



For Patients, By Patients
Partnering to make research stronger

**2024 Virtual Conference
Speaker Booklet**



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DAY 1: VALUING YOUR VOICE AS A PATIENT PARTNER

Learning to centre on your own experiences, embrace patient partnerships and know that you have the right to hold the power and to care for yourself and others as part of the health research team.

Session 1: Embracing the 'lived experience' part of your identity

Session 2: Raising the bar and sharing the power

Session 3: Taking care as a patient partner

Session 4: Ask Me Anything

DAY 2: TACKLING THE CHALLENGING TOPICS ABOUT PATIENT ENGAGEMENT IN RESEARCH

This day will deal head-on with some of the tough conversations that need to happen about patient engagement in research.

Session 1: Exploring some of the ethics of patient partnership in research

Session 2: Navigating difficult experiences when patient engagement doesn't go as hoped

Session 3: Bringing new voices to research and building diversity

Session 4: Ask Me Anything

DAY 3: ADVANCING BEST PRACTICE IN RESEARCH PARTNERSHIPS

This day is all about changing the status quo in patient engagement in research, breaking barriers, and innovating to foster better patient partnerships that ultimately make research stronger.

Session 1: Publishing as (and with) patient partners

Session 2: Highlighting other types of (often non-academic) patient partnerships

Session 3: Learning about different types of recognition for patient partners

Session 4: You Can't Ask That

DAY 1 TIMINGS

	UTC-7 (PST)	UTC+1 (BST)	UTC+10 (AEST)
Session 1	September 10 9:00 am - 10:00 am	September 10 5:00 pm - 6:00 pm	September 11 2:00 am - 3:00 am
Session 2	September 10 10:30 am - 11:30 am	September 10 6:30 pm - 7:30 pm	September 11 3:30 am - 4:30 am
Session 3	September 10 12:00 pm - 1:00 pm	September 10 8:00 pm - 9:00 pm	September 11 5:00 am - 6:00 am
Session 4	September 10 1:15 pm - 2:15 pm	September 10 9:15 pm - 10:15 pm	September 11 6:15 am - 7:15 am

DAY 2 TIMINGS

	UTC-7 (PST)	UTC+1 (BST)	UTC+10 (AEST)
Session 1	September 11 9:00 am - 10:00 am	September 11 5:00 pm - 6:00 pm	September 12 2:00 am - 3:00 am
Session 2	September 11 10:30 am - 11:30 am	September 11 6:30 pm - 7:30 pm	September 12 3:30 am - 4:30 am
Session 3	September 11 12:00 pm - 1:00 pm	September 11 8:00 pm - 9:00 pm	September 12 5:00 am - 6:00 am
Session 4	September 11 1:15 pm - 2:15 pm	September 11 9:15 pm - 10:15 pm	September 12 6:15 am - 7:15 am

DAY 3 TIMINGS

	UTC-7 (PST)	UTC+1 (BST)	UTC+10 (AEST)
Session 1	September 12 5:00 pm - 6:00 pm	September 13 1:00 am - 2:00 am	September 13 10:00 am - 11:00 am
Session 2	September 12 6:30 pm - 7:30 pm	September 13 2:30 am - 3:30 am	September 13 11:30 am - 12:30 pm
Session 3	September 12 8:00 pm - 9:00 pm	September 13 4:00 am - 5:00 am	September 13 1:00 pm - 2:00 pm
Session 4	September 12 9:15 pm - 10:15 pm	September 13 5:15 am - 6:15 am	September 13 2:15 pm - 3:15 pm

Day 1 Session 1

Embracing the 'lived experience' part of your identity: Delve into the personal journeys of individuals who have embraced their patient identities to drive change and advocate for others.

Angie Clerc-Hawke



Angie Clerc-Hawke has a lived experience of chronic pain and recovery. She founded Our Recovery, a not-for-profit organisation, which is building a social support and learning program for people with chronic pain to engage in a meaningful life. In collaboration with University of Technology Sydney, Angie is co-leading a consumer-led research project that is co-designing and evaluating the Our Recovery program. Angie has a background in medical science. She is also trained and experienced in facilitating participatory processes and consumer involvement in health research and service design.

