

# Paris Conference

# for an International Childhood Cancer Data Partnership

Dismantling Barriers  
& Accelerating Progress

7/8 NOVEMBER 2023  
Paris – Newcap Event Center

# Agenda

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# Introduction



**Pr. IFRAH Norbert**  
French National  
Cancer Institute  
*President*

Dear esteemed colleagues,

As we gather in Paris, I extend a warm welcome to all of you - professors, doctors, researchers, healthcare professionals, and patient advocates. Your presence from diverse corners of the world promises valuable and insightful discussions.

The French National Cancer Institute (INCa) is honored to host the Paris Conference for an International Childhood Cancer Data Partnership. A special thank you to our dedicated colleagues at the United States National Cancer Institute (NCI) for their crucial role in initiating and co-organizing this significant event.

Childhood cancers, thankfully rare, present a substantial challenge due to their diversity and the limited data available for groundbreaking research on causes, treatments, and long-term effects.

This is why we advocate for an International Childhood Cancer Data Partnership – bringing together countries with high-quality data and a readiness to share, in order to answer critical research questions.

While legal, ethical and technical challenges exist, our collective duty drives us to explore every avenue, for the benefit of childhood cancer patients and their families.

This conference is held within the framework of the G7 Cancer initiative, fostering international cooperation among leading research institutes from France, the United States, Canada, the United Kingdom, Germany, Japan, and Australia. It is also aligned with the European Union's ambitious Europe's Beating Cancer Plan and the French Ten-Year Cancer Control Strategy, both of which prioritize research and progress on pediatric cancers.

Our hope is that this conference serves as a pivotal starting point. We welcome all ideas, regardless of scale, as we identify enthusiastic stakeholders, potential solutions, and practical steps. Together we will work towards trustworthy ways to exchange data, tailoring databases to our objectives and respecting each nation's specific legislation.

With deep appreciation for your unwavering dedication, I eagerly anticipate the insights and collaborations that will emerge from this Conference.

Bienvenue à tous !

**Pr. Norbert Ifrah, President of the National Cancer Institute**

# Speakers' bio

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## Pr. AITKEN Joanne

Australia

Cancer Council Queensland;  
School of Public Health, The  
University of Queensland

*Director of Research; Honorary  
Professor*

### Session:

Workshop #3 Data Governance & Data exchange – Session 1

*November 7 – 2.30 – 3.45pm*

**Role:** Discussant

Professor Joanne Aitken is Director of Research at Cancer Council Queensland, Director of the Australian Childhood Cancer Registry, a Ministerial appointee to the Advisory Council of Cancer Australia, and President and Chair of the Board of the International Association of Cancer Registries.

She is a cancer epidemiologist with a special interest in the epidemiology of skin cancer and cancer in children and she is actively involved in national and international cancer surveillance practice and policy. Her work has been cited over 16,000 times in the scientific literature.



**Dr. BERTAGNOLLI Monica**  
USA  
National Cancer Institute  
*Director*

**Session:**  
Opening - Day 1

*November 7 – 9.30 - 10am*

**Role:** Discussant

Monica Bertagnolli, M.D., began work as the 16th director of the National Cancer Institute (NCI) on October 3, 2022. Throughout her career, Dr. Bertagnolli has been at the forefront of the field of clinical oncology, in particular, advancing current understanding of the gene mutation that promotes gastrointestinal cancer development and the role of inflammation as a driver of cancer growth. As a physician–scientist, she led gastrointestinal science initiatives from 1994 to 2011 within the NCI-funded Cooperative Groups Program (now known as NCI’s National Clinical Trials Network), and from 2011–2022 served as group chair of the Alliance for Clinical Trials in Oncology, a National Clinical Trials Network member organization. In addition, from 2007–2018, she served as the chief of the division of Surgical Oncology for the Dana-Farber Brigham Cancer Center.

Dr. Bertagnolli has championed collaborative initiatives to transform the data infrastructure for clinical research and is the founding chair of the minimal Common Oncology Data Elements (mCODE) executive committee. She also is a past president and chair of the board of directors of the American Society of Clinical Oncology and has served on the board of directors of the American Cancer Society and the Prevent Cancer Foundation. In 2021, she was elected to the National Academy of Medicine, having previously served on the National Academies National Cancer Policy Forum.





## BETTIO Manola

Italy

European Commission, Joint  
Research Centre (JRC)

*Scientific researcher*

### Session:

Roundtable - Discussing legal challenges for data sharing and initiatives to address them

*November 7 – 11:40am – 12:40pm*

**Role:** Discussant

Manola's education is in Demography and Social Statistics, and in Medical Statistics. She started her professional career in the veterinary epidemiology field. In 2011 she joined the European Commission (EC) at Eurostat, in the environmental and agricultural statistics field, and continued working in the same research area later at the EC Joint Research Centre (JRC).

She finally moved to her interest research domain in Public Health in 2013, where at the JRC she coordinates the Cancer Information group, hosting and managing data from European population-based cancer registries contributing to the European Cancer Information System (ECIS), and supporting the coordination of activities of the European Network of Cancer Registries (ENCR).



## BIRZ Suzi

USA

University of Chicago  
*Pediatric Cancer Data Commons,  
 Regulatory and Data  
 Governance Consultant*

### Session:

Roundtable - Discussing legal challenges for data sharing and initiatives to address them

*November 7 – 11.40 - 12.40am*

**Role:** Discussant

### Session:

Workshop #3 Data Governance & Data Exchange – Session 1

*November 7 – 2.30 - 3.45pm*

**Role:** Discussant

Suzi Birz leads the legal and regulatory efforts for the University of Chicago's Data for the Common Good (D4CG). D4CG is dedicated to building communities, platforms, and ecosystems that maximize the potential of data to drive discovery and improve human health. D4CG's flagship project, the Pediatric Cancer Data Commons, is structured around disease consortia. Ms. Birz works with each one to establish the consortium via the execution of a memorandum of understanding, establish an executive committee, and adopt policies guiding the operations of the consortium. She works with data contributors to execute data contributor agreements, and following the approval of a research project, with investigators to execute data use agreements.

In her D4CG role, she leads the activation and operations of the Scientific Advisory Committee, the External Advisory Board, and the AYA Research Council.

Prior to her work with D4CG, she helped several health care organizations meet patient privacy regulations.





## BLANC Patricia

France

Imagine for Margo – children  
without cancer

*President*

### Session:

Keynote - Patient advocates

*November 7 – 10 - 10.30am*

**Role:** Discussant

Patricia Blanc is president, founder and representative of the association Imagine for Margo.

The association was founded in 2011 by Patricia Blanc and her husband, parents of Margo, who died of a brain tumour at the age of 14.

For over 10 years, Imagine for Margo has been mobilising, raising awareness and collecting donations to accelerate research into children's cancer.

Since its creation, thanks to the support of donors, partners and volunteers, Imagine for Margo has raised 20 million euros to fund 42 cutting-edge research programs and 28 innovative treatments, enabling more than 3,000 children to benefit from personalized treatments in France and Europe.

Patricia Blanc is also very active in advocacy efforts towards French and European politicians, regulators and pharmaceutical industry to make laws and research more adapted to better treatments for children with cancer.



## Dr BOTTA Laura

Italy

Istituto Nazionale dei Tumori  
Foundation

*Senior biostatistician – Cancer  
epidemiology*

### Session:

Workshop #4 Innovative Models & Data Management - Session 3

*November 8 – 10 – 11.15am*

**Role:** Discussant

Dr. Botta got her Master Degree in “Biostatistics and applied statistics” at the University of Milano Bicocca, Italy, in 2012 and she is a third year PhD student in “Biostatistics and Epidemiology” at the University of Burgundy, Dijon, France.

Dr. Botta has 10 years’ experience in research working at the Fondazione IRCCS Istituto Nazionale dei Tumori (Milano-Italy) and has been involved in statistical analysis and data management in several national and international projects for both epidemiological (e.g. EURO CARE, RARECARENet, BENCHISTA) and clinical research.

The cancers she deals with are mainly rare cancers, with a focus on childhood, adolescent and young adult, head and neck and sarcomas.

In recent years, she has developed new statistical methodologies to estimate the excess risk of death from non-oncologic causes in cancer patients and she is involved in the development of the EURACAN registry using the federated approach.



