assessment increased sensitivity and enabled more objective identification of insufficiently closed cryotubes. The frequency and recurrence of inadequate closures indicate a clear need to improve capping practices via operator training and routine closure checks, underscoring the value of PT-

based monitoring to reduce preanalytical variability and long-term storage risks.

HarmoNICo – Omics Interlaboratory Testing for the BBMRI.it-NICo Network

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Topic: 5C: Tools and Processes for Quality Implementation and Use Cases

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Keywords: BBMRI.it, Core Facilities,

FAIR, NGS, harmonization, proteomics, transcriptomics

Introduction

In the era of big data, protocol harmonization and adherence to FAIR principles are essential for the reliability, reproducibility of omics-driven research. The HarMoNiCo initiative launched a pilot phase of interlaboratory testing focused on transcriptomics and proteomics across the BBMRI.it-NiCo (Network of Italian Core facilities) collaboration. The project aims to evaluate intra- and inter-laboratory variability to ensure reproducibility and data integrity across core facilities, fostering reliable analyses of biobanked samples and enhancing their translational value.

Materials and Methods

The first phase included four branches, namely transcriptomics, proteomics, fluorescent optical microscopy and analysis of Extracellular Vesicles (EVs).

The transcriptomics branch involved five core facilities performing RNA-Seq on a standardized human total RNA sample spiked with synthetic fragments [1],[2]. Concurrently, the proteomics pilot addressed the challenge of methodological heterogeneity across eight laboratories, analysing a commercial HeLa Protein Digest Standard, through label-free data acquisition (DDA or DIA) across five replicates [3],[4],[5].

Flexibility in instrumental settings, reagents and protocols was allowed to reflect each laboratory's real-world analytical setups, while data were centrally processed to mitigate variability arising from different bioinformatics pipelines.

Results

The obtained results facilitated the identification of performance drifts and the development of best practices for omics services. Future goals include scaling the initiative to involve a larger

cohort of Italian and European core facilities and biobanks. This expansion will enhance the statistical robustness of harmonized protocols and align the network with European interoperability and large-scale data integration requirements.

BBMRI.nl initiative to measure temperature variation within ULT freezers in Dutch biobanks using a cheap and effective method

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Topic: 5C: Tools and Processes for Quality Implementation and Use Cases

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Keywords: ULT, freezers, temperature, validation

Maintaining stable storage temperatures with sufficient safety margin is essential to prevent degradation of biomolecules resulting in loss of reliable research data. Validation of biobank equipment is therefore important. For ultra-low temperature freezers validation is usually not part of the annual maintenance and or done with

a single inserted probe that doesn't measure temperature variation within freezers. Multiprobe validation of full freezers remains difficult without the use of expensive equipment and adaptations to freezers.

We investigated the use of dry ice loggers to validate the temperature variation within freezers at different central biobank facilities in the Netherlands. The 88165 AZ Dry Ice Temperature USB Data logger was selected as it's small and thin and therefore fits between boxes within the trays. The loggers have a measurement range between -82°C and +70°C. Multiple probes were calibrated using dry ice and a 9-point test was used to map freezers at different central biobank facilities in the Netherlands.

Preliminary results show large temperature variations within the measured freezers. It seems that each type of freezer has its own temperature variation, which can be more than 10 degrees. Furthermore, these warm areas heat up quicker in case of freezer failure, resulting in reduced response time.

Paving the way for accreditation: the BBMRI-ERIC audit programme

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Keywords: BBMRI-ERIC Quality Label, audit programme, standards

Successful biobank operation relies on standardised processes and compliance with various requirements. The BBMRI-ERIC audit

programme offers a structured approach enabling biobanks to demonstrate operation in accordance with international and/or European standards and supports progress toward future accreditation.

Biobanks start by requesting one or more of the 12 BBMRI-ERIC Self-Assessment Surveys (SAS), each based on international or European standards. After access is granted, biobanks complete the SAS and may use the results internally or submit them to the BBMRI-ERIC Headquarters Quality Management Department (BBMRI.QM) for review. Submission initiates a remote audit for biological material collections or a remote plus on-site audit for biobank management systems. On-site audits are performed by trained auditors of BBMRI.QM or from the Nodes on behalf of BBMRI-ERIC, using a standardised checklist. Successful audits result in a BBMRI-ERIC Quality Label. Biobanks receive searchable Quality Labels at biobank or collection level in the BBMRI-ERIC Directory, and those with audited management systems additionally obtain a certificate and trophy.

The audit programme was conceptualised in a peer-to-peer audit style. Twelve SAS were developed and implemented in REDCap. Document templates were created; process flows were implemented and continuously improved. To date, 14 Quality Labels are visible at biobank and 51 at collection level in the Directory. Currently, 15 biobanks within our community have been accredited by national accreditation bodies.

The audit programme is well received by the biobank community. It enables peer-based evaluation against international and/or European standards, fostering continuous improvement,

enhancing operational quality, and strengthening readiness for formal accreditation.

The use of dry ice loggers has proven to be an effective, cheap method to measure temperature variation within freezers which is applicable to all biobanks. However, the results also show the need for recommendations on the accepted temperature variation range within a freezer and the maximum accepted temperature.

6C: Ensuring excellence: Elevating data quality in biobanking

Building an Interoperable Brain Metastasis Data Infrastructure: The RENACER Network Experience

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Topic: 6C: Ensuring Excellence: Elevating Data Quality in Biobanking

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Keywords: database; REDCap; Data management workflow; brain metastasis; FAIR; data sharing

Introduction

The Spanish National Brain Metastasis Network (RENACER) is a multidisciplinary, patientcentred initiative coordinated by the CNIO Biobank that

brings together 21 hospitals to address therapeutic resistance, mortality and quality-of-life impact in brain metastases, by establishing a living cohort (n=641 patients) including fresh tissue and liquid biopsy samples, together with comprehensive characterization (molecular and MRI data, and longitudinal clinical follow-up across the therapeutic pathway).

Materials and methods

A centralised REDCap database was designed to integrate biospecimen, clinical and complementary data sources (RNA-seq, WES, MRI and neurocognitive assessments). Version control system was implemented, and data are hosted on secure institutional servers with role-based access control and GDPR-compliant pseudonymisation. Analytical and reporting pipelines were developed using R, Python and cBioPortal.

Results

A structured workflow covers data collection, curation, harmonisation (standard ontologies and variable coding) and quality assessment through checks of completeness, consistency, validity and identifier uniqueness. The database contains 1,172 variables, with essential fields exceeding 70% completeness, supported by structured data curation and continuous quality monitoring, strengthening data reliability, interoperability and secure multiinstitutional reuse.

Discussion and conclusions

RENACER provides a unique and robust infrastructure to advance brain metastasis research and responsible data sharing while facilitating clinical translation. Alignment with

emerging European data-sharing frameworks is reinforced by regulatory compliance, interoperability and secure data reuse for research and innovation.

References: Valiente M, Ortega-Paíno E. Updating cancer research with patient-focused networks. *Trends in Cancer*. 2024;10(1):1–4. doi:10.1016/j.trecan.2023.09.002.

A Reproducible Framework for Creating Validated Health Indicators from Middle Eastern Biobank Data

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Topic: 6C: Ensuring Excellence: Elevating Data Quality in Biobanking

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Keywords: Biobank, Health indicators, Middle East, Translational science, Validation

Background

Large-scale biobanks generate complex, multidimensional health data that require standardized analytical approaches to ensure reproducibility and clinical interpretability. Although international clinical guidelines provide validated thresholds for health indicators, their systematic application in Middle Eastern populations remains limited. We developed and validated a framework to transform raw biobank data into clinically meaningful health indicators using established standards.

Methods

Data from 2,400 Qatar Biobank participants (50% male; mean age 40.6 ± 13.4 years; range 18–90

years) were integrated across five sources: demographics, anthropometry, questionnaires, spirometry, and cognitive assessments (CANTAB). Health indicators were derived across five domains using published thresholds: physical function (EWGSOP2 grip strength; WHO BMI), cardiovascular risk (ESC/ESH blood pressure; WHO and IDF Middle East central obesity), pulmonary function (GLI-2012 z-scores; GOLD criteria), cognitive function (CANTAB scores), and self-reported chronic conditions. Construct validity was assessed using known-groups comparisons and correlation analyses.

Results

The framework produced 24 validated indicators, including continuous measures, standardized z-scores, and binary classifications. Prevalence estimates included obesity (39.5%), central obesity (60.6%), measured hypertension (7.5%), self-reported diabetes (15.8%), and forced expiratory volume in one second below the lower limit of normal (30.1%). Validation analyses showed expected patterns, including large sex differences in grip strength (Cohen's $d = 2.41$), age-related decline, and appropriate discriminant validity between health domains (physical–cardiovascular correlation $r = 0.11$).

