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Epidemiology
Statistics

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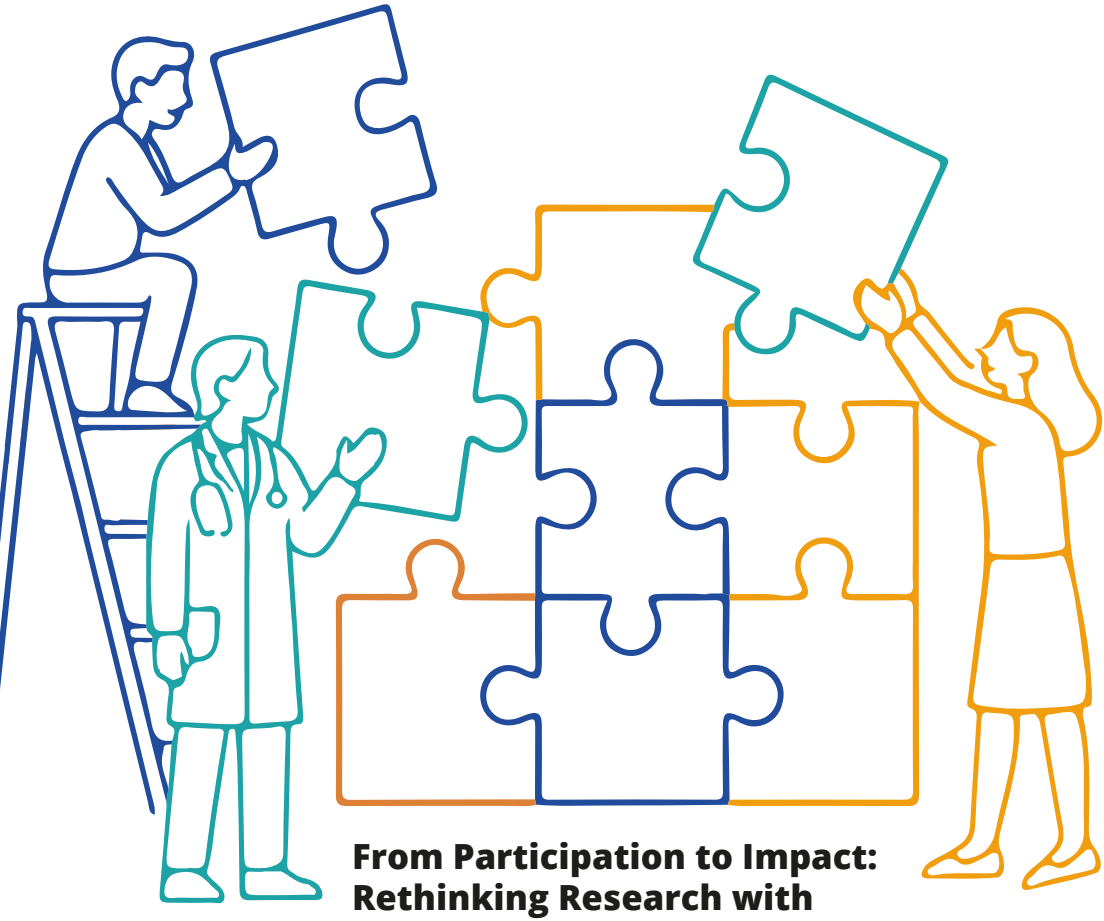

From Participation to Impact: Rethinking Research with Citizens and Stakeholders

Université Paris Cité

Université Sorbonne Paris Nord

Inserm
La science pour la santé
From science to health

INRAE

From Participation to Impact: Rethinking Research with Citizens and Stakeholders

9h00 - 9h30: Registration and Welcome Coffee

9h30 - 10h15: **Keynote lecture,** Dr Susanne Hecker *(Museum für Naturkunde Berlin, Germany)*