## Dr. BOUSQUET Philippe-Jean

France

French National Cancer Institute  
*Director of Health survey, data-  
science, and assessment division*

### Session:

Workshop #3 Data Governance & Data Exchange - Session 2

*Nov. 7 – 4.15 - 5.30pm*

**Role:** Discussant

Philippe Jean Bousquet is a medical Doctor (MD) specialized in Public Health with a special interest in this discipline, that led him to defend a university thesis in epidemiology and biostatistics, and to obtain the authorization to supervise research (Univ. Montpellier I). After spending a year as a researcher at Imperial College in London, he worked as a methodologist at the Montpellier-Nîmes university hospital centers. During this period, he also became a member of the Persons' Protection Committee (CPP), an expertise that he consequently completed by becoming a member of the Committee for the Evaluation of Research, Studies and Health Assessments (Cerees) for three years.

After he joined the French National Cancer Institute in 2010, he was able to develop the topics relating to the observation of cancers, health information systems and evaluation. This approach conducted him to perfect his knowledge in data science (at Polytechnic Executive School), in order to initiate the Oncology Data Platform and to reinforce partnerships with the main contributors in this field, including the cancer registries. He is one at the initiative of the "Filière intelligence artificielle et cancer". He also took the responsibility regarding the issue of insurability for people with cancer, by being now a member of the Monitoring and Proposal Committee of the Aeras convention (that permit to people with an aggravated health risk to be able to get insurance and to get loans from banks).



## BRETON Thierry

France

French National Cancer Institute  
*Director-general*

### Session:

Closing Day 2

*November 8 – 4 – 4.30pm*

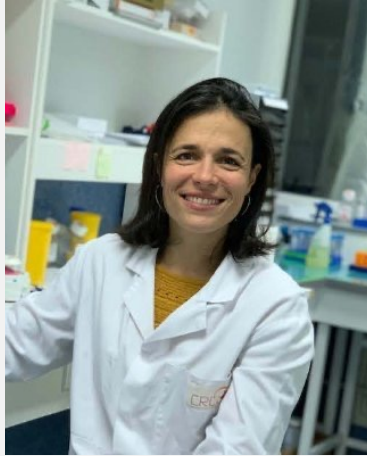
**Role:** Discussant

Thierry Breton has been director-general of the French National Cancer Institute (INCa) since 2014.

He is a member of the General Inspectorate of Social Affairs (IGAS), a government audit and inspection office for health, social security and cohesion, employment and labour policies.

Mr Breton's professional path has been shaped by his keen interest in public-health policies and social affairs.

Before joining INCa he was officer in charge of labour and employment at the General Secretariat of Social Affairs Ministries, and adviser for social affairs at the Health Ministry Office. He teaches political economy in health at the University of Paris Dauphine-PSL.



## Dr. CASTETS Marie

France

INSERM - Share4Kids

*Co-director, CR1 INSERM team  
focused on cell death and cancer  
co-director*

### Session:

Workshop #2 Interoperability – Session 2

*November 7 – 4.15pm – 5-30pm*

**Role:** Discussant

Dr Marie Castets is the leader of the team « Cell death and Childhood Cancers » at CRCL. Her aims are to elucidate childhood cancer resistance to cell death by focusing on their developmental origin context, heterogeneity, and dynamics, to move towards more efficient and less toxic innovative therapeutic strategies, with a focus on brain tumors and sarcomas.

She also leads the national pediatric cancer research network @react4Kids, which brings together 400 French and European scientists with two objectives: to boost collaborations between teams and share resources and expertises. She is the PI of the Share-4Kids project, whose goal is to create a shared open-access multi-omic data warehouse for pediatric cancers. Her work has been recognized by the Fondation de France (2012) and the French Academy of Medicine (2012) & Sciences (2013).



**Dr. CASTRO Rosa**  
Belgium  
Deutsche Stiftung  
Weltbevölkerung (DSW)  
*Senior Advocacy Officer*

**Session:**

Workshop #3 Data Governance & Data Exchange - Session 2

*Nov. 7 – 4.15pm - 5.30pm*

**Role:** Discussant

Rosa Castro is a Senior Advocacy Officer at global health NGO, DSW. She has over 10 years of experience in academia and as policy expert in EU health policy, including at the European Public Health Alliance (EPHA), and the Federation of European Academies of Medicine (FEAM).

She has a law degree, LL.M. and PhD in European Law and Economics and an MA in Bioethics and Science Policy. She was a postdoctoral Fellow at the European University Institute, and at Duke University, USA, and has lectured on intellectual property and international health law.





## Pr. CLAVEL Jacqueline

France

INSERM

*Epidemiologist and Research  
professor*

### Session:

Workshop #2 Interoperability – Session 2

*November 7 – 4.15pm – 5-30pm*

**Role:** Discussant

Jacqueline Clavel, MD, PhD is research professor at Inserm and has devoted most of her research to the development of epidemiological research on childhood cancers.

One of her main areas of research aims to improve knowledge of childhood cancer risk factors, and has contributed to document the role of environmental, genetic, perinatal and lifestyle risk factors. A growing part of her research is devoted to the long-term epidemiological follow-up of childhood cancer survivors. The development of infrastructures capable of providing standardized and quality-controlled information on a national and comprehensive basis has been crucial to this area of research.

With her team, she created the National registry of childhood cancer and then the Childhood Cancer Observation Platform, which complements the registry with several databases, in particular the national COHOPER cohort of all patients diagnosed since 2000. The field can now rely on invaluable data from tens of thousands of children.



## Pr. COLEMAN Michel

UK

London School of Hygiene &  
Tropical Medicine

*Head of the Cancer Survival Group*

### Session:

Workshop #3 Data Governance and data exchange

*November 7 – 2.30pm - 5.30pm*

*November 8 – 10am - 1pm*

*November 8 (Wrap-up in panel session) – 2.30 - 4pm*

**Role:** Facilitator

Since 1995, he has been Professor of Epidemiology and Vital Statistics at the London School of Hygiene & Tropical Medicine. He was Deputy Chief Medical Statistician at the Office for National Statistics from 1995 to 2004 and Head of the Cancer and Public Health Unit at the School from 1998 to 2003.

He has previously worked for the World Health Organisation at the International Agency for Research on Cancer in Lyon (1987-1991), and was Medical Director of the Thames Cancer Registry in London (1991-1995).

His main interests include trends and inequalities in cancer incidence, mortality and survival, and the application of these metrics to public health policy and cancer control.

He holds a post as Honorary Consultant in Oncology at UCL Hospitals NHS Foundation Trust. He is Head of the Cancer Survival Group, and sits on the School's Information Governance Board.



## CROCHET Hugo

France

Léon Bérard Centre

*Chief information system and data officer*

### **Session:**

Workshop #3 Data Governance & Data Exchange – Session 3

*November 8 – 10 – 11.15am*

**Role:** Discussant

At Léon Bérard Comprehensive Cancer Center, Hugo Crochet is contributing to several innovative projects regarding health data, artificial intelligence and big data to accelerate cancer research.

Léon Bérard is a major actor in real-world data (RWD) and collaborates with key players in the field such as the Health Data Hub, Owkin, Therapanacea, and more. Recently, Léon Bérard announced a strategic partnership with GLEAMER, Europe's leading AI company in radiology.

Léon Bérard is a member of the Unicancer federation and actively contributes to Unicancer's big data projects, including ConSoRe, a big data search engine.

Léon Bérard Centre is part of the French consortium that will receive European funding to prepare for the implementation of the European Health Data Space at national level (#EHDS).



## Dr. CUTILLO Leucio Antonio

Italy

European Commission,

Joint Research Centre (JRC)

*Project officer and Scientific  
researcher / Disease Prevention Unit*

### Session:

Workshop #4 Innovative Models & Data Management - Session 1

*November 7 – 2.30 – 3.45pm*

**Role:** Discussant

Leucio Antonio Cutillo is research scientist working to support knowledge generation on rare diseases. His educational background includes a MS in computer engineering from Politecnico di Torino, a 'Diplôme d'Ingénieur en Systèmes de Communication' from EURECOM, and a Master in 'Image et Géométrie pour le Multimédia et la Modélisation du Vivant' from Télécom ParisTech.

