human
exposome
assessment platform

HEAP Symposium 2024

Humanity and the Environment: Moving Exposome Research from Information to Action

27–28 May 2024
Hosted by IARC at its new headquarters building in Lyon, France, and online

International Agency for Research on Cancer

World Health Organization

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Welcome to IARC

The International Agency for Research on Cancer (IARC) is delighted to host the final symposium of the Human Exposome Assessment Platform (HEAP) project, "Humanity and the Environment: Moving Exposome Research from Information to Action".

In recent years, researchers have made huge advances in understanding environmental exposures, their biological mechanisms, and their health effects. Despite this, many gaps persist in our scientific knowledge. For example, the incidence of cancer is rising, and the role or roles of the exposome in this increase are not fully understood.

The HEAP research projects demonstrate the breadth of the potential new approaches that can be implemented in gathering and analysing scientific data: from wearable sensors and consumer receipts to cohort studies and health registries, all aiming to provide answers to these questions, now and in the future.

The symposium will also explore the legal and ethical challenges faced by exposome researchers in their work, which often involves managing and sharing sensitive data in the context of collaborative and international research projects. As the scientific need for accessing, processing, and interpreting data grows, so does the imperative of addressing those legal and ethical challenges.

As the specialized cancer agency of the World Health Organization, IARC plays an important role in coordinating exposome research across many countries and institutions. IARC is proud to be a HEAP consortium partner, leading the project's Education and Dissemination Work Package and using best practices from previous European Union projects, such as the B3Africa biobanking project, to produce learning and communications materials for future generations of international exposome researchers.

Elisabete Weiderpass
IARC Director

Welcome to the
HEAP Symposium 2024

The final HEAP symposium, hosted by the International Agency for Research on Cancer (IARC) online and at the new IARC headquarters building in Lyon, France, will take place on Monday 27 and Tuesday 28 May 2024.

IARC headquarters building, Auditorium
25 avenue Tony Garnier
69366 Lyon CEDEX 07, France

The HEAP
consortium partners

Project coordinator

Karolinska Institutet

International Agency for Research on Cancer
World Health Organization

UNIVERSITY OF WARSAW

Med Uni Graz

lygature

eutops
European Translational Oncology Prevention and Screening Institute

STATENS SERUM INSTITUT

CSC

UNIVERSITY OF OULU

HOPSWORKS

Tays

27 May

Research infrastructures and data:
advancing knowledge about the environment and our health

09:00–09:30	**Tour of the IARC Biobank**	Zisis Kozlakidis, IARC
09:30–09:45	**Welcome to IARC and opening remarks**	Joakim Dillner, KI Zisis Kozlakidis, IARC
09:45–10:15	**Keynote: European exposome research infrastructures**	Jana Klánová, EIRENE
Session 1: Scientific results of the HEAP project		Roxana Merino Martinez, KI
10:15–11:00	**Personal exposometers for monitoring the environment**	Allison Zhang, Stanford University, KI
11:15–12:00	**DNA methylation in cancer prevention – opportunities and challenges**	Martin Widschwendter, EUTOPS, University of Innsbruck
12:00–12:45	**The consumer exposome – consumer purchase data and chronic disease**	Frederik Trier Møller, Statens Serum Institut
Session 2: The HEAP platform in action		Zisis Kozlakidis, IARC
13:45–14:30	**International collaboration in comprehensive exposome research**	Ville Pimenoff, University of Oulu, KI
14:30–15:15	**Bioinformatics in action – building and using the HEAP platform**	Alex Ormenisan Hopsworks Dhananjay Mukhedkar, KI Sara Arroyo Mühr, KI Ainhoa García-Serrano, KI
15:30–17:00	**Plenary session on "From Information to Action": the impact of the HEAP project**	Roxana Merino Martinez, Joakim Dillner, KI

28 May

Exposome research:
ethics, law, and future perspectives

09:15–09:30	**Welcome and opening remarks**	Joakim Dillner, KI Evert-Ben van Veen, Lygature
Session 1: Exposome research and public health ethics		Evert-Ben van Veen, Lygature
09:30–09:40	**Introduction**	Evert-Ben van Veen, Lygature
09:40–10:00	**Ethical and legal topics in exposome research in the EU: results from the EHEN Ethics and Law Working Group**	Daniel Groos, Lygature
10:00–10:35	**Health equity versus individualism: on mission creep in public health**	Caspar W. Safarlou, UMC Utrecht
10:55–11:30	**Discussion**	
Session 2: Governance of research projects		Olenka van Ardenne, Lygature
11:30–11:35	**Introduction**	Olenka van Ardenne, Lygature
11:35–11:55	**Open science and cross-border research: new models of governance**	Evert-Ben van Veen, Lygature
11:55–12:20	**Engaging with healthy people in lifestyle studies: what have we learned during HEAP?**	Sandra Plaikner, Ingrid Lieb, Tamara Schmid, Lifestyle study team, EUTOPS, University of Innsbruck
12:20–12:40	**An introduction to the European Health Data Space (EHDS) and secure processing environments (SPEs)**	Melvin Thomas, TMF Berlin (technology platform for medical research)
13:40–14:00	**Impact of the European Health Data Space (EHDS) on cross-border research**	Artur Rocha, Vasco Rosa Dias, INESC TEC