Conclusions

This reproducible framework supports standardized derivation of clinically interpretable health indicators from biobank data, enabling cross-population comparisons and translational population health research in Middle Eastern settings.

From Samples to Data: A Proficiency Test Concept for Data Quality in Biobanking Networks

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Topic: 6C: Ensuring Excellence: Elevating Data Quality in Biobanking

Presenter Name: Julian Dörenberg

Keywords: Data Quality, Process Quality, Proficiency Testing

Introduction

Quality-assured biological specimen and associated high-quality data are essential for biobanking. Since 2018, the German Biobank Network (GBN) has conducted proficiency tests (PT) for biospecimen. This programme has been extended to include data quality (DQ) and the GBN Working Group on Data Quality has developed a concept for external quality assessment of data-related processes.

Materials & methods

The data quality proficiency test (DQPT) is based on import and export of a predefined dataset at participating biobank sites. The dataset intentionally contains data quality issues (DQI). During import, sites report the DQI they identify. DQPT site performance is assessed in two

components: (1) the number of predefined DQI detected and (2) the number of additional DQI introduced during local processing and subsequent data export.

Results

During development of the DQPT concept, we identified several key requirements for constructing a fit-for-purpose test dataset. To enable a meaningful assessment, the dataset must include DQI that represent data quality dimensions relevant to biobanking; accordingly, we included at least one predefined DQI for each selected dimension. In addition, iterative feedback loops are essential, allowing sites to report DQI and receive (partially) corrected datasets, as interrelated DQI may not be identifiable within a single feedback loop.

Discussion

Proficiency testing is a well-established approach to assess process quality. The DQPT concept extends the existing GBN PT programme to cover data-related processes in biobanks and supports quality-assured biobanking throughout the entire lifecycle of biosamples and associated data.

8C: Mastering pre-analytics: Key to reliable biobanking and biomedical research

The effect of 11 years of storage on selected biomarkers in human blood

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Topic: 8C: Mastering Pre-Analytics: Key to Reliable Biobanking and Biomedical Research

Presenter Name: Ronny Baber

Keywords: biomarkers, long-term storage, storage experiment

In the age of precision medicine, biobanks are important in biomarker research. One of their main tasks is to store biosamples that reflect the biological or biochemical state of the donor at the time their blood was collected. However, the influence of biobank-associated conditions or long-term storage on biosamples is not well understood.

This study examines the potential impact of various biobank-related factors, including storage duration, temperature, storage containers (e.g. plastic straws, cryotubes, and normal screw-cap tubes), and fill level, on serum and plasma. To this end, EDTA and citrated plasma and serum samples from patients at Leipzig University Hospital that were no longer required for diagnostic purposes by the Institute for Laboratory Medicine, Clinical Chemistry and Molecular Diagnostics were pooled to produce over 4,500 aliquots for analysis over a period of more than 10 years. The samples were stored in ultra-low temperature freezers (-80 °C) and in the gas phase of liquid nitrogen (<-150 °C). When the samples were frozen, a baseline analysis of 58 analytes was performed using various analytical methods. Clinically relevant biomarkers can be categorised by class (e.g. electrolytes, enzymes, hormones, metabolites, coagulation factors) and organ system.

The results after 11 years of storage at -80 °C and in the gas phase of liquid nitrogen (<-150 °C) are

presented. Furthermore, the influence of different storage tubes and fill levels on the stability of biomarkers in stored serum and plasma samples is demonstrated.

From Cytokines to Metabolites: Decoding Pre-Analytical History Using an NMR-Based Quality Score for Biobanks

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Topic: 8C: Mastering Pre-Analytics: Key to Reliable Biobanking and Biomedical Research

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Keywords: Metabolomic, Pre-analytical variability, Quality Control

Although ELISA-based assays [1] have been published for assessment of blood precentrifugation conditions, metabolomics-based quality indicators capable of capturing the combined impact of multiple pre-analytical variations within a single biospecimen remain limited [2] and have been addressed in our study. This study measured nuclear magnetic resonance (NMR) detectable metabolomic signatures and evaluated a metabolomics-based biospecimen quality control (QC) score that could be applicable to biobank collections.

Serum and plasma biospecimens from healthy cohorts were collected under standardized conditions and exposed to controlled pre-centrifugation delays (≤ 3 h, 24 h, and up to 53 h) at different temperatures. NMR spectroscopy was performed for untargeted metabolomic

profiling and quantification of low-molecular-weight metabolites. A composite metabolomic QC score developed by lifespin GmbH was evaluated on this dataset using univariate statistical analyses.

Prolonged pre-centrifugation delays and elevated processing temperatures induced alterations in metabolites, such as glucose, lactate, and pyruvate, reflecting glycolytic activity, cellular hypoxia, and redox imbalance. The metabolomic QC score accurately discriminated biospecimens processed within acceptable pre centrifugation limits (≤ 3 h) from those exceeding 24 h for both serum and plasma. Additionally, the score differentiated processing temperatures and freeze–thaw cycles while also mirroring the results of IL8 and IL16 ELISA assays [1] and the plasma LacaScore [2].

NMR-based metabolomic profiling enables robust retrospective qualification and quality stratification of serum and plasma biospecimens. The proposed metabolomic QC score represents a complementary tool for assessing biospecimen fitness for metabolomics and other downstream applications, particularly in biobank collections with incomplete preanalytical annotation.

1. Kofanova O. et al. ClinChemLabMed.2018;56(7):1054-1062.
2. Trezzi J.P. et al. Metabolomics.2016;12:96.

Targeted Red Blood Cell lysis enhanced PBMC isolation does not impact cell viability, distribution or functionality.

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Topic: 8C: Mastering Pre-Analytics: Key to Reliable
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Presenter Name: Alanna Maguire

Keywords: LeucoSep, PBMC, Red blood cell lysis

Ficoll processing is the gold standard method for isolating peripheral blood mononuclear cells (PBMCs). However, Ficoll separation is labor-intensive and prone to technical variability, which is amplified in high-throughput, College-of-American-Pathologist (CAP) accredited laboratories. LeucoSep processing vastly improves throughput and consistency, but red blood cell (RBC) contamination, which negatively impacts downstream workflows, is observed in 5-10% of samples. This study investigated targeted RBC lysis and its impact on PBMC viability, distribution and functionality.

Six blood tubes (2xEDTA, 2xNaHep, 2xACD) were drawn from four donors. Duplicates were processed together in single LeucoSep tube. The PBMC layer was harvested and divided equally into 2 aliquots: one was RBC lysed, the other was not. AO/PI staining was used to determine cell counts and viability. Cells were analyzed using flow cytometry and the ELISpot assay to assess cell distribution and cell functionality respectively.

RBC lysis effectively depleted RBC contamination and preserved PBMC viability (>94%) irrespective of blood collection tube type. Only RBC-lysed-EDTA PBMC viability was significantly reduced compared to their unlysed counterparts (95% vs 97%, $p = 0.029$). Lymphocytes and monocyte populations exhibited ~80-20% distributions, respectively, across all tube types irrespective of lysed status. Only EDTA lysed and unlysed proportions were found to be significantly different (77% v 79% $p=0.012$ for lymphocytes, 18% v 15% $p=0.024$ for monocytes). ELISpot data showed no difference between lysed and unlysed PBMCs.

PBMC viabilities, distributions, and functionality maintained the expected patterns in tested groups. These findings indicate that RBC lysis has minimal impact on PBMC integrity.

Optimizing Cryopreservation Methods for Biobanking 3D Bioprinted Models

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Topic: 8C: Mastering Pre-Analytics: Key to Reliable Biobanking and Biomedical Research

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Keywords: Cryopreservation, bioprinting

Introduction: Long-term preservation of complex 3D bioprinted constructs represents a challenge for biobanking, as both structural integrity and cell viability must be maintained to ensure downstream usability. Cryopreservation of cell-laden hydrogels is under optimization, since freezing and thawing processes can affect matrix stability and biological functionality. This study aims to optimize cryopreservation protocols for 3D bioprinted constructs to facilitate their integration into biobanking workflows with a focus on preserving both mechanical properties and cell viability.