Libby Humphris



Libby Humphris is an experienced public contributor and an honorary research associate at Division of Population Medicine, Cardiff University. She has a keen focus on women's health issues, shared decision making and evaluating involvement and engagement impact. Libby also lives with multiple rare diseases and co-morbidities, raising awareness of rare diseases and sharing her journey navigating life as a disabled woman on her Instagram blog. This led to Libby becoming more involved and using her voice to break down barriers for other patients and the public. She is the co-lead of public engagement and involvement alongside Dr. Denitza Williams at the Evidence Centre.



Oluwafemi Ajayi

Oluwafemi Ajayi was born with sickle cell disease and she has lived through it miraculously for over 4 decades. She is a patient advocate for sickle cell and she also supports and empowers people like herself through her non-profit organization; 'Gail Sickle Initiative. She is a PhD fellow at the University of South Africa, written and co-authored some articles and publications and an active member of different global organizations where advocacy and patient inclusion is priority. She looks forward to a world without pain.

Facilitated By



David Gilbert

Director, InHealth Associates

David believes that people affected by life-changing illness are inherent leaders who bring jewels of wisdom, passion and insight from the caves of suffering. He is a mental health service user and author of The Patient Revolution - how we can heal the healthcare system. He was a pioneer of Patient (Lived Experience) Leadership and the first Patient Director in the UK NHS. He is also Writer in Residence at The Bethlem Gallery.

Day 1 Session 2

Raising the bar and sharing the power: Explore how power dynamics on research teams can be enriched by addressing implicit biases, building trust and promoting communication strategies that promote a more collaborative relationship.

Cherelle Augustine



Cherelle is a young lady living with Sickle Cell Disease. Since childhood and throughout her lifetime, she has campaigned for Sickle Cell Disease, educating members of the public, clinicians, paramedics, schools and politicians alike. Currently working for NIHR ARC NWL in the UK, she is part of the Ethnicity & Health Unit and continues to co-produce with researchers to improve the quality of care and standard of life for those living with Sickle Cell and other patients using social, community and healthcare systems.

Patrick Gee, PhD.



Patrick Gee, Ph.D., is a Healthcare Consultant/Community Activist fighting against systemic issues such as poverty, social and racial injustices, criminal justice reform, health equity, and education reform. Patrick is the Founder and Chief Executive Hope Dealer at iAdvocate, a faith-based health and wellness organization that serves the undervalued, underserved, and disenfranchised communities of color.

Patrick graduated from American University, Washington, DC, with a Doctor of Philosophy in Justice, Law, & Criminology in 2012. Patrick is a patient advocate living with Diabetic Kidney Disease. He travels the country sharing his lived experience with medical providers, pharmaceutical companies, researchers, and patients to create access to a better quality of life, access to care, treatments, and solutions for those living with diabetes, kidney disease, heart disease, hypertension, and health equity challenges.



Zahra Alidina

Zahra Alidina is an undergraduate student at McMaster University, studying Biology. She has experience working at SickKids as a research student. She has been involved as a patient partner for several years in various organizations including C4T (Canadian Collaborative for Childhood Cannabinoid Therapeutics), CIHR, and SKIP (Solutions for Kids in Pain). She is passionate about working through different barriers that patients and families experience and involving them in research.

Facilitated By



Fez Awan

My name is Fez Awan I am in my 30s. Born and raised in Lancashire UK to Pakistani parents. I was born with chronic kidney disease, and I have had 3 kidney transplants to date, one was a live donation from my father. And used all modalities of dialysis within my life time. I now have developed other long term conditions but chronic kidney disease (CKD) was my primary illness from birth.

Day 1 Session 3

Taking care as a patient partner: Reflect on the importance of self, collective and structural care as a patient partner and how to protect against burnout.

Christopher Munt



I have enjoyed a career that stretches all the way back to 1985. I have been privileged to look back on roles in Social Work, academic teaching and research, project leadership roles in NHS transformation programmes, community development, and supporting service user led organisations. A standout engagement has been working for the WHO in the Middle East, assisting colleagues to move towards more community based therapeutic provision in mental health. I was awarded the MBE in 2011, for services to Mental Health. At the same time, I look forward to new opportunities to bring closer together the wisdoms of professional and lived experience. I believe that the profession of Social Work, has regard for lived experience embedded in its values of Advocacy, Social Justice, and Unconditional High Regard.