28 May

Exposome research:
ethics, law, and future perspectives *(continued)*

Session 3: Future enablers of exposome research		Joakim Dillner, KI
14:30–14:50	**International biobanking and exposome research**	Wagida Anwar, Ain Shams University
14:50–15:10	**Perspectives on environmental exposure and human health**	Isabella Annesi-Maesano, Montpellier University Hospital
15:30–15:45	**Long-term outlook of HEAP secure cloud infrastructure**	Stefan Negru, CSC – IT Center for Science
15:45–16:00	**The International Human Exposome Network (IHEN)**	Martine Vrijheid, ISGlobal Zisis Kozlakidis, IARC
16:00–16:30	**Plenary session on sustainability**	Joakim Dillner, KI
16:30–16:45	**Closing remarks**	Joakim Dillner, KI

Keynote
"European exposome research infrastructures "

This presentation gives an overview of the main developments in European research infrastructures in recent years, focusing on EIRENE (Research Infrastructure for Environmental Exposure Assessment in Europe), which is the first European Union infrastructure on the human exposome and is a focal point of international exposome research.

EIRENE will enable large-scale interdisciplinary research on chemical exposures, through harmonized workflows from data collection to data processing and end results.

> **PRESENTER: Jana Klánová** is the director of the RECETOX centre at Masaryk University in Brno, Czechia, and the coordinator of the European Strategy Forum on Research Infrastructures (ESFRI) research infrastructure for the human exposome (EIRENE).
>
> She is a professor of environmental chemistry at Masaryk University. Her research interests are in environmental health sciences and environmental determinants of health.

"Personal exposometers for monitoring the environment "

Personal exposometers are wearable devices equipped with miniaturized sensors. They capture both biological and chemical exposures and can be worn by study participants to monitor their personal exposures over time.

These devices offer new ways of monitoring our environmental exposures and understanding their associated health risks. They can be worn by study participants to longitudinally monitor their personal exposome. The high-resolution exposure information provides the data foundation for exposure risk assessment.

> PRESENTER: **Allison Zhang** is a postdoctoral scholar who is working on a HEAP project to pilot continuous personal exposome profiling of 100 volunteers during their pregnancies.
>
> She is part of a team at Stanford University, USA, led by Michael Snyder, which has been focusing on improving the design of wearable personal exposome monitors (PEMs) and multi-omic profiling.

PRESENTATIONS

"DNA methylation in cancer prevention – opportunities and challenges"

The incidence of cancer continues to rise as lifestyles change and people live longer; a shift towards cancer prevention is urgently required. Reliable methods for measuring an individual's risk of cancer would support innovation in cancer screening, by targeting those at highest risk, and lead to new approaches to primary cancer prevention.

Ideally, risk-predictive tests should take both genetic and environmental factors into account and be biologically stable and technically reproducible. The latest evidence suggests that the epigenome and, in particular, DNA methylation-based tests meet all of these requirements.

This presentation summarizes the latest research, using data from cervical cancer screening and cancer prevention settings. It outlines the challenges and opportunities that these data present to researchers.

PRESENTER: **Martin Widschwendter** is the director of the European Translational Oncology Prevention and Screening (EUTOPS) Institute at the University of Innsbruck, Austria.

He leads the HEAP Epigenomic Analysis Work Package (WP8), which uses cohort study data to analyse the epigenome to identify alterations triggered by environmental exposures.

"The consumer exposome – consumer purchase data and chronic disease"

Consumer purchase data (CPD), from loyalty programmes and digital receipts, is emerging as a promising source to assess the effect of consumer products on our health.

HEAP researchers at Statens Serum Institut in Copenhagen, Denmark, have developed a European General Data Protection Regulation (GDPR)-compliant, secure, encrypted web application to allow study participants to consent to share their consumer data from three of the five largest retail chains in Denmark. These data are then linked to individual-level health outcomes.