Passionate about security and privacy, he earned his 2012 Ph.D. from Télécom ParisTech, focusing on Security and Privacy in Online Social Networks. Subsequently, during his PostDoc at Politecnico di Torino's TORSEC group, he delved into cloud system security. In 2019, he expanded his expertise with a Master in Cybersecurity and Critical Infrastructure Protection from Università degli Studi di Genova.

Following a diverse career spanning entrepreneurship, project management, and teaching, his love for research led him in 2021 to the Joint Research Centre of the European Commission. Here, he devised SPIDER, an innovative system enabling the pseudonymisation, linkage, and secure exchange of privacy-critical data, facilitating the creation of cohorts of unique patients without revealing their identities.



## Dr. DURBIN Eric

USA

Kentucky Cancer Registry  
University of Kentucky

- *Assistant Professor, Division of Biomedical Informatics*
- *Director, Cancer Research Informatics Shared Resource Facility*

### Session:

Workshop #2 Interoperability

November 7 – 2.30pm - 5.30pm

November 8 – 10am - 1pm

November 8 (Wrap-up in panel session) – 2.30 - 4pm

**Role:** Facilitator

Eric B. Durbin, DrPH, MS, is an Assistant Professor in the Division of Biomedical Informatics at the University of Kentucky (UK) College of Medicine.

He serves as the Director of the Surveillance, Epidemiology, and End Results (SEER) Kentucky Cancer Registry (KCR). He also serves as Director of the Cancer Research Informatics Shared Resource Facility at the National Cancer Institute (NCI) Designated UK Markey Comprehensive Cancer Center. He has over 33 years of experience in population-based cancer surveillance and informatics support for basic, clinical, population, and translational cancer research. His research interests include biomedical informatics methods in cancer surveillance, precision cancer surveillance, and cancer epidemiology. Dr. Durbin's current research is focused on the integration of multi-omics data to support decision-making in precision medicine and cancer prevention and control. His research team develops informatics methods to support population-based cancer research and collaborates in the development of machine learning methods to derive clinical biomarkers from narrative medical documents and pathology digital whole slide images. He also leads epidemiological studies exploring environmental, genetic, molecular, and other factors associated with the high incidence rates of childhood brain and central nervous system tumors in Kentucky and Appalachia.



**Pr. FRAZIER Lindsay**  
USA  
Dana-Farber Cancer Institute  
*Pediatric Oncologist*

**Session:**

Roundtable - Discussing legal challenges for data sharing and initiatives to address them

*November 7 – 11:40am – 12:40pm*

**Role:** Discussant

Dr. Frazier is Professor of Pediatrics and Institute Physician at Dana-Farber Cancer Institute. She received her MD from Dartmouth and completed residency and fellowship at the Dana-Farber/Boston Children's Cancer and Blood Disorders Center. Dr. Frazier also holds a master's degree from the Harvard Chan School of Public Health.

Dr. Frazier leads the Malignant Germ Cell International Consortium (MaGIC) comprised of the world's leading experts in the etiology, epidemiology, treatment and survivorship of germ cell tumors.

Dr. Frazier also leads the Center for Adolescent and Young Adult Oncology at the Dana-Farber Cancer Institute.

Dr. Frazier is passionate about mentorship and mentorship training and is currently a Principal Facilitator of mentorship training nationally with the Center for the Improvement of the Mentored Experience in Research (CIMER) based at the University of Wisconsin.





## Dr. GELEIJNSE Gijs

Nederland

Integraal Kankercentrum

Nederland

*Data Science Team Lead and  
Innovation Program Manager*

### Session:

Workshop #4 Innovative Models & Data Management

*November 7 – 2.30pm - 5.30pm*

*November 8 – 10am - 1pm*

*November 8 (Wrap-up in panel session) – 2.30 - 4pm*

**Role:** Facilitator

Dr Geleijnse is leading the Data Science team at IKNL and oversees IKNL's innovation program. He holds a MSc in Computer Science and PhD in Artificial Intelligence, with over 12 years' experience at Philips Research as industrial scientist and project manager in clinical informatics. He is interested in means how novel technology and data can be used to improve decision making and improve our understanding of health and care.

At IKNL, he works on innovations centered around the Netherlands Cancer Registry. He addresses ways to make the flow from patient record data to insights faster and more effective. In several projects, he explores how Artificial Intelligence (AI) and Privacy-Enhancing Technologies (PETs) can be used to support cancer registration and help to mitigate the current challenges in data sharing. He is involved in several Horizon projects shaping the European Health Data Space and pioneering the establishment of modern, federated registries.

He leads the Blueberry project, with the goal to establish a sustainable, scalable European clinical registry for rare solid cancers in adults (EURACAN ERN). He works with the European Medicine Agency on data harmonization, quality and federated analyses.

Besides the work on the set-up of a modern registry, Dr. Geleijnse is committed to extracting value from cancer registry data for a diverse audience. Innovations such as the Dutch Cancer Atlas, the synthetic Netherlands Cancer Registry and personalized statistics for patients contribute to the registry's societal impact.



**Dr. GIBSON Paul**  
Canada  
McMaster Children's Hospital  
*Pediatric Oncologist*

**Session:**

Workshop #1 Harmonization of clinical and biological Data – Session 2

*November 7 – 4.15 - 5.30 pm*

**Role:** Discussant

Dr. Gibson is a Graduate of Queen's University's Medical School. He completed Pediatric Residency training at B.C. Children's Hospital prior to subspecialty training at The Hospital for Sick Children. He joined the Section of Pediatric Hematology and Oncology at Children's Hospital, London Health Sciences Centre full time in 2010 before moving to join the Division of Pediatric Hematology and Oncology at McMaster Children's in 2019.

Dr. Gibson has been Associate Medical Director of the Pediatric Oncology Group of Ontario (POGO) since 2015. His role with POGO includes medical support of the 8 POGO Satellite programs across the province and leading POGO's efforts in drug and technology access.

Dr. Gibson has served as the chair of the Management Committee Cancer in Young People in Canada (CYP-C), Canada's national pediatric cancer registry since 2021. He is Associate Chief Medical Information Officer of Hamilton Health Sciences helping lead the corporate migration to the Epic Electronic Health Record.



**Dr. GIRY Claire**  
France  
Ministry of Health  
*Research & Innovation general  
director*

**Session:**  
Opening Day 2

*November 8 – 9.30 – 10am*

**Role:** Discussant

Claire Giry is a former student from the Ecole Normale Supérieure (ENS) de Lyon, and holds a PhD in Molecular and Cellular Biology from Université Claude Bernard Lyon I. Throughout her career, she has been strongly involved in research and innovation management and policies. In particular, she was responsible for developing national, European and international partnerships at the 'Commissariat à l'Energie Atomique et aux Energies Alternatives' (C.E.A.) and the 'Institut National de la Santé et de la Recherche Médical' (Inserm), the French National Institute for Health & Medical Research.

Claire Giry was also technical advisor to the Prime Minister for Higher Education & Research between 2007 and 2009, then head of the joint department of the Directorate General for Higher Education & Professional Integration (D.G.E.S.I.P.) and the Directorate General for Research & Innovation (D.G.R.I.) in the Higher education and research french Ministry.

She then led the "Centers of Excellence" program at the French General Investment Commission, before joining Inserm in 2012 where she notably held the role of Vice CEO.

Claire Giry was named Director General for Research & Innovation at the Ministry of Higher Education, Research & Innovation in 2021.



**GODERRE Johanna**  
USA  
National Cancer Institute  
*Health Data Scientist*  
*Surveillance Informatics Branch*

**Session:**

Workshop #2 Interoperability

*November 7 – 2.30pm - 5.30pm*

*November 8 – 10am - 1pm*

*November 8 (Wrap-up in panel session) – 2.30 - 4pm*

**Role:** Facilitator

Ms. Goderre is the Technical Lead for the National Childhood Cancer Registry at the US NCI and manages real-world data acquisition and interoperability projects to enhance cancer surveillance data and data sharing initiatives. Ms. Goderre has over 18 years of experience in health research and evaluation, public health informatics, health systems delivery, and the information systems necessary to support research in those fields.

In 2014, she transitioned from epidemiologic research programs to information technology solutions and standards for US commercial and federal health services. Since then, she has successfully led requirements analysis to ensure healthcare systems capture and report high-quality data and led evaluations of information exchange efforts for state and federal governments.