Shyamsundar Muthuramalingam



Dr. Shyamsundar Muthuramalingam, with a Ph.D. in Chemistry and personal experience as a kidney transplant recipient, is a leading advocate for patient engagement in health and medical research in Australia. His journey through kidney disease and haemodialysis has fuelled his passion for consumer advocacy and community engagement. Dr. Muthuramalingam has significantly shaped engagement strategies across key organizations like ANZDATA, SAHMRI, The George Institute for Global Health, and Kidney Health Australia. He's instrumental in promoting consumer voices in research agendas, study implementation, and translating findings to improve care. As a Steering Committee member at the PxP Conference, he will share insights on enhancing patient partnership in research, emphasizing the impact of lived experience in clinical trials. His work exemplifies the 'For Patients, By Patients' ethos, making him a pivotal figure in advancing patient-centred research.

Facilitated By



Rae Martens

Rae Martens is a disabled patient advocate from Calgary, Alberta, Canada. She has been a partner in research in a variety of contexts as parent of a disabled and medically complex child, as well as a two-time cancer survivor. When she is not partnering in research, she functions as a Knowledge Broker, building relationships between researchers and people with lived experience, ensuring the partnerships that develop are healthy ones.

Day 1 Session 4

Ask Me Anything

Derek Stewart



Born too many years ago in Ayr, Scotland, Derek was treated successfully for throat cancer in 1995. A former teacher, Derek worked with young people experiencing difficulties in adjusting to mainstream education in Glasgow then in Nottinghamshire where he now lives. He subsequently became actively involved in numerous aspects of patient involvement and advocacy at a local, national and international level being the founder Chair of the Consumer Liaison Group for the National Cancer Research Institute, UK. He was Chair of a Primary Care Trust and of Nottingham Crime & Drugs Partnership which led to the award of OBE in 2006. Derek now has a particular interest with health and care methodology research in making all studies as relevant, efficient and effective as possible.

Linda Wilhelm



Linda Wilhelm is the President of The Canadian Arthritis Patient Alliance, a national, volunteer, patient driven organization that has worked to improve the lives of people living with arthritis since 2002. She is co-chair of the Steering Committee for the Chronic Pain Strategy for Patient Oriented Research (SPOR) Network, as well as a member of the networks patient advisory committee. She is also a member of The Evidence Alliance (SPOR) Network. Linda has participated in past Health Canada expert advisory panels and numerous conferences concerning access and drug safety issues. She is a former member of both the Expert Advisory Committee for Vigilance of Health Products and the Drug Safety and Effectiveness Network's steering committee.

Facilitated By



Rae Martens

Rae Martens is a disabled patient advocate from Calgary, Alberta, Canada. She has been a partner in research in a variety of contexts as parent of a disabled and medically complex child, as well as a two-time cancer survivor. When she is not partnering in research, she functions as a Knowledge Broker, building relationships between researchers and people with lived experience, ensuring the partnerships that develop are healthy ones.

Day 2 Session 1

Exploring some of the ethics of patient partnership in research:

Learn some of the basics about research ethics, and learn patient partners' perspectives on the ethics related to patient engagement in research



Isabel Jordan

Isabel Jordan draws from her lived experience to provide leadership and guidance in health care and health care research to support meaningful patient partnership practices that are aligned with patient-oriented research. Isabel was a founding member of the Rare Disease Foundation. Under her leadership, the organization built partnerships between families and researchers through their Research Micro-Grant Program. Isabel is the Strategic Lead in Patient Partnerships in the Chambers Lab at Dalhousie University as well as the Patient Partnership advisor for SKIP, a knowledge mobilization network that seeks to bridge the gap between treatment practices and evidence-based solutions for children's pain in Canadian health institutions.



Jim Elliott

Jim Elliott led the work of the Health Research Authority on the involvement of patients and the public in health research [part time] from 2012 to 2023 as part of his work as an advocate for patients in research. Jim led the creation of a partnership of major research organisations with the aim of making patient and public involvement usual practice, leading to the Shared Commitment to Public Involvement in Health and Social Care Research, launched in March 2022. He retired from the HRA at the end of March 2024.



Vina Mohabir

Vina Mohabir (she/her) has lived with chronic pain since she was a teenager after an accident in 2010 and recently beat stage 3 breast cancer. Vina is passionate about sharing her story and advocating for the unique needs of disabled, diverse and low-income youth. Patient engagement is one of her passions, and she works to facilitate patient engagement in pain research, policy, education, and clinical practice in Canada and internationally. She currently works at the iOUCH Pain Research lab at The Hospital for Sick Children in Toronto.