CPD can also enable the creation of personal chemical cosmetics footprints and can help detect the source of disease outbreaks. Results from a collaboration with another Danish consumer cohort reveal associations between dietary and smoking purchases and chronic disease. Perhaps these and future results will pave the way for personalized prevention and could be used to improve the healthiness of algorithms used in loyalty programmes.

PRESENTER: **Frederik Trier Møller** is a senior registrar, epidemiologist, and innovator who has established research infrastructures and conducted extensive epidemiological studies using Danish registers.

He leads the HEAP Consumer Cohort Work Package (WP4), which is collecting CPD from volunteer research participants and using the data to analyse the impacts of consumer purchases on health.

"International collaboration in comprehensive exposome research "

Personalized longitudinal monitoring will change our understanding of abiotic and biotic exposures. By using wearable devices, researchers can collect longitudinal cumulative aerosol exposure samples from our daily environment. Ultimately, personalized wearable profiling may even enable predictions about individuals' health.

This collaborative human exposome monitoring project combined wearable sensor technology with Finnish longitudinal cohort data, biobanking, European General Data Protection Regulation (GDPR)-compatible sensitive data management, and advanced scientific computational inference.

The results demonstrate the feasibility of the proof-of-concept study among 100 pregnant and non-pregnant Finnish women using filter-based wearable device longitudinal monitoring, and show that using wearables monitoring enables high-resolution personalized exposure analyses.

> PRESENTER: **Ville Pimenoff** is an associate professor at the University of Oulu, Finland, and a visiting researcher at Karolinska Institutet, Sweden.
>
> His exposome research uses data from internationally unique cohorts, such as the Finnish Community–Randomized Trial of HPV Vaccination and the Finnish Maternity Cohort (biospecimens and registry data from pregnancies in Finland since 1983), including a pilot of adding wearable sensor data from pregnant volunteers to the cohort.

"Bioinformatics in action – building and using the HEAP platform "

HEAP provides a robust informatics tool tailored to the needs of exposome researchers. It summarizes four years of collaboration between researchers and software engineers from HEAP consortium partners. This tool facilitates the management and integration of heterogeneous data sources, offers analytics and machine-learning capabilities, and enables the interpretation of chronological and causal relationships from big data.

This presentation begins with an overview of the HEAP IT platform's key technical features and continues with practical demonstrations, followed by an overview of the applications of parallel computation in cancer research.

The presentation concludes with HEAP use-case demonstrations, including Biopipe, an open-source validated bioinformatics pipeline developed for taxonomy profiling of human cancers, and a demonstration of non-targeted deep-sequencing strategies enabling full microbiome characterization up to species level.

> PRESENTERS:
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> **Alex Ormenisan** is a co-founder and a senior software engineer at the HEAP consortium partner Hopsworks. He specializes in architecting back-end solutions for large-scale distributed systems. His research interests include machine learning, metadata management, and data governance.
>
> **Dhananjay Mukhedkar** is a software engineer at Hopsworks and one of the architects of the HEAP IT platform. He works with HEAP researchers at Karolinska Institutet, Sweden, to develop bioinformatics pipelines for genomic sequence data.
>
> **Sara Arroyo Mühr**, the metagenomics coordinator at HEAP, is a pioneering researcher in high-throughput sequencing for microorganism analysis. Her work spans molecular microbiology, biomarkers, cancer diagnostics, bioinformatics, and machine learning, driving innovation in these fields.
>
> **Ainhoa García-Serrano** is a bioinformatician at Karolinska Institutet, Sweden, where she is completing a PhD on the role of the microbiome in carcinogenesis. Her research focuses on bioinformatics tools and pipelines for metagenomic characterization, viral discovery, and machine learning for microbiome feature selection.

"Ethical and legal topics in exposome research in the EU: results from the EHEN Ethics and Law Working Group"

What are the most pressing ethical and legal issues encountered by exposome research consortia?

From participant-facing governance to the European Health Data Space (EHDS), since 2020, the European Human Exposome Network (EHEN) Ethics and Law Working Group has facilitated many fruitful and lively exchanges of experiences about the ethical and regulatory challenges in exposome research.

This presentation summarizes and shares the outcomes of these discussions with a wider group.

> PRESENTER: **Daniel Groos** is a legal researcher at the HEAP consortium partner Lygature for their Health Law, Privacy and Ethics (HPE) portfolio.
>
> He is part of the HEAP Ethics and Regulations Work Package (WP2) and is the coordinator of the EHEN Ethics and Law Working Group. His work focuses on privacy and data protection in large-scale research consortia.

"Health equity versus individualism: on mission creep in public health"

Is health equity a good political and ethical ideal?