Materials and Methods: Alginate–gelatin (ALG-GEL) bioinks with different polymer concentrations were used to fabricate cylindrical constructs via extrusion-based 3D bioprinting². Printing accuracy and structural stability were evaluated under culture-like conditions. Human dermal fibroblast (AG01522)–laden constructs were cryopreserved using different freezing media and protocols. Controlled-rate freezing was performed using a Planer-PLC to precisely regulate cooling ramps. Post-thaw analyses included structural integrity assessment and cell viability assays (Live/Dead staining/AlamarBlue) were conducted at different time points.

Results: Among the tested formulations, the ALG4%–GEL4% formulation exhibited the highest structural stability, maintaining construct integrity for up to two weeks. Cryopreservation at –80 °C or in nitrogen vapor did not induce significant structural alterations. Skin fibroblast–laden constructs cryopreserved using optimized freezing media maintained high cell viability up to 7 days post-thaw. Freezing medium composition and cooling rate were identified as critical factors of preservation outcomes.

Conclusions and Discussion: Optimized cryopreservation protocols can preserve both structural and biological properties of 3D bioprinted constructs, supporting their integration into biobanking infrastructures for advanced in vitro models and translational research applications.

Optimization of Schirmer Strip Preservation and Extraction for Robust Tear Proteomics in Eye Biobanking

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Topic: 8C: Mastering Pre-Analytics: Key to Reliable Biobanking and Biomedical Research

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Keywords: Ocular Biobanking, Ocular Surface Biomarkers, Schirmer Strip, Tear

Background: Tears are vital for biomarker discovery, yet the lack of standardized preanalytical protocols for Schirmer strips leads to poor proteomic reproducibility. This study compared the effects of various storage conditions and surfactants on protein recovery and downstream proteomic outcomes.

Methods: Tear proteome stability was assessed at 4°C, -20°C, and -80°C over one week. Extraction efficiencies of 1% SDS, NP-40, and DOC were benchmarked against PBS using BCA assays and LC-MS/MS to evaluate recovery, coverage depth, and reproducibility.

Results: The tear proteome showed remarkable resilience, maintaining >90% integrity at -20°C and -80°C. Minimal degradation at 4°C after one week suggests a flexible logistical window for clinical acquisition. Regarding extraction, although surfactants yielded only moderately

higher total protein recovery compared to PBS, downstream proteomic analysis revealed that reagent selection was the primary determinant of functional depth. SDS significantly enhanced the recovery of lipid-related metabolic proteins, likely due to superior solubilization of membrane-associated components, whereas DOC and NP-40 were more effective for capturing immune-related components and inflammatory mediators. The optimized workflows consistently identified over 1,200 unique proteins per strip with a coefficient of variation <15%.

Conclusion: This study demonstrates the high stability of Schirmer-strip-collected tears under standard storage conditions and identifies the distinct functional proteomic profiles resulting from different extraction methods. These findings provide a valuable reference for the systematic establishment of high-quality ocular biobanks, facilitating the harmonization of large-scale cohort data and the acceleration of precision ophthalmology.

11C: Samples ready for multi-omics research

Biobanking a comprehensive longitudinal sample and data collection from healthy blood donors

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Topic: 11C: Samples Ready for Multi-Omics Research

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Keywords: blood donor, control, health progression, longitudinal collection

Introduction

Healthy donor effect is a concept used to describe a donor population with lower morbidity rates than the general population. Active blood donors with long-lasting donation careers have been shown to have a distinctive protective genetic profile against several diseases extending beyond blood donation criteria¹, forming a unique control set for biomedical research. Additionally, recurring longitudinal sample sets can be efficiently collected along regular blood donations without separate recalls.

Material & methods

Recruitable participants are blood donors, from whom DNA has already been biobanked (n~68 000). Each subsequent sampling consists of plasma, serum, and PBMC's, which are collected alongside donated blood. A complete blood count (CBC) is measured from whole blood at each time point.

Results

Deliberate longitudinal sample collection has been ongoing since January 2025. However, similar sample sets have been collected since 2021². More than 600 longitudinal sample sets have so far been collected, from at least two separate timepoints. CBC measurements are acquired from whole blood and results outside reference values are evaluated by a physician. Longitudinal collection of plasma has been identified as a priority from the standpoint of current multi-omics research and is therefore

being streamlined to accommodate quick and efficient.

Discussion

Our longitudinal project serves to strengthen the already existing collection from a healthy donor population. Individual biobank donors benefit from potentially significant information concerning their health being returned after sampling. Health-related research can benefit from well-defined healthy controls, especially when combined with clinical and registry data alongside disease progression.

References

1. Clancy et al., 2024, [org/10.1101/2024.06.18.24309089](https://doi.org/10.1101/2024.06.18.24309089)
2. Honkanen et al., 2025, [org/10.1101/2025.09.30.679473](https://doi.org/10.1101/2025.09.30.679473)

Biobanking For a National Multi-Omics Cancer Project

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Topic: 11C: Samples Ready for Multi-Omics Research

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Keywords: Multi-Omics, digital precision medicine, pan-cancer

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Multi-omics cancer studies provide an essential foundation for advancing personalised medicine by generating comprehensive molecular profiling datasets and systematically collecting high-value patient samples. In Finland's first digital precision medicine pan-cancer initiative, Helsinki Biobank (HBB) has served as the central access point for samples, metadata and clinical information, ensuring full compliance with the national Biobank Act as well as stringent protection of patient privacy.

Project-specific clinical and analytical requirements dictated the selection of sample types and sampling points for each patient. Dedicated expert groups provided support in molecular biology, histopathology, liquid sample processing, and data management, all coordinated by a Project Manager. Study participants were assigned pseudonymous identifiers, enabling secure linkage of samples and data.

Using integrated, multi-step processing pipelines, HBB handled and distributed samples for a wide spectrum of analyses, including whole-exome sequencing, RNA sequencing, tissue microarray construction, liquid biopsy assays, Peripheral Blood Mononuclear Cells (PBMC) isolation, and procurement of viable tumour cells from study participants. For a defined subset, HBB implemented an accelerated processing workflow to enable rapid turnaround of clinically relevant molecular findings with potential therapeutic implications. Comprehensive sample metadata and clinical variables were retrieved through institutional management systems, electronic health-record platforms and a hospital data lake.

Over the past eight years, HBB has successfully delivered samples and data for two national

large-scale research initiatives. With its extensive operational experience and wide-ranging collection of samples and datasets, HBB is well positioned to support future national and international multi-omics projects.

Integrated multiomics classification of triple negative breast cancer

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Topic: 11C: Samples Ready for Multi-Omics Research

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Keywords: QTL, RNA-seq, Triple-negative breast cancer, classification, cluster analysis, proteomics, treatment, whole exome sequencing

Triple-negative breast cancer (TNBC) is the most aggressive and heterogeneous BC subtype [1] primarily treated with systemic chemotherapy. To identify novel therapeutic targets, we used LC-DIA-MS/MS-based proteomics, RNA sequencing, and whole-exome sequencing for a set of 96 samples. Proteomics data were measured on timsTOF Pro in diaPASEF mode, providing a hybrid library containing 11,564 protein groups (FDR=1%) [2]. Hierarchical clustering utilizing proteomics data for 1,223 mostly correlated transcript–protein pairs stratified TNBC into 7 clusters: (i) mesenchymal stem like, (ii) basal/mesenchymal, (iii) cell cycle, (iv) immunomodulatory, (v) luminal androgen receptor, (vi) hormonal receptor+secretion and (vii) immunomodulatory+cell cycle. Among 225,001 germinal mutations identified, high impact ones included known tumor suppressor genes (*BRCA1*, *BRCA2*, *BARD1*, *BRIP1*, *PALB2*, and *CHEK1*), distributed mainly in Clusters 7 (30.00%) and 2 (23.83%). Out of 12,070 somatic mutations, *TP53* was the mostly mutated gene (67.71%), with the highest frequency in cluster 7 (86.36 %, $p=0.038$). Protein quantitative trait locus (pQTL) analysis identified 2 gene variants associated with changes in OAS1 protein levels. Analysis of proteomics data using AlteredPQR tool assigned alterations of relevant protein complexes. In summary, our study represents the most complete proteomics-driven multiomics study on TNBC tissues, providing highly relevant molecular classification of the patients.