Facilitated By



Dr. Simone Uwan

Simone Eastman Uwan MD (known to the Sickle Cell community as Dr. Simone) was born in Guyana South America and migrated to the United States with her family when she was 14 years old. She had a love for science and math and attended "Clara Barton High School for Health Professions" in Brooklyn, NY. She was awarded a scholarship to attend Barnard College at Columbia University in Manhattan, NY. There she majored in biology and pre-medical Sciences. It was during her college years that she was diagnosed with Sickle Cell disease, even though she had active symptoms all her life.

Day 2 Session 2

Navigating difficult experiences when patient engagement doesn't go as hoped: Get equipped with tools to help deal with challenges, foster resilience and build networks for mutual support when patient engagement doesn't go to plan.

Michael Falcon



Michael is a humanitarian, licensed to practice occupational therapy, and the Director of Capstone Education and Assistant Professor in the Occupational Therapy Doctorate program at Hawai'i Pacific University. His expertise in international program development and consultation, Facilitated through a global community-based perspective, has allowed him to work with communities and interprofessional colleagues from across the globe. He has the honor of being one of the founding members of GAPPA, the Global Alliance of Partners for Pain Advocacy and currently serves on several Executive committees, Working groups and Task forces with IASP. Michael has lived with chronic pain for over 15 years.

Nichole M. Jefferson, M.J



Nichole Jefferson, a risk management and compliance analyst for Wells Fargo, currently resides in Dallas, Texas. When diagnosed with end-stage renal disease in 2003, not only was she unaware of what it meant, she had no idea she was at high-risk for developing kidney disease. Though Nichole experienced both forms of dialysis (HD and PD), she preferred the convenience peritoneal dialysis offered. On June 12, 2008, she received the gift of life, a kidney transplant. Due to the many obstacles she faced following her transplant, Nichole realized that a transplant was simply another form of treatment and not a cure. This realization sparked her quest for knowledge, which later initiated her enthusiasm for advocacy. This enthusiasm and advocacy are what assisted Nichole in her fight for her second transplant which she had on April 24, 2024.



Sally Crowe

Sally retired from facilitating and project managing in the UK and international health and social care sector after 30 years. She worked with and for public, private and charitable organizations with a special interest in patient and public involvement in health and social care services and research prioritization. Now contributing to research from a public perspective as a user of healthcare services and as a part time carer. Sally is also a qualified Coach and likes to work with people involved in research in some way.

Facilitated By



Thomas Smith

A member of the European Health Parliament and a EUPATI Fellow, Thomas is an internationally recognised consultant operating with life sciences companies all over Europe. He works with regulatory bodies like the European Medicines Agency as an Expert Patient Reviewer and the Health Research Authority as a member of a Research Ethics Committee. Tom's personality, objective thought, and conviction has led him to work with major national and global broadcast media, the pharmaceutical and MedComms. Industry, Clinicians and the governance of NHS Foundation Trusts. Tom combines experience of Policy, Clinical Research and media representation to emphasise that meaningful patient engagement is the key to sustainable innovation in healthcare. Before his career in Patient Engagement Consulting began, Thomas was a senior leader in local government and responsible for the effective delivery of £87M worth of social regeneration services per annum.

Day 2 Session 3

Bringing new voices to research and building diversity: Engage with discussions about increasing diversity in patient partner spaces and explore strategies for creating more inclusive environments.

Oluwafemi Ajayi



Oluwafemi Ajayi was born with sickle cell disease and she has lived through it miraculously for over 4 decades. She is a patient advocate for sickle cell and she also supports and empowers people like herself through her non-profit organization; 'Gail Sickle Initiative. She is a PhD fellow at the University of South Africa, written and co-authored some articles and publications and an active member of different global organizations where advocacy and patient inclusion is priority. She looks forward to a world without pain.

Patrícia de Luca, MSc.



Master of Science from the School of Physical Education and Sport at the University of São Paulo (EETF-USP), Bachelor's and Teacher's degree in Physical Education from the same institution. Experience in exercise prescription, research, ethics, health education and advocacy, with an emphasis on cardiovascular diseases, diabetes and obesity. She worked voluntarily at ADJ Diabetes Brasil for more than 10 years, and on the Ethics Committee of the Faculty of Pharmaceutical Sciences at USP as a Representative of Research Participants for 8 years. Co-founder of the Brazilian federation of rare diseases (FEBRARARAS). Co-founder of the Cardiovascular Advocacy Group (GAC). Co-Founder and part of the Organizing Committee of the Intersectoral Forum of CCNTs in Brazil (FórumCCNTs). Former president and current Executive Director of the Brazilian Association of Familial Hypercholesterolemia (AHF).