From the perspective of individualism, this presentation discusses health equity and its role in the ever-expanding scope of public health.

> PRESENTER: **Caspar W. Safarlou** is a PhD candidate in Bioethics in the Department of Global Public Health and Bioethics of the Julius Center at the University Medical Center Utrecht, The Netherlands.
>
> His work focuses on the ethical aspects of exposome research, and he recently published a systematic review on this topic. He has also written on the nature-versus-nurture debate in exposome research, privacy, and ethical aspects of non-hypothesis-driven research.

"Open science and cross-border research: new models of governance,,

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Society has high expectations of publicly funded scientific research. Thus, research projects are built on trust and need to create trust by interacting with all relevant stakeholders via good self-governance.

This presentation discusses the core elements of good self-governance of research projects. It looks at the various ways in which researchers can implement these, some common challenges, and how these challenges can be addressed.

PRESENTER: **Evert-Ben van Veen** is a lawyer with more than 30 years of experience in health and privacy law. He leads the HEAP Ethics and Regulations Work Package (WP2) and chairs the European Human Exposome Network (EHEN) Ethics and Law Working Group.

His work has focused on ways to reconcile the practical needs of scientific research with fundamental legal and ethical questions, for example helping to refine the text of the European General Data Protection Regulation (GDPR) to show a more balanced approach to scientific research.

"Engaging with healthy people in lifestyle studies: what have we learned during HEAP?,,

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The LIFE-Tirol and SUN-Tirol studies were set up in 2022 at the European Translational Oncology Prevention and Screening (EUTOPS) Institute, Austria, and investigate the health-promoting effects of intermittent fasting, exercise, stress reduction training, and smoking cessation and how well these measures are accepted by the Austrian population.

About 800 healthy participants were divided into five intervention groups in LIFE-Tirol and two groups in SUN-Tirol, and the participants visited the study centre in Tirol, Austria, five times over an eight-month period. During the visits, they were monitored for factors including changes in quality of life, quality of sleep, and stress, and the researchers collected biological samples (blood, urine, stool, cervical and buccal swabs for epigenetic markers) and measured blood pressure and many other parameters.

This presentation provides an overview of our experience of conducting the practical aspects of this study, including challenges faced and lessons learned with regard to planning, recruitment of personnel and study participants, and implementation.

PRESENTERS:

Sandra Plaikner is a study coordinator at the EUTOPS Institute, Austria. She holds a medical degree and a master's degree in Nutrition and Food Technology and was involved in planning and setting up the LIFE-Tirol and SUN-Tirol studies. She hopes that the EUTOPS team, with its prevention studies, can help to shift the focus of governments and health-care systems towards prevention rather than aftercare.

Ingrid Lieb has 15 years of experience as a registered nurse, including many years in geriatric long-term care. Her role in the EUTOPS team focuses on the care of participants in the LIFE-Tirol and SUN-Tirol studies, supporting them in making a positive contribution to medical research. She sees her work as an opportunity to improve individual lives and to make a significant contribution to the health and well-being of future generations.

Tamara Schmid is a registered nurse and holds a Bachelor of Science in Nursing from FH Gesundheit, Reutte, Austria. She has completed nursing internships in a range of health-care settings in Europe and Africa and is a member of the EUTOPS research team.

"An introduction to the European Health Data Space (EHDS) and secure processing environments (SPEs)"

What does the European Health Data Space (EHDS) Regulation mean for exposome researchers? And is the EHDS likely to realize its goal of making health data usable for cross-border research?

This presentation explores the potential and limitations of the EDHS's provisions for secondary use of health data for scientific research.

PRESENTER: **Melvin Thomas** is a research associate at TMF e.V. He holds a law degree from the Free University of Berlin, Germany.

His main research focus is data protection. Through his role at TMF, which is an interdisciplinary organization with a strong research network, he has insights into a range of legal areas and technological challenges associated with medical research.

"Impact of the European Health Data Space (EHDS) on cross-border research"

High-value research, particularly in fields such as personalized health, relies on high-quality data and tools to find and process these data. Achieving this in accordance with European values requires that data are processed ethically and in a way that respects the rights of data subjects.

This presentation summarizes our experiences of setting up an international network for epidemiological studies across the life of individuals, and associated challenges in the implementation of European Health Data Spaces.

PRESENTERS:

Artur Rocha has been a senior researcher at the Institute for Systems and Computer Engineering, Technology and Science (INESC TEC), Portugal, since 1998. He is the coordinator of Human-Centered Computing and Information Science (HumanISE).