1. Bouchal P et al, Cell Rep. 2019 16;28(3):832-843.e7

2. Lapcik P et al, Sci Data. 2024 18;11(1):794.

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MULTIOMICS AND TUMOR BANKING: COMPREHENSIVE PLATFORMS INTEGRATING CANCER DIVERSITY, BIOMARKER DISCOVERY, AND PERSONALIZED CANCER CARE

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Topic: 11C: Samples Ready for Multi-Omics Research

Presenter Name: Abhishek Mohanty

Keywords: Artificial intelligence, Biobanks, Cancer Diversity, Multi-OMICS, Precision Oncology

Statement of the Problem: Biobanks are innovative biomedical research infrastructure supporting investigations into cancer, covering aspects from its etiology, disease advancement, and therapy. The biobanks have contributed significantly to the advancement of personalized medicine, providing biospecimen resources and expertise in tissue handling that are required to understand the impact of various factors on cancer biology such as genetic, ecological and lifestyle on human disease, mortality, and wellbeing. With biobanks connecting to clinical, pathological, and epidemiological information,

understanding how their contribution to the discovery and development of biomarkers in the field of therapeutics is vital for their ongoing management, funding, and sustainability.

Proposed Solution: Cancer biospecimen contain the biological information that reflects the nature of a patients 'disease, biobanks must be managed as part of the data generation and analytics continuum that drives precision medicine. The advancement of multi-OMICS analytics with artificial intelligence, systems biology and deep machine learning has elevated the field of personalized onco-medicine only serving to emphasis biobanking human biospecimens as an informatics concern as well. In this presentation we will explore the impact of biobanking in facilitating bench-to-bedside oriented and multi-OMICS data driven translational cancer research and biomarker discovery, much needed assets to enable precision medicine.

Conclusion: Biobanking serve as fundamental components of multi-OMICS approach in cancer management, making them the cornerstones of personalized medicine by providing the biological samples and associated data needed for comprehensive molecular profiling, biomarker discovery, and personalized treatment strategies, thereby aiding in the tailoring of individualized patient treatment and precision oncology.

Multi-omics analyses of osteogenically induced adiposederived stem cells as a tool for biomed research

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Topic: 11C: Samples Ready for Multi-Omics Research

Presenter Name: Stefan Rudziński

Keywords: ADSC, biobanking, immunomodulation, multi-omics, osteogenic differentiation, regenerative

medicine Introduction

Advances in multi-omics technologies place increasing demands on biobanks to deliver biospecimens suitable for integrated multi-omics studies. Adipose-derived stem cells (ADSCs) are widely studied in the context of osteogenic differentiation. In this study, we demonstrate that the osteogenically induced ADSCs preserve their immunomodulatory potential despite the initiated differentiation process.

Materials and methods

ADSCs from four donors were isolated, expanded, divided into 2 technical replicates for each donor/condition, and cultured in either standard medium or osteogenic medium for 10 days. All procedures, including cell seeding, culture medium turnover (every 3 days), incubation conditions (37°C, 5% CO₂), cell harvesting, and rapid stabilization in -80°C, were standardized across all samples. Cell pellets were then thawed and processed for RNA or protein isolation and subsequent RNA-seq (NovaSeq 6000, Illumina) or LC-MS/MS (ZenoTOF 7600) pipelines to compare undifferentiated and differentiated ADSCs.

Results

For proteomic analysis, 854 significantly regulated proteins (p <0.05; no FC threshold) were observed in MaxQuant analysis. Further analysis with stricter thresholds (-log₁₀ p > 5 and > 10) showed that identified changes in proteomics aligned with pathways related to

osteogenic differentiation, immune events, and cell cycle and cell senescence, with upregulated proteins such as STAT3, HLA-A, HLA-C, ICAM1, LTA4H, LTF, and CAT. The transcriptomic analysis yielded over 16,000 significant identifications. Both analyses showed 444 pairs with weak linear correlation (Pearson $r = 0.074$).

Discussion & conclusion

This study shows that osteogenically induced ADSCs preserve their immunomodulatory potential, as observed in the proteomic landscape, and highlights the challenges associated with multi-omics analyses.

Track four: Advancing biobanking: Skills, partnerships and sustainable solutions for the future

3D: Returning biobank data to participants: Closing the loop

Advancing precision medicine through return of biobank results

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*Topic: 3D: Returning biobank data to participants:
Closing the loop*

Presenter Name: Minja Pehrsson

Keywords: Return of results, precision medicine

Advancing precision medicine through return of biobank results

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Large-scale biobank datasets offer major opportunities to advance personalized medicine. We present three implemented use cases demonstrating how the return of biobank results can accelerate the translation of research findings into clinical practice, delivering tangible benefits to biobank participants.

First, opportunistic screening of biobank samples enables identification of individuals at increased risk for conditions with available preventive or therapeutic interventions. Finnish hospital biobanks have developed a scalable model for transferring findings to donors and healthcare. Screening for hereditary cancer risk identified over 200 previously undiagnosed donors, all referred to preventive care, demonstrating how biobanks can operationalize early detection and risk-based prevention at scale. Second, biobanks' extensive health data repositories can accelerate rare disease diagnosis. Systematic clinical data analysis combined with genetic testing of biobank samples identified several previously undiagnosed individuals with rare conditions, who were then directed to appropriate care pathways. This illustrates the potential of biobanks to proactively detect rare diseases unrecognized in routine care. Third, integrating tumour molecular profiling from biobank samples into oncology decision-making supports precision medicine and more refined cancer treatment strategies. This shows how biobank-derived results can directly inform personalized therapeutic decisions.

These cases support a more active role for biobanks in returning clinically relevant results to strengthen research–healthcare integration and maximise health impact. A prerequisite for a functioning return process is close collaboration

between the biobank, clinical services, and diagnostics.

Biobank participants' choices regarding unsolicited findings and feedback

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Topic: 3D: Returning biobank data to participants: Closing the loop

Presenter Name: Peggy Manders

Keywords: ELSI, return of results, unsolicited findings

During the first Europe Biobank Week (Vienna – 2016), the Department of Human Genetics at Radboudumc, Nijmegen, The Netherlands presented its policy on dealing with unsolicited findings. Here, patients may choose single candidate gene testing or genetic testing with a higher diagnostic yield accompanied by a chance of unsolicited findings. Following positive advice from an expert committee unsolicited findings are linked back to the patient.

This approach has served as a basis for the biobank participant consent template where biobank participants can give permission for research with the possibility of unsolicited findings and feedback or withhold permission. In the latter case, the participant's material can only be used for research where there is no chance of unsolicited findings. A survey was conducted to determine the response of biobank participants.

A total of 72 collections were contacted of which 22 responded (31%). Four collections indicated

the data was not readily available. The results from the 18 collections that responded show that a large majority of participants give permission for research with the possibility of unsolicited findings and feedback (median: 91%, range: 60-10%). A small group of participants withheld permission (median: 6%, range: 0-40%).

Sharing unsolicited findings with biobank participants involves participant autonomy and risk of distress. Our results show that if participants are well informed about the possibility of finding unsolicited findings and the associated feedback, they're more likely to agree to research with the possibility of unsolicited findings and policies that include unsolicited finding feedback.

6D: Patient-centric biobanking: Strategies for engagement and participation

Biobanking for long covid

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Topic: 6D: Patient-Centric Biobanking: Strategies for Engagement and Participation

Presenter Name: Eric Vermeulen

Keywords: Long covid, patient and public involvement and engagement

Introduction – summarising the background/problem

Biobanking is very important for patients with long covid. Identifying underlying biological mechanisms, discovering biomarkers and comparisons with related conditions are crucial for people with this condition that is complex and poorly understood. Biobanking also offers

patients the opportunity to be involved and engaged in research.

Material & methods used to obtain and analyse the data

Description of practices. Interviews with biobank staff and patient representatives in the context of the NMCB biobank in the Netherlands

Results or findings from your work

Biobanking for patients with long covid is crucial for the patient group because of the focus on biological factors. The medical condition of the patients makes adaptations of biobanking practices necessary. The patient group is very interested to participate in procedures of the biobank, is involved in different levels of governance.

Discussion and conclusion that will help others in their work

Biobanking represents attention for biological factors at play in long covid. It is therefore considered to be very important by the long covid patient group. The biobank can organise patient and public involvement and engagement at different levels. Patient representatives co-create with biobank staff.

Stakeholder engagement in European cancer research biobanking: preliminary insights from a scoping review

Authors:

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Topic: 6D: Patient-Centric Biobanking: Strategies for Engagement and Participation

Presenter Name: Arthur Haerinck

Keywords: biobank, stakeholder engagement

Introduction: Cancer poses a growing societal challenge in Europe, underpinning the ambition of the EU Mission on Cancer to improve the lives of more than three million people by 2030. Achieving this requires next to scientific innovation, sustained societal collaboration. Advances in artificial intelligence (AI) and cross-border health data sharing, such as the European Health Data Space, intensify the need for trust, legitimacy and public support. Biobanks are pivotal infrastructures in this landscape, operating at the intersection of patients, researchers, healthcare systems, industry and policymakers. As biobanks increasingly integrate large-scale data and AI-driven research, stakeholder engagement is essential to address ethical, legal and societal implications and to ensure sustainable innovation.