Stephanie Paravan



Stephanie's journey into healthcare began in 2013 with the sudden illness of her youngest child. As his condition progressed Stephanie realized the difficulties of navigating the medical system as a parent. Her son's condition advanced and he is now part of both Complex Care and Palliative Care in Ottawa. Stephanie used her experience to become involved as a Family Partner in various organizations. This includes Co-chairing the former Champlain LHIN PFAC, sitting on the Steering Committee for the Kids Come First Health Team and supporting the launch of Kids Health Alliance.

Facilitated By

Raissa Amany



Raissa Amany is a national award-winning social activist, speaker, and consultant, known for her work on youth engagement in health spaces. She is the Executive Director of the Young Canadians Roundtable on Health where she leads over 70+ youths from across Canada in national child health advocacy. Beyond pediatrics, Raissa is a prominent youth expert in child and youth mental health and addictions where she serves on numerous national and provincial advisory boards and councils. Outside of her activism, she is pursuing an undergraduate Health Sciences degree at the University of Ottawa.

Day 2 Session 4

Ask Me Anything

Karen van Meeteren



Karen van Meeteren is a passionate professional with over ten years of experience in promoting patient participation, leveraging her unique perspective as a parent of a child with complex care needs combined with her background in science education and communication. Karen is driven to connect research and practice in ways that mutually reinforce each other. Her work encompasses both substantive projects, such as addressing parental burnout and developing tools to measure language comprehension in non-verbal children, as well as projects focused on effective collaboration, including the development of the involvement matrix and the training of researchers and experts by experience. Karen strives to make a lasting impact through her work in healthcare and in the lives of people with disabilities and their parents.

Trishna Bharadia



Trishna Bharadia (The Spark Global), is a multi-award winning patient engagement consultant and health advocate. She lives with several long term conditions, including multiple sclerosis, which she was diagnosed with in 2008. Based in the UK, she works nationally and internationally with multiple stakeholders, including industry, academia, non-profits and charities, to better embed the patient voice into the healthcare ecosystem and medicines development lifecycle. She is a visiting lecturer in patient engagement at the Centre for Pharmaceutical Medicine Research at King's College London university and is a patron/ambassador for several health- and disability-related charities, including MS Society UK and ADD International.

Facilitated By



Rebecca Esparza

Rebecca Esparza, MBA, is a two-time cancer survivor (ovarian and thyroid). She has travelled all over the world to represent cancer survivors at various cancer advocacy activities, speaking engagements, committees and forums. Her long term survivorship of ovarian cancer (20 years) has motivated her to speak up for the underserved and marginalized; especially those without access to healthcare and/or health insurance.

Day 3 Session 1

Publishing as (and with) patient partners: Learn about the different roles that patient partners can take on in the publishing process, and the benefits of amplifying patient voices in more traditional academic settings.

Harry Iles-mann



Harry is first and foremost a young person who has been living with complex chronic illness and disability since early childhood and the recipient of two liver transplants as a young adult, having spent more than 50 weeks admitted to hospital between 2020-2024 alone. He is a Health Consumer Leader, disability, complex chronic illness and mental health Advocate, Digital Health Expert Advisor to the Australian Digital Health Agency, and The Consumer Representative Advisor to the Australian Department of Health and Aged Care's Digital Health Branch.

Nidhi Swarup



Nidhi is the Founder and President of the Crohn's & Colitis Society of Singapore since 2012. The charity focuses on patient education, public awareness, patient support group and promotes research into Crohn's Disease, Ulcerative Colitis, and related inflammatory bowel diseases (IBD). She has facilitated the formation of IBD Patient Support Groups in Thailand, Malaysia, Philippines, and India. She has been interviewed by leading Newspapers, TV, and Radio channels. She is the anchor for the Podcast on Spotify, Apple and other channels 'Life Takes Guts with Nidhi Swarup.'



Sophia Walker

Sophia Walker has built on her experience of living with type 1 diabetes since the age of six to advocate for the increased role of the patient perspective in treatment development, healthcare delivery, and outcomes research. She has a background in clinical trial management, pharmaceutical market access, and commercialisation and communication strategies. She was previously the Accelerated Access Lead at JDRF UK, the type 1 diabetes medical research charity. She holds an MSc in Health, Community, and Development from the London School of Economics.