His interests include personalized health research, platforms and methods for collaborative research, privacy-preserving distributed computation, the Semantic Sensor Web (Internet of Things), and big data processing. He has extensive expertise in fields such as mental health, epidemiology, and immunogenetics, where the storage and processing of sensitive data and controlled FAIR (findable, accessible, interoperable, and reusable) data sharing are of great importance.

Vasco Rosa Dias is the Data Protection Officer (DPO) at INESC TEC and the Institute of Public Health of the University of Porto (ISPUP). Whereas INESC TEC focuses on new technologies, information and communication technologies (ICT), and computer science, ISPUP is a public health research institute.

He is also a member of the Ethics Committee of INESC TEC and has integrated the ethics and privacy governance bodies of several European Union (EU) or international research projects. He is a member of the Pool of Experts of the European Data Protection Board for new technologies. His main topics of interest and research cover the fields of EU law, technology regulation, and data protection.

"International biobanking and exposome research"

This presentation focuses on exposome research and experiences within Egypt as an advanced health-system approach, yet located within a middle-income country, and the lessons learned for exposome research in resource-restricted settings.

The presentation also discusses evidence-based implementation synergies, including drafting and designing health-system improvement programmes and campaigns for noncommunicable diseases.

PRESENTER: **Wagida Anwar** is the director of the Molecular Epidemiology Unit in the Faculty of Medicine at Ain Shams University, Egypt.

She also serves as a public health consultant and adviser for the World Health Organization (WHO), the Egyptian Environmental Affairs Agency, the Ministry of Foreign Affairs, and the Ministry of Health and Population, and as a director of the Ain Shams Center of Genetic Engineering and Biotechnology at Ain Shams University. Her research spans many scientific fields, with a particular emphasis on the relationship between environmental pollution and cancer, especially as it relates to the liver, bladder, and hepatitis.

"Perspectives on environmental exposure and human health"

Exposome research is increasingly understood as a necessity in providing a holistic evidence base for understanding human health at both an individual and a population level.

Previous and current research has focused on epidemiological studies on the prevalence, severity, and environmental determinants of allergic and respiratory diseases in Africa (francophone African countries, Mozambique and Cabo Verde) as well as French Polynesia and New Caledonia, and has involved collaborating with national and international authorities.

A more recent research stream has been the respiratory health effects of climate change and wildfires. This presentation covers past and recent research outcomes, as well as the future outlook.

PRESENTER: **Isabella Annesi-Maesano** is a research director at the French National Institute of Health and Medical Research (Inserm) and a professor of environmental epidemiology. She is the deputy director of the Desbrest Institute of Epidemiology and Public Health, a joint research unit of Inserm and the University of Montpellier, France.

Her research focuses on the etiopathogenesis of allergic and respiratory diseases and associated comorbidities using an exposome approach. The main risk factors taken into account are air pollution and climate change. In this context, she has coordinated several international research projects, including one on the exposome (www.heals-eu.eu), which recruited pairs of twins.

"Long-term outlook of HEAP secure cloud infrastructure "

How will HEAP's secure IT platform, developed by CSC – IT Centre for Science, Finland, continue to support exposome research in the future?

The HEAP IT platform enables researchers to manage sensitive data from multiple sources, including health data from large population-based cohorts and metabolomics data from biological samples.

Through examples from HEAP's pilot projects, this presentation shows how the secure infrastructure has been designed around the needs of exposome researchers, from data collection to publication of results, and looks at scenarios for future development.

> PRESENTER: **Stefan Negru** is a development manager at CSC – IT Center for Science, Finland, and leads the HEAP Secure Infrastructure for Big Data Work Package (WP10).
>
> His background is in semantic web technologies, linked data, graph databases, and visual analytics. He has a PhD in Knowledge Engineering in the context of human–computer interaction.

"The International Human Exposome Network (IHEN) "

Recent years have seen a proliferation of exposome research projects and the launch of several new research infrastructures.

To keep pace with these developments, the International Human Exposome Network (IHEN) project, launched in February 2024, will improve global research cooperation on the exposome.

Funded by Horizon Europe, IHEN will bring together exposome tools, metadata, and resources in a FAIR (findable, accessible, interoperable, and reusable) toolbox and will develop a roadmap for future exposome research and innovation.

> PRESENTER: **Martine Vrijheid** is a research professor and the director of the Environment and Health over the Lifecourse Programme at ISGlobal, Barcelona, Spain.
>
> A member of the IHEN leadership team, she is currently the coordinator of ATHLETE (Advancing Tools for Human Early Lifecourse Exposome Research and Translation), which, alongside HEAP, is one of the nine Horizon 2020 projects in the European Human Exposome Network (EHEN).

heap-exposome.eu

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