Methods: As part of the PERIFORMANCE project, a scoping review was initiated following PRISMA-ScR guidelines to map current stakeholder engagement practices in European cancer research biobanking. Peer-reviewed and grey literature published between 2016 and 2026 will be systematically screened, including guidelines, policy documents and engagement materials from 22 BBMRI-ERIC member states.

Results: Preliminary findings indicate substantial heterogeneity in engagement activities, varying in scope, format, and formalization. Despite this diversity, recurring objectives emerge, including awareness-raising, transparency in data handling, understanding stakeholder expectations, harmonizing practices, and fostering sustainable collaboration.

Discussion and conclusion: The preliminary synthesis provides already an interesting

landscape of existing knowledges and practical applications for stakeholder engagement. Upon completion, the review will serve as a practical resource for biobanks and their networks, as well as other research infrastructures to optimize their stakeholder engagement activities.

Stakeholder engagement in European cancer research biobanking: preliminary insights from a scoping review

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Patient-Engaged Surgical Oncology Biobanking as a Platform for Translational Precision Oncology

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Topic: 6D: Patient-Centric Biobanking: Strategies for Engagement and Participation

Presenter Name: Yue Zhao

Keywords: Biobank, Liquid biopsy, Precision oncology

Introduction: Comprehensive biobanking is essential for advancing precision oncology by enabling large-scale tumor analysis for cancer patients.

Objective: To establish a high-quality, clinically annotated biobank supporting translational research specific strategies in surgical oncology.

Methods: By collaborating with Patient Self-Help Group for Esophageal Diseases and Gastric Cancer, Cologne Surgical Oncology Biobank has established standardized protocols for processing, storing and analyzing tissue biopsies and liquid biopsies. All samples were collected

with clinical annotations to support translational research. Preliminary data were obtained from metabolomics analysis targeting 250 markers in the serum of Esophageal Adenocarcinoma (EAC) patients before and after neoadjuvant therapy.

Results: Since November 2016, 4,716 liquid biopsies from 4,375 patients have been collected. Our cohort includes 1339 esophageal or esophagogastric junction adenocarcinomas, 686 colorectal cancers, 359 gastric cancers, among others. Our biomarker-oriented studies based on this resource analyze the samples including cfDNAs, CTCs, miRNAs, cytokines through various omics approaches. Insightful metabolomic dynamics were observed in CROSS-treated and FLOT-treated EAC patients.

Conclusions: Our biobank serves as a pivotal platform for investigating cancer biology, supporting integrative profiling to uncover mechanisms of tumor development, progression, and treatment response. Sustained biobanking efforts are essential to facilitate precision medicine approaches, and future studies leveraging this resource may identify novel biomarkers and specific therapeutic targets.

Inclusive Consent Strategies Across Donor Life Stages in Biobanking

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Topic: 6D: Patient-Centric Biobanking: Strategies for Engagement and Participation

Presenter Name: Teresa Botta-Orfila

Keywords: ELSI, Informed consent, accessibility in research, patient engagement

Introduction: Patient-centric biobanking requires continuous adaptation of ethical, legal and social implementation (ELSI) frameworks to evolving research practices. As biomedical research increasingly relies on advanced biological derivatives, biobanks must ensure participant understanding of sample use while safeguarding autonomy, inclusiveness, and transparency. In this context, informed consent (IC) should function as an operational tool enabling clear, inclusive, and age-appropriate communication in routine biobank practice.

Materials and Methods: We revised our IC to address emerging needs, including plain-language explanations of advanced uses of biological samples, post-mortem donation, consent by legal representatives, and assent by minor donors over 12 years of age. In parallel, we developed a multilingual information leaflet for minors and their families. The database from our Laboratory Information Management System (LIMS) is analyzed by computational pipeline which allows alerts to ensure re-consent of donors enrolled as minors upon reaching legal adulthood, while also promoting awareness of core biobanking principles and data quality.

Results: The revised IC improved clarity and transparency regarding downstream uses of biological samples. Plain-language explanations, multilingual materials with inclusive and accessible formats, enhanced participant understanding and accessibility. Tailored resources for minors supported early engagement and autonomy, while LIMS-based re-consent alerts strengthened governance, traceability and regulatory compliance. An

informative Biobank leaflet for minors is currently under development in multilingual formats.

Discussion and Conclusion: Integrating ELSI principles into operational tools reinforces trust, accountability and engagement, supporting robust patient-centered biobanks and positioning them as responsible partners in inclusive, transparent research ecosystems long-term commitment.

8D: Synergising resources: Public-private collaboration in biobanking infrastructure and research

NURTuRE: biobanking as community infrastructure

Authors:

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Topic: 8D: Synergising Resources: Public-Private Collaboration in Biobanking Infrastructure and Research

Presenter Name: Gaia Cantelli

Keywords: biobanking, biopsies, blood, data, kidney, multiomics, nephrology, plasma, renal, urine

The National Unified Renal Translational Research Enterprise (NURTuRE) is the UK's first national kidney biobank and a scalable model for synergistic public-private collaboration in biobanking. Established and led by Kidney Research UK, NURTuRE was designed to address fragmentation in kidney research infrastructure by integrating academic, NHS, data custodian, and industry capabilities within a single, harmonised framework. Its overarching objective is to accelerate equitable translational research through high-quality biospecimen collection linked to comprehensive longitudinal clinical data.

NURTuRE comprises national cohorts of approximately 3,000 participants with chronic kidney disease (CKD) and over 700 participants with idiopathic nephrotic syndrome (INS), with ongoing expansion to acute kidney injury (AKI). Biospecimens include plasma, serum, urine, DNA, and kidney tissue, processed and stored using standardised operating procedures. These resources are linked to over 150 phenotypic variables and long-term outcomes via the UK Renal Registry, NHS Digital, and secure trusted research environments, enabling robust, reproducible analyses.

The biobank is underpinned by formal partnerships with academic institutions (including the University of Bristol and the University of Nottingham) and a diverse portfolio of industry collaborators, including AstraZeneca, UCB, Travele Therapeutics, Evotec International GmbH, and Nephrolyx GmbH. Governance structures ensure ethical oversight, data security, sustainability, and equitable access for both academic and commercial research.

NURTuRE demonstrates how coordinated public-private biobanking infrastructure can maximise research value, enhance translational impact, and provide a reproducible model for disease-focused biobanks across Europe.

Public-Private Collaboration in Action: Building a Sustainable National Biobank Platform in Germany

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Topic: 8D: Synergising Resources: Public-Private Collaboration in Biobanking Infrastructure and Research

Introduction - background/problem

Europe's health research increasingly depends on access to large, high-quality biobank resources. While several countries operate strong national infrastructures, fragmentation, limited scale, and sustainability challenges remain. Germany is launching a major initiative to establish a National Biobank Platform, designed to consolidate distributed resources, strengthen public-private collaboration, and enhance European competitiveness in biomedical research.

Material & methods

This contribution presents the strategic, structural, and governance framework of the "Biobank Platform for Germany", developed through an unprecedented alliance between academic biobanks, the Network of University Medicine (NUM), industry associations, and policy stakeholders.

Results

The platform will function as a digital one-stop-shop within the NUM, connecting academic biobanks with other powerful infrastructures such as the NUM Study Network or the Data Integration Centres. This integrated setup enables standardised discovery, access coordination, and harmonised sequencing as well as data services. Crucially, the initiative introduces mechanisms to return generated research and analysis data to the infrastructure. The aim here is to facilitate reuse and to increase scientific value over time. Industry partnerships

contribute use cases, technical expertise, and sustainable financing beyond public grant cycles.

Discussion and conclusion

This initiative represents one of Europe's most ambitious biobanking investments. Its scale, population diversity, and interoperability strategy offer advantages complementary to existing models such as UK Biobank. Beyond infrastructure, it serves as a best-practice example of coordinated political advocacy and stakeholder alignment.

Public-private collaboration in Finnish Biobanks

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Topic: 8D: Synergising Resources: Public-Private Collaboration in Biobanking Infrastructure and Research

Presenter Name: Johanna Mäkelä

Keywords: Collaboration, Partnerships, Public-private, Sustainability, co-creation, impact

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Introduction: For the past 10 years in Finland, the Finnish Biobanks have successfully collaborated and partnered with researchers from both academia and private sector. The national Fingenious(R) service was established to foster and ease the collaboration in both academic and private collaborations. So far over 500 projects have been completed, of which 1/3 are industry-driven.