Facilitated By



Clare Ardern

Dr. Clare Ardern is an Australian-trained physiotherapist and Assistant Professor in the Department of Physical Therapy at The University of British Columbia in Vancouver, Canada (traditional, ancestral and unceded land of the Coast Salish people). She teaches evidence-based physiotherapy practice with a health equity focus, and her research team works to bring patients, clinicians and health policy-makers together to co-design, implement and evaluate digital health solutions for musculoskeletal problems. In the last decade, Dr Ardern has led musculoskeletal rehabilitation and digital health research in Australia, Qatar, Sweden and Canada. She has served the global musculoskeletal rehabilitation community as Editor-in-Chief of the Journal of Orthopaedic & Sports Physical Therapy (JOSPT) since 2018, and hosts the weekly JOSPT Insights podcast, which is downloaded more than 30 000 times each month.

Day 3 Session 2

Highlighting other types of (often non-academic) patient partnerships: Delve into how and why patient partners are pushing boundaries and partnering in creative ways with all kinds of teams.



Ella Balasa

Ella Balasa is a patient advocate, consultant, and a person living with cystic fibrosis - a rare genetic lung disease. She was diagnosed at 18 months old and has experienced countless hospitalizations since being a child. Because of her healthcare experiences, Ella has committed her time to empowering patients and advancing research and healthcare strategies through her connections with researchers, pharmaceutical companies, and patient organizations. Having a biology background, she advocates for the development of novel therapies for the treatment of antibiotic-resistant infections, which have significantly affected her life. She has spoken publicly about this issue as well as the value of the patient voice within research at healthcare conferences, at the FDA, on various podcasts, and congressional meetings.



Thelma Barber

Thelma is a two-time kidney transplant recipient living with chronic kidney disease, hypertension, and type 2 diabetes. Despite experiencing symptoms at just 12 years old, it took nearly a decade for Thelma to receive a diagnosis of IgA Nephropathy (Nephrotic Syndrome) in 1993 and chronic kidney disease in 1998. Today, she is a passionate advocate for all people with kidney disease, especially African Americans and those from financially disadvantaged backgrounds. She's fighting for equal access to quality healthcare and transplants for all, as well as much needed legislation for the kidney community with the National Kidney Foundation, Kidney Advocacy Committee-Voices for Kidney Health.

Zac Miles

Zac Miles is an Identified Peer Support Worker for the Persistent Pain Management Service on the Sunshine Coast, Australia. He has lived experience in persistent pain as a carer and is a proud Aboriginal man from the Dunghutti and Anaiwan tribes in Australia. He loves working closely with his culture and uses his life experiences in the effort to make a positive change in his community. He has also recently been invited to be a part of the Queensland persistent pain clinical network steering committee.

Facilitated By



Runcie C.W. Chidebe

Runcie C.W. Chidebe is a patient advocate, global health consultant, researcher, psychologist and the executive director of Project PINK BLUE. He is one of the leading voices advocating for Nigeria government to make cancer control a national health priority. He has been engaged in supporting women battling with cancer, hosting oncology trainings for doctors/nurses, fundraising for indigent patients, cancer awareness, founded Nigeria's first patient navigation and the first cancer support group in Abuja, Nigeria.

Day 3 Session 3

Learning about different types of recognition for patient partners:

Explore the importance of transparency when discussing different forms of monetary and non-monetary recognition for patient partners in research.



Jack Nunn

Jack Nunn's research area is in creating and evaluating equitable and ethical ways for people to get involved in all aspects of research and science. Jack is the founder and Director of the not-for-profit education organisation 'Science for All', working to involve people in doing research by building partnerships between the public and researchers (ScienceforAll.world). From 2022-2024, Jack was the Public Involvement Strategic Lead at La Trobe University (part-time, fixed-term). Jack completed a PhD in 2021 in the department of Public Health at La Trobe University, where he explored genomic research and how people can be involved in shaping the future of this research. Jack is a member of Australia's NHMRC 'Consumer Statement Advisory Committee'; Member of the Cochrane Consumer Executive; Co-Chair of Citizen Science & Open Science Community of Practice; and a member of the 'Standardised Data on Initiatives (STARDIT)' Steering Committee.