She has authored publications about research and data programs and technical data standards. She holds a Master of Public Health and a Public Health Geographic Information Systems Certificate from the University of Illinois at Chicago (UIC).



## GOODHAND Peter

Canada

Global Alliance for Genomics  
and Health

*Chief Executive Officer*

### **Session:**

Workshop #2 Interoperability – Session 1

*November 7 – 2.30 - 3.45 pm*

**Role:** Discussant

Peter Goodhand is a leader in the global health sector, holding senior executive and board member positions in the genomics research community.

He played a key role in the creation of the Global Alliance for Genomics and Health (GA4GH) to accelerate progress in genomic research and health in June 2013 and is currently the President and CEO of the organization. He also served as President of the Ontario Institute for Cancer Research from 2016-18.

Prior to his role with GA4GH, he was the President and CEO of the Canadian Cancer Society, and before joining the charitable sector, he had a 20-year career in the global medical technology industry.

In addition to his role at GA4GH, he is Co-Chair of the IHCC and sits on several international boards in areas of genomics, cancer, and rare diseases. Peter also had a 12-year experience as a patient advocate, caregiver, and navigator throughout his family's battle with a rare cancer.



**Dr. GUIDRY AUVIL Jaime**  
USA  
National Cancer Institute  
*Director of NCI's Office of Data  
Sharing*

**Session:**

Workshop #4 Innovative Models & Data Management

*November 7 – 2.30pm - 5.30pm*

*November 8 – 10am - 1pm*

*November 8 (Wrap-up in panel session) – 2.30 - 4pm*

**Role:** Facilitator

Dr. Jaime M. Guidry Auvil, the Director of the Office of Data Sharing (ODS) within the National Cancer Institute (NCI), oversees the NCI strategy and approach to development, interpretation and implementation of data sharing and public access policies in cancer research. Dr. Guidry Auvil has led critical, high profile data sharing initiatives for NCI and NIH, including large-scale pediatric cancer research through Therapeutically Applicable Research to Generate Effective Treatments (TARGET) initiative, Gabriella Miller Kids First Pediatric Research Program, and current flagship program for NCI, the Childhood Cancer Data Initiative (CCDI).

Dr. Guidry Auvil is well-published and provides expertise in optimizing data for cancer research as part of several advisory committees within and across United States federal agencies and international organizations. Dr. Guidry Auvil has held scientific research and regulatory positions in industry, academia and government focusing on healthcare biobanking for infectious disease and cancer, as well as research in mental health, addiction and post-traumatic stress. Dr. Guidry Auvil received her doctorate in Tumor Biology from Georgetown University, where she further holds a patent for a small molecule inhibitor targeting adhesion proteins in bone cancer metastases.





## Dr. GUPTA Sumit

Canada

SickKids

*Staff Oncologist and Clinician  
Investigator, Division of  
Haematology/Oncology*

### **Session:**

Workshop #1 Harmonization of Clinical & Biological Data - Session 1

*November 7 – 2.30 - 3.45 pm*

**Role:** Discussant

Dr. Gupta is a pediatric oncologist at the Hospital for Sick Children in Toronto, Canada and the head of the Section of Leukemia and Lymphoma.

He obtained his MD and PhD from the University of Toronto, where he is an Associate Professor.

Dr. Gupta helped co-lead the creation of the Toronto Stage Guidelines and co-leads the Metadata Working Group of the National Childhood Cancer Registry



## Dr. HANSON Heidi

USA

Oak Ridge National Laboratory  
*Group Lead Biostatistics and  
Multilevel Systems Modeling, Senior  
scientist*

### Session:

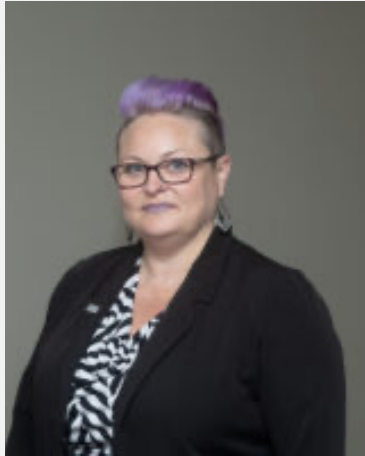
Workshop #4 Innovative Models & Data Management – Session 2

*November 7 – 4.15 - 5.30pm*

**Role:** Discussant

Dr. Hanson is a Group Lead in the Advanced Computing for Health Sciences at Oak Ridge National Laboratory (ORNL) and leads the Modeling Outcomes using Surveillance data and Scaleable Artificial Intelligence for Cancer (MOSSAIC) project. MOSSAIC is a partnership with the National Cancer Institute and a sub-project of the Joint Design of Advanced Computing Solutions for Cancer (JDACS4C).

The APIs developed by her team have been deployed in 16 Surveillance, Epidemiology, and End-Results (SEER) population registry and 1 non-SEER registry to auto-code pathology reports. The tools and tasks lay the groundwork for population scale real-time cancer surveillance, clinical trials matching at the patient level, and prediction of cancer outcomes.



## HILL Stéphanie

USA

North American Association  
of Central Cancer Registries  
(NAACCR)

*Associate Director*

**Session:**

Workshop #2 Interoperability – Session 3

*November 8 – 10 - 11.15am*

**Role:** Discussant

Stephanie Hill is the Associate Director of the North American Association of Central Cancer Registries (NAACCR) where she serves as the main project lead for the National Childhood Cancer Registry, a collaboration between NAACCR and the National Cancer Institute.

Ms. Hill also oversees the inter-agency change management process for the NAACCR Data Standards that are used by all cancer registries throughout North America.

Ms. Hill has a bachelor's degree from Rutgers University and a Master of Public Health from Johns Hopkins University.

She is a Certified Tumor Registrar (CTR) with over 20 years of experience managing both hospital-based and central cancer registries.

She is the former Program Manager of Operations for the New Jersey State Cancer Registry.



**Pr. IFRAH Norbert**  
France  
French National Cancer Institute  
*President*

**Session:**  
Opening day 1

*November 7 – 9.30 - 10am*

**Role:** Discussant

Professor Ifrah has completed most of his career as a clinical hematologist and academic in Angers University Hospital, where he was Head of the Blood Diseases Department and in turn Vice-President in charge of research then President of the Medical Commission for two terms (2007-2015). In 2014, he created a Research and Care Federation dedicated to leukemia (GOAL).

Norbert Ifrah has held numerous positions in Medical societies and Boards of Directors: President of the 47th section of the National Council of Universities, of the National research Coordination Committee, of the Federation of France Hospitals Cancer pole, of the College of French Hematologists. Member of the Board of Directors of the French Society of Bone Marrow Transplantation and Cellular Therapy, of the French Blood Establishment, then of the French National Cancer Institute.

A member of an Inserm and CNRS research unit, he led a national research network on adult acute leukemia for fifteen years. He is a signatory of more than 250 international publications, mainly in the field of hematological malignancies.



## JEGO Chloé

France

INSERM

4.UNCAN.eu

*Project manager*

### Session:

Workshop #3 Data Governance & Data Exchange - Session 2

*Nov. 7 – 4.15pm - 5.30pm*

**Role:** Discussant

Chloé Jégo is a Doctor in molecular biology. She graduated her PhD in October 2019, at Gustave Roussy, in Inserm U1170 (now U1287), under the supervision of Eric Solary. She dedicated those 4 years of research on the characterization of medullar Mesenchymal Stem Cells (MSCs) from Chronic Myelomonocytic Leukemia (CMML) patients.

Following her academic achievements, Chloé travelled and worked around Australia for 2 years, where she gained a profound appreciation for the power of global collaboration and knowledge exchange. This experience sparked her interest in promoting open science practices and strengthening international collaborations in her field..

She is now part of the project management team as a scientific project manager and coordinates 4.UNCAN.eu CSA with Eric Solary. The culmination of the CSA's efforts is set to deliver a comprehensive blueprint to the European Commission on November 30th. This blueprint will provide invaluable recommendations on the establishment of a European Federated Cancer Research Data Hub, marking a significant step toward enhancing data sharing and research collaboration in the field of cancer, notably in pediatric cancer.