Materials & methods: In this analysis we gathered key success factors on public-private collaborations based on our experience in

Finland. We will focus on how to build up from first contact to collaboration and partnerships and what are the potential hurdles along the way. In addition, we will provide an overview of the benefits of public-private collaboration and partnerships for biobanks.

Results and findings: Public-private collaborations have been crucial in the development of Finnish Biobanks and further development is needed to foster the collaborations. We will showcase real-life examples on collaborations and partnerships and share our insights on how biobanks can build successful partnerships with private sector. We will share also the hurdles we have encountered and how the challenges have been solved.

Discussion and conclusion: This analysis will show an overview of current opportunities and challenges in public-private collaboration in Finnish Biobanks.

“It's very complicated to trust companies when you feel like: I don't have the right information!” How can research infrastructures facilitate research by companies in ways that align with citizens' expectations?

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Topic: 8D: Synergising Resources: Public-Private Collaboration in Biobanking Infrastructure and Research

Presenter Name: Miriam Beusink

Keywords: citizen engagement, commercial perspective, commercial use, patient perspective, research infrastructure

Introduction

The success of research infrastructures depends on addressing all stakeholders' interests and concerns. Commercial companies play a key role in research and healthcare innovation, yet citizens often perceive commercial use of data and samples as sensitive. This study explores shared perspectives and points of contrast between citizens and companies, and their expectations regarding the conduct of research.

Methods

Interviews and a focus group with citizens and companies were conducted to investigate concerns regarding companies using health data for research, and how research infrastructures could address shared concerns.

Results

Interviews (20 participants) and one focus group (19 participants) identified concerns and potential solutions of use of data and samples in research, clustered into three themes.

1. Trust. Both groups emphasized the importance of transparency and robust supervision to increase trust. Citizens additionally expected companies to publish results even when findings are unfavorable to commercial interests.
2. Value creation. Citizens recognized that companies may develop healthcare innovations more rapidly than academic or healthcare institutions and noted that complex infrastructures and regulatory barriers can impede this. However, return of benefit to society was considered important, though views differed on its form and extent.

3. Both citizens and companies expressed a desire for improved dialogue and collaboration. Citizens wanted the ability to exclude specific companies from using data, while companies preferred review based on research purpose rather than commercial identity.

Discussion

Further research is needed to determine how shared solutions can be implemented and conflicting interests could be bridged in research infrastructures, to enable socially acceptable commercial use of health data.

11D: Eco-friendly green biobanking: Innovations and solutions

Embedding Environmental Responsibility in Biobank Governance: The CEPH-Biobank Experience

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Topic: 11D: Eco-Friendly Green Biobanking: Innovations and Solutions
Presenter Name: H  l  ne Blanch  
Keywords: BioCF, CEPH-Biobank, CSR, environment, vapor-nitrogen

Biobanks are essential infrastructures for health research, but their activities—from sample collection to long-term ultra-low temperature storage—generate a substantial environmental impact. Energy-intensive freezers, large-scale logistics, and extensive use of consumables raise major sustainability challenges, making environmental responsibility a key issue in biobank governance.

The Jean Dausset Foundation, awarded the Ecovadis Bronze label in 2025, and its Biobank, certified ISO 20387 and ISO 9001 since 2020, are strongly committed to addressing these challenges. As part of the BioCF (French Cohorts' Biobank) project, the French counterpart of the UK Biobank, the CEPH-Biobank centralized about 1.6 million samples, between 2022 and 2025, from several national cohorts previously stored across multiple sites in France and Luxembourg. This large-scale centralization required a significant expansion of storage capacity.

In line with sustainable development objectives and Corporate Social Responsibility (CSR) principles, the CEPH-Biobank implemented measures to reduce its ecological footprint while expanding storage at $-80\text{ }^{\circ}\text{C}$ and in vapor-phase nitrogen. For the CONSTANCES collection, a new generation of vapor-phase nitrogen cryocontainers (Fusion tanks, MVE) was deployed, enabling nitrogen recycling and markedly reducing liquid nitrogen consumption. Eighteen tanks have been operational since July 2025.

In addition, the CEPH-biobank has long promoted plastic recycling and regularly optimizes freezer and cryogenic tank organization to limit electricity and nitrogen use. This experience demonstrates that integrating environmental responsibility into high-throughput biobanking operations is both feasible and essential for advancing sustainable and responsible science.

Learnings from the Green Biobanking Survey of BBMRI.at Biobanks

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Topic: 11D: Eco-Friendly Green Biobanking: Innovations and Solutions

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Keywords: BBMRI.at, energy-intensive, environmental impact, greening

Introduction

The green bio banking survey was conducted within the EvolveBBMRI project and the BBMRI-ERIC Work Programme strategic objective SO3.1 (Foster Greening for biobank operations through mapping the challenges). Preliminary Europe-wide results were presented at the EBW 2025 in Bologna. This abstract focuses on responses from BBMRI.at partner biobanks.

Material and Methods

We reviewed the answers from the BBMRI.at biobanks, clarified ambiguities in personal discussions with the biobanks and requested additional information where needed. To better understand their environmental impact, we also asked partners to provide an overview of their infrastructure (e.g., number of freezers, automated storage systems, and other large equipment).

Results

Nearly all BBMRI.at biobanks rely on the Austrian electricity mix (fossil and renewable sources), operate energy-intensive systems (e.g., HVAC, cryogenics storage, ULT freezers) and report limited awareness of equipment energy efficiency. Specific water management measures are absent, and waste reduction efforts are modest beyond standard separation; only a minority engages in specialized recycling or reuse initiatives. No formal data management strategies target carbon reduction. Identified key barriers include limited product availability, insufficient knowledge and funding, and limited management support.

Conclusion

This survey provides an initial overview of the sustainability landscape of BBMRI.at partner biobanks including awareness and practices related to energy, waste management, water and resource usage, as well as future planning. The findings highlight clear opportunities for improvement and help to identify potentials and the planning of the next steps within the BBMRI.at consortium.

Towards Sustainable Biobanking: The Impact of Ultra-Low Storage Temperature on Sample Quality and Energy Consumption

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Abstract ID: 630

Topic: 11D: Eco-Friendly Green Biobanking: Innovations and Solutions

Presenter Name: Hannah van der Stok

K

eywords: -80°C vs. -70°C, Sustainability, sample integrity

Introduction

Biobanking has proven to enhance scientific research across many fields. Despite the positive impact of biobanking on research quality, its environmental footprint has received comparatively little attention. Ultra-low temperature (ULT) freezers are substantial energy consumers, using the equivalent of 2-3 households daily. Recent initiatives promote raising storage temperatures from -80°C to -70°C to reduce energy consumption and environmental impact. However, concerns persist regarding sample safety and quality, and consensus on biologically optimal ULT storage temperature is lacking. Evidence supporting the necessity of -80°C storage is minimal, and studies reporting no adverse effects of storage at -70°C are limited in scope and size.

Methods

In this study, we systematically evaluated the stability of various biologically relevant biobank samples, including patient-derived blood plasma, cerebrospinal fluid, peripheral blood mononuclear cells (PBMC), RNA, viruses, and bacteria. These samples were stored at -80°C, -70°C, and -60°C and assessed over time.

Results

Mixed-effects modelling of plasma samples revealed no significant differences between -80°C, -70°C, and -60°C at 1,3 and 6 months, indicating comparable analyte stability across storage temperatures. Data for the 12-months timepoint are expected soon, together with initial results for PBMCs, RNA, and bacteria.

Discussion

In the coming years, our aim is to further clarify the relationship between storage temperature

and sample quality to provide a robust scientific basis for optimizing biobanking practices. This will enable laboratories to reduce energy consumption and operational costs while maintaining high standards of sample integrity, supporting both sustainable and high-quality research.

Greener Biobanking Beyond Temperature Adjustment

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Abstract ID: 631

Topic: 11D: Eco-Friendly Green Biobanking: Innovations and Solutions

Presenter Name: Hilde Laeremans

Keywords: Green, HD racks, gases

The ecological footprint of laboratory operations receives increasing attention in recent years, particularly due to their substantial impact on the environment. Within this context, biobanking represents a significant contributor, as long-term storage of biological samples at -80 °C is highly energy intensive and therefore a major source of environmental impact. While some biobanks have explored raising storage temperatures as a mitigation strategy, Lifelines has chosen an alternative approach that prioritizes sample quality while substantially reducing environmental burden.