Kimberly Strain

Kimberly Strain lives in British Columbia, Canada, and has been a patient partner in a variety of initiatives since 2012 including committees, a patient research partner, a member of Patient Voices Network, and a co-author of the Patients Included charters. She also is on the Board of Directors for the Institute for Safe Medication Practices Canada and recently was co-chair for the Solutions for Kids in Pain (SKIP) Patient and Caregiver Advisory Committee. In her spare time, Kimberly has a passion for photography and the arts.



Kwanele Asante

Kwanele Asante is the Former Chairperson of the Ministerial Advisory Committee on Cancer Prevention and Control, Republic South Africa. She serves on the World Health Organisation's Civil Society Working Group on Non-Communicable Diseases. Kwanele has received several awards for her African cancer equity activism, including the Harvard Global Health Catalyst – 2016 African Ambassador Award. She serves as a community representative on the South African Medical Council's Bioethics Advisory Panel and she is a former member of the External Advisory Board of the STARS Program at Harvard Medical School, USA.

Facilitated By



Sarah Lukeman

Sarah Lukeman is a cancer survivor, clinical trial participant and experienced health consumer advocate and representative. She trained as a Chemical Engineer, worked in the mining industry, was elected to local government for a term, and is a Tai Chi instructor. She lives in regional NSW and advocates for equitable access to healthcare and a just transition for mining communities. Sarah is a consumer buddy for several discovery science cancer researchers in Australia and been a member of funding panels and conference organising committees. She is regularly invited to speak on Consumer Involvement in Research (CIR) and has co-designed and co-presented training on CIR and the recently launched patient-centred template for informed consent to participate in clinical trials in Australia.

Day 3 Session 4

You Can't Ask That!

Anne McKenzie AM



Anne McKenzie AM has held professional and voluntary roles as a consumer advocate for the past three decades. She has worked in research organisations to increase community involvement in research since 2004, when she commenced at The University of Western Australia and The Kids Research Institute Australia. Anne currently provides consultant services to a range of organisations including universities, health and research organisations, government and non-government agencies and consumer organisations. Since 2007 Anne has developed and delivered training workshops on implementing consumer and community involvement to researchers, clinicians, and consumers. Over 3700 attendees from across Australia have attended 190 workshops.

Janelle Bowden, PhD.



Janelle Bowden, PhD, is a scientist by training and has 20+ years of experience working in and around clinical trial operations in Australia and overseas, for sponsors, sites, and as a consultant. Janelle has a passion for greater consumer participation and involvement in research, and improving the trial participant's experience. Janelle's social enterprise, AccessCR, provides services to organisations involved in the research sector. This work funds our activities to support, build capacity in, connect and advocate for the needs of people looking for, taking part in and contributing to medical research and clinical trials - the Community and Consumer Research Workforce (CCReW).

Facilitated By



Shyamsundar Muthuramalingam

Dr. Shyamsundar Muthuramalingam, with a Ph.D. in Chemistry and personal experience as a kidney transplant recipient, is a leading advocate for patient engagement in health and medical research in Australia. His journey through kidney disease and haemodialysis has fuelled his passion for consumer advocacy and community engagement. Dr. Muthuramalingam has significantly shaped engagement strategies across key organizations like ANZDATA, SAHMRI, The George Institute for Global Health, and Kidney Health Australia. He's instrumental in promoting consumer voices in research agendas, study implementation, and translating findings to improve care. As a Steering Committee member at the PxP Conference, he will share insights on enhancing patient partnership in research, emphasizing the impact of lived experience in clinical trials. His work exemplifies the 'For Patients, By Patients' ethos, making him a pivotal figure in advancing patient-centred research.

Acknowledgements

This speaker booklet has been compiled on the unceded territory of the Coast Salish Peoples, including the territories of the xwməθkwəyəm (Musqueam), Skwxwú7mesh (Squamish), Stó:lō and Səlílwətaʔ/Selilwitulh (Tseil- Waututh) Nations.

We acknowledge that people are attending the PxP 2024 conference virtually from across the globe, on land that has been stewarded by Indigenous Peoples for thousands of years.

2024 Steering Committee



We are hugely grateful to the 2024 PxP Steering Committee for their significant guidance and expertise. Read more [here](#).



CIHR
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locomoteur et de l'arthrite

PxP is made possible thanks to the support of CIHR-IMHA. Read about their team [here](#).