## JORGENSEN Hanna

USA

*Patient representative*

**Session:**

Keynote - Patient advocates

*November 7 – 10 - 10.30am*

**Role:** Discussant

Hanna Jorgenson is a childhood cancer survivor and patient advocate. At the age of 16, she was diagnosed with Osteosarcoma and later with Li-Fraumeni syndrome, a cancer predisposition syndrome. Now 30 years old, her cancer journey has fueled her passion for sharing her story and advocating for cancer patients and their families. Her unique and firsthand understanding of the challenges, uncertainties, and complexities that cancer patients and their families face has driven her passion for data sharing and collaboration to help facilitate research and improve outcomes for all those affected by cancer.





## Dr. MATSUDA Tomohiro

Japan

National Cancer Center

*Head, Office of International Affairs,  
Strategic Planning Bureau*

### Session:

Workshop #3 Data Governance & Data exchange – Session 3

*November 8 – 10 - 11.15am*

**Role:** Discussant

From the early design phase of the Act on Promotion of Cancer Registry which took effect in 2016, Dr. Matsuda has played a central role and contributed to the establishment of the cancer registry system in Japan.

Building on the strong network and trusting relationship he has built in the field of cancer epidemiology and statistics in Europe and Asia as the PI of the IARC Collaborating Center of GICR and the head of the Asian Partnerships Section of ATLAS project, he is striving to advance cancer research, collaborating across nations and disciplines.



## MILLER Robert

USA

Minderoo Foundation

*Principal, Unlocking Patient Data,  
Cancer Mission, Minderoo  
Foundation*

### Session:

Workshop #4 Innovative Models & Data Management - Session 2

*November 7 – 4.15 – 5.30pm*

**Role:** Discussant

Robert Miller is the Principal of Unlocking Patient Data within the Minderoo Foundation's Cancer Mission, which aims to leverage data and technology to impact cancer research.

His professional training is in computer science and health informatics and has evolved into open health data standard collaborations. He joined the OHDSI community in 2016 and shortly after began co-leading the Oncology and GIS working groups.

Before joining Minderoo he was with Tufts Clinical and Translational Science Institute (CTSI, US) for 6 years where he helped establish and translate a range of different, disparate data sources into interoperable standards to support research and clinical delivery. He has also served as an OHDSI SME for national collaboration efforts including the National COVID Cohort Collaborative (N3C) and National Center for Advancing Translational Sciences (NCATS).

His current foci include maturing open oncology data standards, building an international community, and systemically accelerating oncology research through philanthropic funding



## Pr. MILLER Tamara

USA

Emory University School of  
Medicine

*Pediatric Oncologist*

### Session:

Workshop #4 Innovative Models & Data Management - Session 3

*November 8 – 10 – 11.15am*

**Role:** Discussant

Pr. Tamara Miller is an Associate Professor in the Department of Pediatrics, Division of Hematology/Oncology at Emory University and pediatric oncologist at Children's Healthcare of Atlanta.

Her research is focused on improving knowledge of adverse events and outcomes experienced by children during treatment for cancer and performing clinical epidemiology research in supportive care that will improve daily clinical care. Her research aims to develop a novel approach that leverages electronic health record (EHR) data to describe cancer treatments, toxicities, and outcomes.

Using ExtractEHR, the R package that we have developed, they can provide detailed data for cohorts such as registries that can be used to answer clinical research questions. The results of her research will provide clinicians and researchers with a more accurate and detailed understanding of patient experience during chemotherapy that can be used to guide clinical decisions and provide the foundation for future trials.



**Pr. MINARD-COLIN**

**Véronique**

France

Société Française Cancer Enfant  
(SFCE)

*Vice President*

**Session:**

Keynote - Setting the Stage about the Importance of Pediatric Oncology  
Data Sharing

*November 7 – 10.30 – 11.10am*

**Role:** Discussant

Véronique Minard-Colin is professor of Pediatrics at Paris Saclay University.

Specialist in pediatric lymphomas and sarcomas, and in the immunology of childhood cancers, she is head of the Immunotherapy program at Gustave Roussy's Department of Child and Adolescent Oncology, which uses innovative approaches to better understand the mechanisms of immune evasion in childhood cancers to develop effective immunotherapies.

She was elected vice-president of the 'Société Française des Cancers de l'Enfant' (SFCE) in 2019 and is a member of several European boards and groups, including the European childhood non-Hodgkin's lymphoma (EICNHL) and the European Paediatric Sarcoma Soft Tissues Study Group (EpSSG). She is also a member of the scientific advisory committee of the International Society of Pediatric Oncology (SIOP) and, since 2020, a member of the SIOP Europe educational council.



## Dr. NEGOITA Serban

USA

National Cancer Institute

*Chief of the Data Quality, Analysis,  
and Interpretation Branch (DQAIB),  
Surveillance Research Program*

### Session:

Workshop #1 Harmonization of Clinical & Biological Data

*November 7 – 2.30pm - 5.30pm*

*November 8 – 10am - 1pm*

*November 8 (Wrap-up in panel session) – 2.30 - 4pm*

**Role:** Facilitator

Dr. Serban Negoita, MD, DrPH, serves as Chief of the Data Quality, Analysis, and Interpretation Branch (DQAIB) with the Surveillance Research Program (SRP) of National Cancer Institute (NCI).

In this position, he works with SEER registries, NCI experts, and the cancer surveillance community to enhance the quality of cancer surveillance data.

In addition, Dr Negoita's research interests include descriptive statistics of clinical cancer outcomes, and more recently, the effect of COVID-19 pandemic on cancer statistics.

In 2021, Dr. Negoita has been appointed to the Executive Committee of the American Joint Committee on Cancer. In addition, he is the current SEER Program representative to the International Association of Cancer Registries.

Dr. Negoita earned his MD from the University of Medicine and Pharmacy in Bucharest, Romania and his DrPH from the State University of New York.



## Dr. NYGÅRD Jan F.

Norway

Cancer Registry of Norway

*Head of the Registry Informatics  
Department*

### **Session:**

Workshop #2 Interoperability – Session 1

*November 7 – 2.30 - 3.45pm*

**Role:** Discussant

Dr. Jan F Nygård earned his Cybernetics engineering degree from Oslo College of Engineering in 1991, minor in Political Science (1998) and a PhD in Epidemiology (2005) from the University of Oslo.

He began his career at the Institute of Community Medicine, University of Oslo (1992-1998) before joining the Cancer Registry of Norway in 1999. Since 2007, he has led the IT/Registry Informatics Department.

His research focuses on the convergence of big data analytics, machine learning, data privacy, secure computing, and epidemiology. He has published 89 original research papers in peer-reviewed journals, and supervised MSc and PhD students from informatics and medical faculties. He also contributes to reference and steering committees.

In 2017, he was a visiting scientist at Lawrence Livermore National Laboratory, and as of July 1, 2021, he holds the position of Adjunct Associate Professor in the Machine Learning Group at UiT – The Arctic University of Norway.





**Dr. PENBERTHY Lynne**  
USA  
National Cancer Institute  
*Associate Director for the  
Surveillance Research Program*

**Session:**

Keynote – Introducing the international Childhood Cancer  
Data Partnership

*November 7 – 12.40 - 12.55pm*

**Role:** Discussant

Dr. Lynne Penberthy is the Associate Director for the Surveillance Research Program (SRP), which is within the Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI) since 2013. Dr. Penberthy obtained her MD from the University of Michigan and her MPH in epidemiology at Johns Hopkins. Dr. Penberthy's career includes a surgical internship in Baltimore, Maryland, at the Sinai Hospital and a preventive medicine residency at Johns Hopkins University. After her residency, she completed her post-doctoral training in epidemiology with the CDC as an epidemic intelligence service (EIS) officer with the Commonwealth of Virginia. She is licensed to practice medicine in the state of Maryland. Dr. Penberthy has a long history of focus on informatics and automation and has been involved in biobanking both in her academic role as well as at NCI.

In addition to her role as SEER program director, she is the lead for the National Childhood Cancer Registry (NCCR) development and implementation under the Childhood Cancer Data Initiative (CCDI). The latter is a population based system based on cancer registries but brings in a multitude of other data sources to support research on childhood cancer.