To ensure long-term sample integrity, Lifelines maintains ultra-low temperature storage at -80C but focuses on optimizing storage efficiency and cooling technologies. As a first step, all conventional 96-well storage racks are being replaced with high-density racks capable of holding 138 samples. This transition results in approximate 40% increase in storage capacity within the same physical footprint, reducing the

need for additional storage. Although reformatting an entire biobank collection is a complex and labor-intensive process, Lifelines has collaborated with industrial partners to develop a high-throughput reformatting system that preserves sample integrity throughout the process. All decommissioned racks are fully recycled, further contributing to sustainability.

In a second phase, Lifelines will replace traditional cooling gases with carbon dioxide (CO₂), a more environmentally friendly alternative. Additionally, part of the required energy is supplied by an on-site solar park. In the final phase, waste heat generated by the cooling systems will be reused.

Collectively, these measures reduce the ecological footprint of biobanking more effectively than temperature adjustment alone, while maintaining the highest standards of sample quality.

Sustainable Cold Storage Transformation: Achieving Over 500,000 kWh Annual Savings Through Strategic Choices at Amsterdam UMC

Authors:

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Abstract ID: 711

Topic: 11D: Eco-Friendly Green Biobanking: Innovations and Solutions

Presenter Name: Aram de Haas

Keywords: Energy, Environment, Procurement, Reimbursement scheme, Sustainability, Tender, ULT

Introduction:

Sustainability is a critical challenge for (biobanks with extensive) cold storage infrastructure. We implemented interventions to reduce the environmental and financial impact of ULT

storage within and beyond the Biobank core facility.

Methods:

We highlight three (executed) strategies:

1. Raising setpoints of majority of ULT freezers from -80°C to -70°C ,
2. A national freezer clean-out initiative,
3. Developing plans for further cold storage optimization.

Annual energy consumption, CO₂ emissions, and costs were calculated for interventions.

Results:

Implemented:

- **ULT Setpoint Increase:** 60% of 550 freezers (n=330) raised to -70°C , achieving annual savings of 544.500 kWh, 270.572 kg CO₂eq, and €119.790.
- **Clean-Out Campaign:** Freeing storage equivalent to 35 ULTs, further reducing space.

Future Plans & Potential (estimates):

- **Replacement Scheme:** Reimbursement scheme launched in 2026 for retiring 150 old energy-inefficient ULTs (avg. 7,250 kWh/year) and replacing with 100 new (3,000 kWh/year) saving 787.500 kWh, 391.413 kg CO₂, and €173.250 annually.
- **3rd Nordic System:** Acquiring another Nordic Carnot centralized ULT system, replacing 100 solo ULTs, yields additional energy and reliability benefits.
- **Tender pricing:** ULT tender bids equally include purchase price, energy costs, and environmental damage.

Discussion & Conclusion:

Temperature setpoint optimization and efficient sample management have already yielded over half a million kWh and 271 tons CO₂ savings annually. Strategic equipment choices, such as freezer renewal and Nordic system scale-up, will multiply these gains. Immediate, targeted decisions on temperature policy and storage solutions supported by institutional green teams and management bodies offer significant, rapid returns—an approach biobanks can adopt for maximum impact.

Special sessions

9A: Disease domain-specific biobanks – Rare disease insights

Harmonization of Common Data Elements for Rare Disease Biobanks and Registries Using the CARE-SM Semantic Model

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Topic: 9A: Disease Domain-specific Biobanks – Rare Disease Insights

Presenter Name: Kristina Vodomezova

Keywords: rare diseases; biobank data integration; common data elements; semantic interoperability; patient registries

Introduction

Rare disease biobanks are essential for research and diagnostics, yet their value is limited by a lack of semantic interoperability between biobanks and patient registries, hindering collaboration

and reuse of scarce biospecimens. This gap is reflected in the RD-Connect Sample Catalogue, where patient registry data are available for only 1 out of 15 registered biobanks [1].

Methods

The CARE Semantic Model (CARE-SM) [2], originally designed for rare disease patient registries, was extended to support semantic integration with biobank data. Researcher data requests from Amsterdam UMC and biobank management system schemas (OpenSpecimen) were used to identify biobank-related common data elements (CDE) requiring interoperability with registry-related data elements. A three-way mapping was performed between OpenSpecimen data dictionaries, standardized researcher data request schemas, and CARE-SM data elements.

Results

CARE-SM was extended with data elements relevant to rare disease research and biobanking, such as cohort description. Existing elements were refined to support modeling of biospecimen-related concepts, including biobank and consent. All data elements were represented using relevant domain ontologies and aligned with Semantic Science Integrated Ontology, the foundational ontology of CARE-SM.

Discussion and Conclusion

This work presents a preliminary semantic modeling effort aimed at improving biobank data integration. It focuses on harmonizing common data elements between rare disease biobanks and patient registries and demonstrates the feasibility of interoperability testing.

References

- [1] [RD-Connect Sample Catalogue.](#)
 [2] [Alarcón-Moreno P, Wilkinson MD. CARE Semantic Model \(2024\).](#)

Practical application of FISMA in the Duchenne/Becker Biobank at LUMC: Curated registration at the source yields RWD for many purposes

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Topic: 9A: Disease Domain-specific Biobanks – Rare Disease Insights

Presenter Name: Roger Snijder

Keywords: Becker muscular dystrophy, Duchenne Centre Netherlands, Duchenne muscular dystrophy, FAIR, FISMA, Netherlands, Open Terminology Server, biomaterials, real-world data, registration at the source

Duchenne and Becker muscular dystrophy (DBMD) lack curative treatments. Registers can facilitate therapy development, aid in studying epidemiology, assess trial feasibility, collect real-world data (RWD), perform post-market surveillance, and collaborate in (inter)national initiatives.

For all these purposes, it's crucial to gather high-quality, interchangeable, and reusable data from a representative population. Duchenne Center Netherlands has developed and adopted a conceptual framework, FISMA (Framework for Information Specification, Modelling and Architecture), that allows capturing real-world data (RWD) as relevant, re-usable and

semantically interoperable data by adding observational context and enhances data quality at the source.

By implementing FISMA in LUMC's Electronic Health Record (EHR, HiX) as well as its Biobank Information System (BIMS, Sample Navigator), we can collect RWD in a rich observational context, with annotations pertaining standards of care, protocols, scientific validations for used tools, scales and measures, across any specialism that is relevant to clinical care of DBMD patients.

In this poster, we will offset our biomaterials against all relevant categories of observations, for which we have collected FAIR data at the source. Furthermore, we will detail studies and exploratory investigations that have been made possible without any further curation, as FISMA allows for semantic interoperability to suit the purpose of researchers involved. In particular, we will present a biomarker study made possible by the association of clinical data and richly annotated biomaterials, where FISMA aligns with BBMRI's Data Quality's views on material provenance, and expands beyond those standards.

Integration of Neurosciences Biobank of Bologna in ClinicalCare Pathway: A Strategic Model for Rare Disease Research in Hereditary Optic Atrophy

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Topic: 9A: Disease Domain-specific Biobanks – Rare Disease Insights

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Keywords: DOA, LHON, genetic disease, hereditary optic atrophy, hub and spoke, mitochondrial disease, neuroscience biobank of bologna, rare disease, research

Introduction: Dominant optic atrophy (DOA) and Leber hereditary optic neuropathy (LHON) are rare neuropathies caused by mitochondrial dysfunction, characterized by selective retinal ganglion cells degeneration. In the study of rare diseases, the availability of biological samples and associated data is limited, therefore biobanks play a pivotal role by enabling the investigation of large patient cohorts. Emilia-Romagna Region, in Italy, has established local Hub-and-Spoke networks to integrate clinical and diagnostic pathways. In this context, Neuroscience Biobank of Bologna (BNB) acts as a strategic tool to facilitate Hereditary Optic Atrophy patient recruitment and advance research.

Methods: The BNB was involved into routine clinical workflows at the IRCCS Institute of Neurological Sciences of Bologna. Standardized procedures, compliant with ISBER and BBMRI-ERIC standards and GDPR regulations, ensure quality, traceability, and ethical governance. During routine visits, clinics recommends patients to provide informed consent for biobanking. Samples are processed according to

validated SOPs and stored at -80°C . An ISO9001:2015-certified quality system and a Laboratory Information Management System (LIMS) link samples to clinical datasets following FAIR principles.

Results: Since February 2024, 105 samples from 22 patients have been acquired. Blood, saliva, DNA and associated data were collected from each of them. Harmonized clinical dataset and high-quality sample acquisition were generated.

Conclusions: The integration of BNB into the care pathway is a sustainable model for enhancing the collection of high-quality biological samples and associated clinical data. This project describes a validated process for developing innovative research projects, strengthening international collaborations and improving the management of patients with rare optic neuropathies.