10h15 - 10h45: **Programme Malin and the ECAIL study: from action to intervention research, and vice versa,** Sandrine Lioret *(Research Director, Inserm)* & Benjamin Cavalli *(Director of the Association Programme Malin)*

10h45 - 11h15: Coffee break

11h15 - 12h00: **Who Knows? Patient Knowledge and the Missing Loop Between Participation and Impact,** Sara Riggare *(MSc, PhD, Uppsala University, Sweden)*

12h00 - 12h30: **ComPaRe: From Patient-Reported Data to Patient-Partnered Research,** Viet Thi Tran *(Professor of Epidemiology, Université Paris Cité)*

12h30 - 14h00: Lunch

14h00 - 14h45: **Keynote lecture,** Dr Ria Wolkorte *(University of Twente, Netherlands)*

14h45 - 15h15: **Co-creating nutritional interventions with university students and stakeholders: benefits and challenges of participatory research,** Alice Bellicha *(Associate Professor of Nutrition, Université Sorbonne Paris Nord)* & Goran Kaymak *(President of the Solidarity and Participatory Grocery Store Alter'Nature)*

15h15 - 15h45: **From participation to decision-making: methodological challenges in defining what matters in depression research,** Chris Veal *(PhD Student, Université Paris Cité)*

15h45 - 16h15: Closing Remarks

16h30: Closing Reception

Speakers

Dr Susanne Hecker, *Museum für Naturkunde Berlin, Germany, is the Chair of the European Citizen Science Association and head of the Science Programme "Society and Nature " at the Museum für Naturkunde Berlin. Her research focuses on science communication and citizen science, particularly at the intersection of science, society, and politics. She has been promoting the professionalization and establishment of participatory research at both national and international levels over the last decade.*

Sandrine Lioret *(Research Director, Inserm) is an epidemiologist and public health researcher in the CRESS OPPaLE team (Obstetric, Perinatal, Paediatric, Lifecourse Epidemiology). Her research focuses on the early development of social inequalities in health, particularly childhood growth and obesity. She investigates the role of energy balance-related behaviours (including diet, sedentary behaviours, especially screen time, and physical activity) in shaping these inequalities, through observational research in large birth cohorts such as EDEN and ELFE and intervention research among families experiencing social disadvantage. She is the principal investigator of the ECAIL randomised controlled trial, evaluating the Malin programme, a multicomponent early-life nutrition intervention co-designed through a participatory approach with Programme Malin and its long-standing partners, including the French Red Cross and French paediatric learned societies. Implemented in the Hauts-de-France region from 2017 to 2026 in collaboration with Lille University Hospital and Valenciennes Hospital, ECAIL enrolled over 600 pregnant women experiencing social disadvantage, who were followed by trained dietitians until their child reached age 2. The intervention group was offered the Malin programme, while the control group received usual care. Quantitative and qualitative data are being used to assess intervention effects on breastfeeding, complementary feeding, diet, lifestyle patterns, early growth and overweight, alongside a mixed-methods process evaluation. The latter aims to understand how the intervention was implemented and experienced, whom it reached and engaged, the mechanisms through which it may operate, and how contextual factors may shape its implementation and effects.*

Benjamin Cavalli *is Director of Programme Malin, a French non-profit organisation supporting families during the key period surrounding the arrival of a child. Continuously co-designed with parents, the programme combines parenting and nutrition support with practical measures designed to empower families in their everyday choices around food and healthy lifestyles, including access to nutritionally high-quality foods at reduced cost. With a background in social entrepreneurship, social innovation and the social and solidarity economy, he has extensive experience in developing collaborative initiatives addressing poverty and social exclusion. At the French Red Cross, where he was responsible for food aid and involved in social innovation, he contributed to the development of Programme Malin from its early stages. He subsequently played a key role in its development and transition into an independent non-profit organisation, and continues to lead its scale-up through partnerships involving public institutions, social and solidarity economy organisations, healthcare and early childhood professionals, researchers and private-sector stakeholders. To date, more than 300,000 children have been enrolled in Programme Malin across France. He has also contributed to the development of the ECAIL trial, reflecting his commitment to bridging social innovation and scientific research to inform and evaluate public health interventions.*