**Pr. PETIT Arnaud**  
France  
Armand Trousseau Hospital  
*Pediatric Oncologist*

**Session:**

Workshop #1 Harmonization of clinical and biological Data – Session 3

*November 8 – 10 - 11.15am*

**Role:** Discussant

Professor Arnaud Petit, pediatric oncologist, head of the Pediatric Hematology and Oncology Department at Armand Trousseau Hospital (AP-HP).

He is part of the Hematopoietic and Leukemic Development research team (UMRS\_938).

He is chairman of the Leukemia Committee of SFCE (French Society against childhood cancers and leukemia) and co-chair of AML committee of the I-BFM Study group.

He is in charge of CONECT-AML (Consortium of French research teams involved in pediatric AML) and DOREMy project (French pediatric AML database).



## Dr. RANCE Bastien

France

Université Paris Cité

AP-HP Paris Hospital

*Associate professor of medical informatics*

### Session:

Workshop #1 Harmonization of Clinical & Biological Data - Session 2

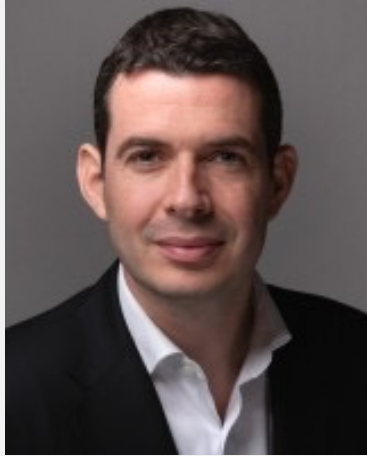
*November 7 – 4.15pm – 5-30pm*

**Role:** Discussant

Dr. Batién Rance is associate Professor of Medical Informatics at University of Paris Cité, School of Medicine and European Hospital Georges Pompidou, Assistance Publique - Hôpitaux de Paris.

Specialties: Secondary use of healthcare data, health data warehouses, artificial intelligence in medicine, data integration for the life sciences, medical informatics, medical terminologies and ontologies.

He is head of the data platform of the CARPEM research program (CAnCER Research for PErsonalized Medicine) which brings together 350 researchers and physicians dedicated to cancer care and research. Their domain of competences covers Immunology, Genomics, Metabolism, Cellular Biology, Bioinformatics, Mathematics, Biostatistics, Medical Informatics, Microfluidics, Epidemiology and Ethics.



## RINAUDO Paul

France

ADLIN-Science

CEO

### Session:

Workshop #2 Interoperability – Session 2

*November 7 – 4.15pm – 5-30pm*

**Role:** Discussant

Paul Rinaudo is entrepreneur and experienced Managing Director with a demonstrated history of working in the industrial and financial sector.

He is passionate about biology, teamwork and innovation.

He is the Founder & CEO of ADLIN Science, a digital Healthtech which aims to accompany scientific researchers in the emergence of precision medicine, by developing tools enabling groundbreaking innovations in omic sciences and actively participate to the public research funding dilemma.



## Dr SAULTIER Paul

France

AP-HM, Inserm,  
LEA platform

*Associate professor*

### Session:

Workshop #2 Interoperability – Session 3

*November 8 – 10am - 11.15am*

**Role:** Discussant

Dr Paul Saultier currently works as an associate professor at the Department of pediatric hematology, immunology and oncology, La Timone Children Hospital, APHM and at the C2VN, INSERM 1263, Aix Marseille University in Marseille, France.

His main clinical and research interest is childhood leukemia survivorship. He is one of the coordinators of the LEA program. This program was implemented in 2004 in France and aims at promoting and studying long-term health in childhood survivors of leukemia. This program investigates the medical, genetic, socioeconomic, behavioral, and environmental determinants of long-term complications of survivors of childhood leukemia.



## Dr. SCHLEIERMACHER

**Gudrun**

France

Institut Curie

*Practitioner and assistant director at  
SIREDO center (Curing more children  
with cancer)*

### Session:

Workshop #1 Harmonization of clinical and biological Data – Session 1

*November 7 – 2.30 – 3.45pm*

**Role:** Discussant

Physician-scientist originally from Heidelberg, Germany, Gudrun Schleiermacher is a pediatric oncologist and researcher at Institut Curie, Paris, France.

In addition to care for children and adolescents with cancer, she is involved in clinical and translational research programs. Her work focusses the study of molecular mechanisms involved in cancer progression and clonal evolution in neuroblastoma and other pediatric cancers, based on biomarker studies using liquid biopsies and on single cell analysis. Future aims are to integrate biomarkers into integrative treatment approaches, while working towards a better understanding of the underlying genetic and epigenetic modifications involved in the oncogenesis and tumor progression. She is also involved in personal and precision medicine approaches at a national and international level.





## SCHOBER Niklas

Austria

CCI Europe and UNCAN.eu

*Patient advocate*

### **Session:**

Opening Day 2

*November 8 – 9 – 9.30 am*

**Role:** Discussant

Niklas Schober is a childhood cancer survivor and patient advocate. At the age of 12, he was diagnosed with a Non-Hodgkin Lymphoma.

Now 18 years-old, he looks back at a journey shaped through optimism and confidence. After two years of chemotherapy and the victory against his cancer, he started to take part in projects such as CCI Europe and UNCAN.eu, where he advocated for cancer patients and their families and fought for improvements in cancer therapies, with a view on social and psychological aspects.

Because of the special perspectives of someone who has actually felt how it is to have and fight cancer, he truly understands problems and challenges regarding cancer.



## Dr. STELIAROVA-FOUCHER

**Eva**

France

International Agency for  
Research on Cancer  
*Scientist*

### Session:

Roundtable - Discussing legal challenges for data sharing and initiatives to address them

*November 7 – 11:40 - 12:40 am*

**Role:** Discussant

### Session:

Workshop #1 Harmonization of Clinical & Biological Data

*November 7 – 2.30pm - 5.30pm*

*November 8 – 10am - 1pm*

*November 8 (Wrap-up in panel session) – 2.30 - 4pm*

**Role:** Facilitator

Eva Steliarova-Foucher is a scientist at the International Agency for Research on Cancer (IARC) of WHO.

She obtained the degree Doctor of natural sciences (RNDr) at the Comenius University, Bratislava, Slovakia in 1986, the MSc degree at the London School of Hygiene and Tropical Medicine, UK in 1989 and the PhD degree the Slovak Academy of Sciences in Bratislava in 1994.

She worked at the Slovak National Cancer Registry during 1985-1994.

Based at IARC since then, she currently leads the Childhood Cancer Team and several international childhood cancer projects.

She had coordinated international consortia of cancer registries and is a member of the International Society of Paediatric Oncology (SIOP) since 2015.



## THOMAS Steven

Canada

Statistics Canada

*Section chief*

### Session:

Workshop #4 Innovative Models and Data management – Session 1

*November 7 – 2.30 - 3.45pm*

**Role:** Discussant

Steven Thomas is the section chief in charge of the Centre for Confidentiality and Access and is the Principal Confidentiality Officer at Statistics Canada.

He has a degree in statistics from Memorial University of Newfoundland and has worked at Statistics Canada since 1997.

The confidentiality and access group is responsible for research, development and support for statistical disclosure control strategies for both economic and social statistics.

The disclosure control strategies include methods for the safe release of tabular data as well as public microdata files in the form of anonymized and synthetic datasets.



## Dr. VOLCHENBOUM Samuel

USA

University of Chicago

*Associate Professor of Pediatrics &  
Pediatric Cancer Data Common  
Director*

### Session:

Keynote - Setting the Stage about the Importance of Pediatric Oncology  
Data Sharing

*November 7 – 10.30 - 11.10 am*

**Role:** Discussant

Dr. Volchenboum is an associate professor of pediatrics and the associate chief research informatics officer for the Division of Biological Sciences at the University of Chicago.

He is the Dean of Masters Programs, and he designed and launched the UChicago Master's in Biomedical Informatics. His clinical specialty is pediatric hematology / oncology, caring for kids with cancer and blood diseases.

His research group includes the University of Chicago's Data for the Common Good (D4CG), dedicated to building communities, platforms, and ecosystems that maximize the potential of data to drive discovery and improve human health. D4CG's flagship project, the Pediatric Cancer Data Commons is dedicated to liberating and democratizing international data for pediatric malignancies.