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[3]<https://doi.org/10.1016/j.spen.2017.06.001>.

9B: Disease domain-specific biobanks – Oncology insights

Disease Domain–Specific Biobanks in Oncology: Insights from the ISOBM Perspective

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Topic: 9B: Disease Domain-specific Biobanks – Oncology Insights

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Keywords: ISOBM, diseases focused biobanks, oncology

Disease Domain–Specific Biobanks in Oncology: Insights from the ISOBM Perspective

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Disease domain–specific biobanks play a crucial role in advancing oncology research by enabling systematic collection, characterization and utilization of high-quality biospecimens and associated with detailed clinical and molecular data. From the perspective of the International Society of Oncology and Biomarkers (ISOBM), oncology-focused biobanks represent essential infrastructures for biomarker discovery, validation, and clinical translation.

Oncology biobanks serve as specialized platforms that reflect the complexity and heterogeneity of cancer. By focusing on specific tumor types, disease stages, or treatment contexts, they enable deep phenotyping and longitudinal sampling that are critical for understanding tumor biology, therapy response, resistance mechanisms, and disease progression. ISOBM has long emphasized the importance of standardized pre-analytical and analytical procedures, robust quality control, and fit-for-purpose sample collection to ensure reliability and reproducibility of biomarker research outcomes.

Through its research and education activities, ISOBM provides guidance on best practices in biospecimen handling, biomarker qualification, and data integration, thereby supporting oncology biobanks as key enablers of translational research. These biobanks act as interfaces between clinical oncology, laboratory medicine, and bioinformatics, facilitating collaboration among clinicians, researchers, and

industry partners. Their disease-oriented focus allows for more efficient study design and accelerates the pathway from discovery to clinical implementation.

In conclusion, oncology-specific biobanks, aligned with ISOBM principles, are indispensable facilitators within the cancer research ecosystem. By integrating high-quality biospecimens with biomarker expertise, they enhance the development of precision oncology and contribute to improved patient stratification, diagnosis, and therapeutic decision-making.

9C: Disease domain-specific biobanks – Neuroscience insights

From Federated Pilot to National Node: Advancing Neurodegenerative Biobanks through Data Quality and Phenotype Clustering

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Topic: 9C: Disease Domain-specific Biobanks – Neuroscience Insights

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Keywords: data quality improvement, federated biobanking, multi-institutional data sharing, neurodegenerative diseases, phenotype clustering

Biobanks supporting neurological and neurodegenerative research manage rich clinical and genomic datasets, yet transforming heterogeneous clinical documentation into research-ready data remains a major bottleneck. Although privacy-preserving federated data sharing is conceptually established, its implementation across real, multi-institutional biobank environments and scalability toward national infrastructures remain challenging.

We present a follow-up project of the Semmelweis Federated Platform (FedX), focusing on the federated integration of biobank datasets from Semmelweis University and the University of Szeged to model a national-level federated biobank node. The system is evaluated through two pilot use cases: neurodegenerative disorders and hereditary cancer syndromes, enabling comparative methodological insights across disease domains.

The neurodegenerative pilot focuses on structured, disease-specific phenotype profiles enriched with family history, comorbidities, multi-ontology annotations, and longitudinal clinical events. This approach enables the identification of phenotype-based clusters and subtypes, including patients with complex movement disorders, overlapping motor and cognitive features, or atypical disease trajectories outside predefined diagnostic categories. Federated analyses provide feedback on

phenotype completeness and informational content, supporting iterative refinement of local clinical data.

Our experience shows that federated analysis acts not only as a privacy-preserving solution but also as a data quality improvement mechanism. Aligning analytical questions with concrete research goals motivates data custodians to structure their datasets, while analysts gain access to consistent virtual cohorts. We summarize biobank-operational lessons on neuro-specific annotation, motivation-driven data sharing, and FAIR-oriented reuse of routine clinical data in federated settings.

The role of biobank in introduction of a new biomarker - NfL (neurofilament light chain) to clinical practice – from research to diagnostics thanks to biobank

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Topic: 9C: Disease Domain-specific Biobanks – Neuroscience Insights

Presenter Name: Marta Kalousová

Keywords: NfL; neurofilament light chain; multiple sclerosis; biobank; biomarker

Introduction: Biobanks can help with testing of possible biomarkers for diagnosis and monitoring of various pathological states as they provide standardly processed and stored biological samples and possibly their analysis by special instruments including high sensitivity bioanalyzers.

Material & methods: The levels of neurofilament light chain (NfL), a biomarker of neuroaxonal damage, have been determined by single molecule array technology (Simoa) in serum and by enzyme linked immunosorbent assay (ELISA) in cerebrospinal fluid and evaluated in patients with neurological diseases, especially multiple sclerosis.

Results: Based on literature data as well as own research and method testing, NfL has been subsequently implemented into routine clinical practice in the Czech Republic - CSF evaluation for differential diagnostics of neurological diseases with special focus on multiple sclerosis and serum assessment for monitoring of patients with multiple sclerosis - the course of the disease, activity of the disease and prognosis, helping to decide the type of therapy and evaluate the therapy response. Special laboratory examination so could enable early treatment in patients with disease activity and possibly partially replace imaging in stable patients in the future thus saving costs for expensive examinations.

Discussion and conclusion: Excellent cooperation among biobank, research and

diagnostic laboratories and clinicians can lead not only to valuable research results but also to implementation of special diagnostic tools to clinical medicine with clear benefits for patients as well as for the health care system.

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The Role of the CRESM Biobank and Its Sample Sharing in Advancing Multiple Sclerosis Research

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Topic: 9C: Disease Domain-specific Biobanks – Neuroscience Insights

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words: CRESM, Multiple Sclerosis, access policy,

research Introduction

Research biobanks are essential for enabling high-quality, reproducible results. Unlike study-specific repositories, their mission is to provide regulated access to biospecimens and data, supporting open science. The Regional Reference Multiple Sclerosis Center Biobank (BB-CRESM) is the first institutional biobank in Italy focused on

multiple sclerosis (MS) and part of the BBMRI-ERIC. It operates under formal governance, standardized procedures, and GDPR-compliant policies. This work describes how BB-CRESM facilitates advances in MS research by regulated access to biospecimens and data

Methods

- Formal governance and legal, ethical, and quality documentation, including defined access and cost-recovery policies.
- Availability of more than 165,000 aliquots (serum, plasma, RNA, whole blood, blood cells, cerebrospinal fluid) and associated data from >3,200 patients with MS and other neurological diseases and 250 healthy participants.

Results

From 2020 to 2025, BB-CRESM distributed over 1,000 samples (serum, plasma, CSF, PBMCs preserved in RNA Later or DMSO, and isolated B and T cells) to external researchers from San Raffaele University of Rome, ISS, Sapienza University, IRCCS Besta Milano, University of Nottingham, Basel, Naples and Turin. Projects involved EBV genotyping, biomarker discovery, microglial miRNA profiling, and oxidative stress studies in MS, neuromyelitis optica spectrum disorder, and COVID-19 diagnostics. Cost-recovery agreements were tailored for both academic and private projects. BB-CRESM also supported internal CRESM research studies and diagnostic activities.

Conclusions

By providing regulated access to high-quality biospecimens and data, BB-CRESM enables reproducible and ethically conducted research,

fosters national and international collaborations, accelerates biomarker discovery, and enhances the translational impact of studies in MS and related diseases.

Banking the Brain

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Keywords: Biobank, Brain

Banking the Brain is a project that aims to improve how we collect, organize, and share biological samples and medical data to better understand brain diseases like Alzheimer's, Parkinson's, and depression. Although Flanders has excellent researchers and hospitals already working together, they often collect samples and data separately, which makes it harder to do large, meaningful studies.

The infrastructure that will be established brings together experts from all five Flemish universities to create a shared system, both physical and digital, for storing and accessing brain and neurological disease-related samples and data. By working together more efficiently, researchers can better understand how brain diseases develop, find new treatments faster, and attract clinical trials and companies to the region.

A key part of the infrastructure is the creation of a central online platform, called the BioPortal, which will help scientists quickly find and access the right data and samples, while respecting privacy and ownership rules. The project also puts in place long-term strategies to make sure the system remains useful, cost-effective, and future-proof.

In short, Banking the Brain will make brain research in Flanders stronger, faster, and more connected leading to earlier diagnoses, better treatments, and improved healthcare for people affected by brain disorders.

The Banking the Brain Infrastructure was approved by the Flemish government and will be placed on the Flemish infrastructure roadmap. It will intimately collaborate with BBMRI.be and BBMRI-ERIC.