Sara Riggare *(MSc, PhD), Uppsala University, Sweden, is a researcher living with Parkinson's disease who pioneers innovative approaches to health and selfcare. Combining personal experience with scientific rigor, she advances the field of chronic disease management. Her research spans digital health, co-design, and self-tracking, centering the patient as a knowledgeable partner. She challenges traditional healthcare models and promotes new ways for patients to contribute to knowledge, practice, and innovation. Her research can be described under the umbrella of Advancing Patient-Led Knowledge, Self-Care, and System Innovation through Personal Science and Participatory Research, as it consistently explores how individuals living with chronic conditions can generate, apply, and share their own knowledge to improve health outcomes and influence healthcare systems. Through personal science, she investigates how self-tracking and experimentation empower patients to better manage their own care. At the same time, her work in participatory research and co-design highlights the value of involving patients as equal partners in developing digital tools, shaping research agendas, and driving innovation from within the system.*

Prof. Viet-Thi Tran *is a Full Professor of Epidemiology at Université Paris Cité and at the Assistance Publique Hôpitaux de Paris (AP-HP), in Paris France. He leads a research group around novel methods to generate primary evidence in the METHODS team, which is specialized on therapeutic evaluation in chronic conditions. His work revolves around three topics: 1) minimally disruptive medicine (i.e., how to care for patient in a way that respects his life goals), and especially how digital tools may help achieve such minimally disruptive medicine; 2) citizen science methods (i.e., how to involve patients in research and in evidence generation); and 3) novel methods in therapeutic evaluation (e.g., target trial emulation, virtual controls, etc.). He co-leads ComPaRe, a citizen science platform of 65000 patients who are volunteer to donate some of their time to advance research on their chronic conditions by enrolling in studies they would be eligible for.*

Photo credit : Jane Duursma

Dr Ria Wolkorte *is an assistant professor at the University of Twente, the Netherlands, with a background in biomedical sciences and clinical movement sciences. Her research focuses on understanding and advancing citizen science as a research approach as well as applying citizen science to health research. She works on projects exploring fatigue and self-management mostly with people living with chronic conditions and cancer. She is also co-chair of the Health Working Group of the European Citizen Science Association.*

Alice Bellicha *is an Associate Professor at Université Sorbonne Paris Nord (USPN) and at the CRESS-Nutritional Epidemiology Research Team. She is coordinating the Master's degree in Nutrition and Public Health and holds a Junior Chair of Scientific Mediation at the French University Institute. Her research projects are draws on a combination of epidemiological, interventional, and participatory methods. They are structured around three complementary research axes: (1) the identification of dietary patterns and their determinants; (2) the analysis of the associations between dietary patterns and health outcomes; and (3) building on these findings, the co-creation, implementation and evaluation of nutritional interventions with citizens and relevant stakeholders.*

Goran Kaymak *is a student at Sorbonne Paris Nord University (USPN) and President of Alter'Nature, a solidarity-based and participatory food initiative operating across all three of USPN's campuses. This organisation is committed to tackling food insecurity among students and promoting access to a healthy, sustainable diet. Goran is also actively involved in the university's institutional activities, having previously served as Vice President for Student Affairs. Together with Alice Bellicha, he is involved in a participatory research project focusing on students' diets, which includes, in particular, the organisation of USPN's first Student Citizens' Assembly.*

Christopher Veal *is PhD Student at the CRESS METHODS Team. His research focuses on the development of a Core Outcome Set (COS) for depression, with particular attention to the involvement of people with lived experiences, healthcare professionals, and informal caregivers. Through this research, he explores how methods to elicit and aggregate individual preferences can address the methodological challenges of large-scale consultation. His work examines how people's diverse perspectives can be translated into collective representations and ensure that people's participation in research has a meaningful influence on decision-making.*

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