He is the director of the Informatics Core for the Clinical and Translational Science Award (CTSA), and he is director of the UChicago Clinical Informatics fellowship program.



## Dr. WESTERMANN Frank

Germany

German Cancer Research Cancer  
(DFKZ)

*Head of the Department of  
Neuroblastoma Genomics*

### Session:

Workshop #1 Harmonization of clinical and biological Data – Session 3

*November 8 – 10 - 11.15am*

**Role:** Discussant

Head of the Department of Neuroblastoma Genomics at DKFZ and Hopp Children's Cancer Centre at NCT Heidelberg KITZ.

Dr. Westermann has worked on the ITCC (Innovative Therapies For Children With Cancer) International Data Integration Platform to prioritize drug development and access for children with cancer. The aim of this project is to take a decisive step towards the systematic prioritization of new cancer therapies for children in Europe and beyond through better use of and access to existing genomic and clinical data.

He has extensive experience in molecularly characterizing childhood cancers, particularly neuroblastoma, and in developing molecular classification systems that are now used in the clinic.

He is member of the clinical sequencing progra "INDividualized Therapy FOr Relapsed Malignancies in Childhood" (INFORM). The concept of the INFORM registry is to biologically characterize tumor samples (collected through routine standard of care biopsies at the time of the current tumor manifestation) for all pediatric patients with relapsed or refractory high risk disease of the 12 most common but also selected rare entities for whom no further standard of care therapy is available.



**Dr. WIGGINS Chuck**  
USA  
New Mexico Tumor Registry  
*Director and Principal Investigator*

**Session:**

Workshop #3 Data Governance and data exchange

*November 7 – 2.30pm - 5.30pm*

*November 8 – 10am - 1pm*

*November 8 (Wrap-up in panel session) – 2.30 - 4pm*

**Role:** Facilitator

Charles Wiggins, Ph.D., is Director and Principal Investigator for the New Mexico Tumor Registry, a founding participant in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program.

He is also Professor in the Division of Epidemiology, Biostatistics and Preventive Medicine, Department of Internal Medicine at the University of New Mexico School of Medicine.

Dr. Wiggins has over forty years of experience in cancer surveillance and epidemiology.

He served as President of the North American Association of Central Cancer Registries from 2015-2017 and is President Elect for the International Association of Cancer Registries.

Dr. Wiggins has a strong commitment to conducting population-based cancer surveillance and research that will benefit the diverse communities of New Mexico and the United States, and strives to focus the New Mexico Tumor Registry's activities toward reducing disparities and diminishing the burden of cancer.



# Agenda

Day 1 - 7 November 2023

09:00 am | Welcoming Coffee

09:30 am | Opening - Day 1

- **Norbert IFRAH** – President, French National Cancer Institute (INCa)
- **Monica BERTAGNOLLI** – Director, US National Cancer Institute (NCI)

10:00 a.m | Keynotes - Patient Advocates

- **Patricia BLANC** – President and Founder, Imagine for Margo
- **Hanna JORGENSON** – Cancer Survivor and Patient Advocate

10:30 am | Keynotes - Setting the Stage: The Importance of Pediatric Oncology Data Sharing

Keynotes about pediatrics cancers, statistics and global key issues around data sharing

- **Véronique MINARD-COLIN** – French Society for Childhood Cancers, Gustave Roussy Institute
- **Samuel VOLCHENBOUM** – Pediatric Cancer Data Commons

11:40 am | Roundtable - Discussing the identified issues and how other initiatives address them

- Legal Challenges & Legislative Hurdles
- Federated data, Federated learning & Queries

- **Suzi BIRZ** – Pediatric Cancer Data Commons
- **Lindsay FRAZIER** – Dana Farber Cancer Institute
- **Eva STELIAROVA-FOUCHER** – International Agency for Research on Cancer
- **Manola BETTIO** – European Commission, Joint Research Centre

12:40 pm | Keynote - Introducing the International Childhood Cancer Data Partnership

- What we would like to build
- What we need to think about
- Q&A

- **Lynne PENBERTHY** (US National Cancer Institute)

12:55 pm | Lunch

# Agenda

## Day 1 - 7 November 2023

### 02:30 pm | Workshop - Session 1

4 thematic Workshop sessions continuation:

#### ▲ #1 Harmonization of Clinical and Biological Data

##### Facilitators Workshop #1:

- Serban NEGOITA (US National Cancer Institute)
- Eva STELIAROVA-FOUCHER (International Agency for Research on Cancer)

##### Discussants – Session 1:

- Gudrun SCHLEIERMACHER (Curie Institute)
- Sumit GUPTA (Hospital for Sick Children)

##### Subthemes – Session 1:

- What are the core data elements and how they fit into common data models ?
- Need to harmonize the collection of histology, stage and non-stage prognosticators

#### ▲ #2 Interoperability

##### Facilitators Workshop #2:

- Eric DURBIN (Kentucky Cancer Registry)
- Johanna GODERRE (US National Cancer Institute)

##### Discussants – Session 1:

- Peter GOODHAND (Global Alliance for Genomics and Health)
- Jan NYGÅRD (Cancer Registry of Norway)

##### Subthemes – Session 1:

- How can collaborations enhance the value of treatment and outcome data?
- National standards, mapping and conversions for a childhood data fabric

#### ▲ #3 Data Governance & Data exchange

##### Facilitators Workshop #3:

- Michel COLEMAN (London School of Hygiene & Tropical Medicine)
- Chuck WIGGINS (New Mexico Tumor Registry)

##### Discussants – Session 1:

- Suzi BIRZ (Pediatric Cancer Data Commons)
- Joanne AITKEN (Cancer Council Queensland)

##### Subthemes – Session 1:

- Who "owns" the data?
- Who is responsible for oversight/decisions regarding data sharing?
- What permissions are needed in order to share?
- What specific legal steps need to be accomplished to enable data access?

#### ▲ #4 Innovative Models & Data Management

##### Facilitators Workshop #4:

- Jaime GUIDRY AUVIL (US National Cancer Institute)
- Gijs GELEIJNSE (Netherlands Comprehensive Cancer Organisation)

##### Discussants – Session 1:

- Steven THOMAS (Statistics Canada)
- Leucio Antonio CUTILLO (European Commission Joint Research Centre)

##### Subthemes – Session 1:

- Will anonymization provide a potential solution to data sharing for all or many countries?
- What are the potential drawbacks of anonymization as a solution?

# Agenda

## Day 1 - 7 November 2023

3:45 pm | Coffee Break

4:15 pm | Workshop - Session 2

4 thematic Workshop sessions continuation:

### ▲ #1 Harmonization of Clinical and Biological Data

#### Facilitators Workshop #1:

- Serban NEGOITA (US National Cancer Institute)
- Eva STELIAROVA-FOUCHER (International Agency for Research on Cancer)

#### Discussants – Session 2:

- Paul GIBSON (McMaster Children's Hospital)
- Bastien RANCE (AP-HP, Paris Hospital)

#### Subthemes – Session 2:

- Are there data standards for these core data elements?
- Which registries adhere to these standards?
- Do conversions/ crosswalks exist?

### ▲ #2 Interoperability

#### Facilitators Workshop #2:

- Eric DURBIN (Kentucky Cancer Registry)
- Johanna GODERRE (US National Cancer Institute)

#### Discussants – Session 2:

- Marie CASTETS (Share4Kids) & Paul RINAUDO (ADLIN Science)
- Jacqueline CLAVEL (French National Registry of Childhood Cancers)

#### Subthemes – Session 2:

- Are there existing crosswalks for varying formats/models)?
- Are those crosswalks applicable for this proposed project?

### ▲ #3 Data Governance & Data exchange

#### Facilitators Workshop #3:

- Michel COLEMAN (London School of Hygiene & Tropical Medicine)
- Chuck WIGGINS (New Mexico Tumor Registry)

#### Discussants – Session 2:

- Philippe-Jean BOUSQUET (French National Cancer Institute) & Chloé JEGO (Inserm – UNCAN.eu)
- Rosa CASTRO (Deutsche Stiftung Weltbevölkerung)

#### Subthemes – Session 2 :

- What legal steps/ agreements must be in place to enable data sharing/ access to data?

### ▲ #4 Innovative Models & Data Management

#### Facilitators Workshop #4:

- Jaime GUIDRY AUVIL (US National Cancer Institute)
- Gijs GELEIJNSE (Netherlands Comprehensive Cancer Organisation)

#### Discussants – Session 2:

- Heidi HANSON (Oak Ridge National Laboratory)
- Robert MILLER (Minderoo Center for Federated Cancer Research)

#### Subthemes – Session 2:

- Are there options to consolidate data across a limited set of countries that could then provide a "grouped node"?
- Are there specific considerations for federated queries that relate to interoperability questions?

5:30 pm | End of first day conference

# Agenda

## Day 2 - 8 November 2023

08:30 am | Welcoming Coffee

09:00 am | Opening - Day 2

- Niklas SCHOBER – Cancer Survivor and Patient Advocate
- Claire GIRY – Director General for Research & Innovation, France

10:00 am | Workshop - Session 3

4 thematic Workshop sessions continuation :

### ▲ #1 Harmonization of Clinical and Biological Data

#### Facilitators Workshop #1:

- Serban NEGOITA (US National Cancer Institute)
- Eva STELIAROVA-FOUCHER (International Agency for Research on Cancer)

#### Discussants – Session 3:

- Arnaud PETIT (French Society for Childhood and Adolescent Cancer and Leukemia)
- Frank WESTERMANN (German Cancer Research Center)

#### Subthemes – Session 3:

- What genomic variables will be important for childhood cancer research?

### ▲ #2 Interoperability

#### Facilitators Workshop #2:

- Eric DURBIN (Kentucky Cancer Registry)
- Johanna GODERRE (US National Cancer Institute)

#### Discussants – Session 3:

- Stephanie HILL (North American Association of Central Cancer Registries)
- Paul SAULTIER (LEA Platform)

#### Subthemes – Session 3:

- Are there data exchange layouts applicable to this project (or use cases that could be successfully modeled)?

### ▲ #3 Data Governance & Data exchange

#### Facilitators Workshop #3:

- Michel COLEMAN (London School of Hygiene & Tropical Medicine)
- Chuck WIGGINS (New Mexico Tumor Registry)

#### Discussants – Session 3:

- Hugo CROCHET (Centre Léon Bérard)
- Tomohiro MATSUDA (National Cancer Center Hospital Japan)

#### Subthemes – Session 3:

- What policies and infrastructure need to be in place for users to access the data in a secure environment?

### ▲ #4 Innovative Models & Data Management

#### Facilitators Workshop #4:

- Jaime GUIDRY AUVIL (US National Cancer Institute)
- Gijs GELEIJNSE (Netherlands Comprehensive Cancer Organisation)

#### Discussants – Session 3:

- Tamara MILLER (Emory University)
- Laura BOTTA (Fondazione IRCCS Istituto Nazionale dei Tumori di Milano – BENCHISTA Project)

#### Subthemes – Session 3:

- Would a hybrid model (a combination of options discussed at subthemes 1 and 2 be a feasible option? What types/categories of data could be released via each of these tiers?
- Are there different types of research questions/analysis that can be answered and cancer statistics that can be calculated using the different mechanisms?

# Conference Agenda

## Day 2 - 8 November 2023

11:15 am | **Coffee Break**

11:45 am | **Workshop Wrap-Up – Session 4 – Key Takeaways**

### Animation by Facilitators

- Key barriers that need to be addressed & Potential solutions
- Specific next steps to move forward

### ▲ #1 Harmonization of Clinical and Biological Data

#### Facilitators Workshop #1:

- **Serban NEGOITA** (US National Cancer Institute)
- **Eva STELIAROVA-FOUCHER** (International Agency for Research on Cancer)

#### Subthemes – Session 4:

Key Takeaways

### ▲ #2 Interoperability

#### Facilitators Workshop #2:

- **Eric DURBIN** (Kentucky Cancer Registry)
- **Johanna GODERRE** (US National Cancer Institute)

#### Subthemes – Session 4:

Key Takeaways

### ▲ #3 Data Governance & Data exchange

#### Facilitators Workshop #3:

- **Michel COLEMAN** (London School of Hygiene & Tropical Medicine)
- **Chuck WIGGINS** (New Mexico Tumor Registry)

#### Subthemes – Session 4:

Key Takeaways

### ▲ #4 Innovative Models & Data Management

#### Facilitators Workshop #4:

- **Jaime GUIDRY AUVIL** (US National Cancer Institute)
- **Gijs GELEIJNSE** (Netherlands Comprehensive Cancer Organisation)

#### Subthemes – Session 4:

Key Takeaways

1:00 pm | **Lunch**

2:30 pm | **Panel Discussion**  
**Conclusions from the Workshop sessions & Next Steps**

4:00 pm | **Closing of the Conference**

**Thierry BRETON** – Director General, French National Cancer Institute

**Lynne PENBERTHY** – Associate Director for the Surveillance Research Program, US National Cancer Institute

# Practical information

## Location and access

### Venue



#### Newcap Event Center

3 Quai de Grenelle, 75015 Paris

### Public transport



#### RER

Line C: Champs de Mars-Tour Eiffel Station



#### Metro

Line 6: Bir-Hakeim Station



#### Bus

Line 72: Pont de Bir-Hakeim Station  
Line 82: Champ de Mars Station

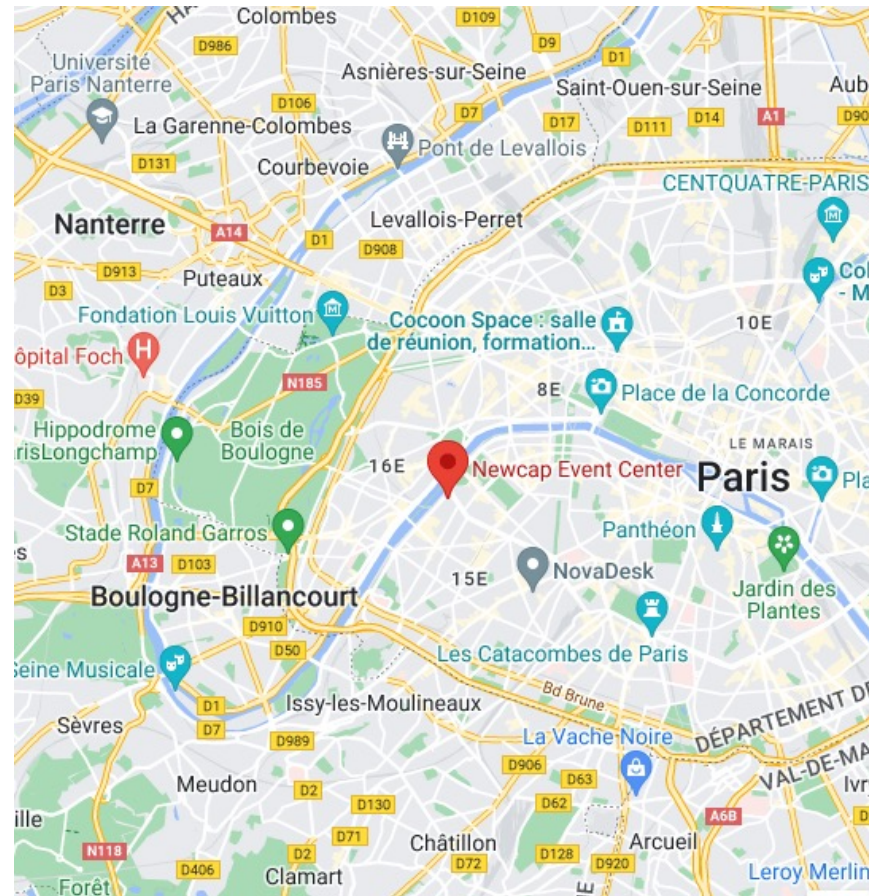
Plan your transportation in advance with RATP website :

[How to go to Newcap Event Center?](#)

### Bike station



Station 15026: Bir-Hakeim





# Practical information

## During the conference

### Wifi

Name: **wifi premium**

Password: **newcapsecurity**

### Conference website

<https://iccdp-parisconference.com/>

### Rooms to access the workshop sessions

**#1 Harmonization of Clinical  
& Biological Data**

**Room A**

**#2 Interoperability**

**Room B**

**#3 Data Governance &  
Data exchange**

**Room C**

**#4 Innovative Models &  
Data Management**

**Room D**