World Health Organization

## INTENTION TO ACTION SERIES

# PEOPLE POWER

## Perspectives from individuals with lived experience of noncommunicable diseases, mental health conditions and neurological conditions

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Intention to action series: people power. Perspectives from individuals with lived experience of noncommunicable diseases, mental health conditions and neurological conditions

(Intention to action series)

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# Contents

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# Acronyms

| | |
|---|---|
| **CSO** | civil society organization |
| **GCM/NCDs** | Global Coordination Mechanism on NCDs |
| **NCDs** | noncommunicable diseases |
| **NGO** | nongovernmental organization |
| **WHO** | World Health Organization |






# Introduction

## Setting the scene

The right to participate is an essential feature of the right to the highest attainable standard of health. Individuals with lived experience should be at the centre of decisions that impact their lives and the lives of those they care about. People living simultaneously with noncommunicable diseases (NCDs), mental health conditions and neurological conditions (hereafter referred to as individuals with lived experience) hold the key to designing effective, inclusive, equitable health interventions that leave no one behind. Their voices can unlock opportunities to overcome barriers in accessing and sustaining health care.

In 2019, 74% of all deaths were due to NCDs *(1)*. At the same time, there is a high global prevalence of mental health conditions and neurological conditions, with one in eight individuals living with a mental condition *(2)*. Notably, in 2019, more than three quarters (77%) of NCD deaths and 77% of global suicides occurred in low- and middle-income countries *(1, 3)*. The interconnected NCD and mental health epidemics require a sustained multistakeholder approach to support prevention and control of NCDs and the promotion, protection and care of mental health *(3, 4)*.

For those with lived experience, the short- to long-term impacts of living with NCDs, mental health conditions and/or neurological conditions are significant on an individual level but also extend to caregivers, families, communities and health systems. The COVID-19 pandemic exacerbated those impacts, while further exposing profound social inequities and fractured health systems around the world. The presence of pre-existing health conditions dramatically increases the risk of developing severe COVID-19 illness, accompanied by higher mortality rates *(5–10)*. The prevalence of anxiety and depression also increased 25% worldwide in the first year of the COVID-19 pandemic, with a range of short- and long-term stressors including isolation, the impact of the virus on health, concerns over financial and employment security, and disruption to mental health services acting as contributing factors *(11)*.

Looking ahead, global public health actors need to invest and engage in new forms of collaboration to develop effective and contextually appropriate solutions to address the lack of action on NCDs and mental health care. This requires moving away from existing "one size fits all" interventions and strategies towards bottom-up, inclusive co-creation processes with an intersectional lens. This will allow key stakeholders to better understand and address the complex drivers and requirements to manage these conditions, ultimately improving health outcomes.

Meaningful engagement of individuals with lived experience has the potential to accelerate improvements in global health outcomes and progress in reaching the health-related Sustainable Development Goals (SDGs). Insights from people with lived experience are invaluable in helping understand barriers and strengthening policies, programmes and services. Although the concept of meaningful engagement and other participatory approaches has been applied to other areas of global public health, it is a relatively new concept and approach within the NCD and mental health agenda. More evidence is required on the direct impact of meaningful engagement alongside standardized approaches on how to operationalize meaningful engagement as a scientific approach.

## Meaningful engagement in action

Engagement with people with lived experience can be achieved using a variety of participatory approaches in different contexts and at various levels, from local to global. To date, engagement of individuals with lived experience of NCDs, mental health conditions and neurological conditions has primarily been led by community-based organizations, clinical research opportunities and self-organized peer support groups in high-income countries. This has been achieved through a multistakeholder approach including individuals, non-governmental organizations (NGOs) and civil society organizations (CSOs) in developing and implementing forms of meaningful engagement. Many community-based organizations have also sought to provide platforms to give a voice to individuals with lived experience through advocacy, awareness raising and campaigns for policy change *(12, 13)*.

Despite this, people living with NCDs, mental health conditions and neurological conditions have rarely been engaged in the co-creation, co-design, or co-production of related programmes, policies, and services. Ultimately, individuals with lived experience have been excluded from many aspects that matter most to them. In addition, representation from voices that are marginalized and communities that are underrepresented needs to be enhanced, in particular from low- and middle-income countries, alongside bridging the gaps between global to local.

Aiming to address and mitigate these deficits, WHO is co-creating a framework – the WHO Framework on Meaningful Engagement of People Living with NCDs, Mental Health Conditions and Neurological Conditions – that will guide WHO and Member States in facilitating the meaningful engagement of people living with NCDs, mental health conditions and neurological conditions. The WHO Framework will advance understanding, knowledge and action for meaningful engagement through an evolving evidence base. The case studies in this report contribute to this effort and support WHO's wider goals around three interconnected strategic priorities to ensure healthy lives and well-being for all at all ages: achieving universal health coverage (UHC), addressing health emergencies and promoting healthier populations *(14).*

## Aim of this report

This report is the first in the WHO *Intention to action series*, which aims to enhance the limited evidence base on the impact of meaningful engagement and address the lack of standardized approaches on how to operationalise meaningful engagement. The Intention to action series aims to do this by providing a platform from which individuals with lived experience, and organizational and institutional champions, can share solutions, challenges and promising practices related to this cross-cutting agenda. The *Intention to action series* also aims to provide powerful narratives, inspiration and evidence towards the Fourth United Nations High Level Meeting on NCDs in 2025 and achieving the 2030 United Nations Sustainable Development Goals (SDGs).

To this end, this report includes six case studies from 12 individuals with lived experience of diverse health conditions. These case studies explore the topics of power dynamics and power reorientation towards individuals with lived experience; informed decision-making and health literacy; community engagement across broader health networks and health systems; lived experience as evidence and expertise; exclusion and the importance of involving groups that are marginalized; and advocacy and human rights.

These are powerful narratives that provide evidence and recommendations for strengthening the role of those with lived experience in the co-creation of relevant policies, programmes and services.

# Methodology – participatory research

In November 2021, WHO held a series of focus groups to engage people with lived experience of NCDs, mental health conditions and neurological conditions. Participants were invited through an open call posted on the WHO corporate website and shared broadly across WHO's global internal and external networks. The objective of these focus groups was to learn from individuals with lived experience and understand how they wish to be meaningfully and effectively involved in advocacy for themselves and others.

Applicants were screened based on lived experience of NCDs, mental health conditions and neurological conditions, country, age and gender identity to ensure diverse and fair representation among the participants. After completing and reviewing WHO declaration of interest forms, 35 individuals from 18 countries were then invited to participate in one of six focus groups (see Fig. 1). Each focus group lasted 90 minutes and was led by an external facilitator, The Social Kinetic, a human-centered design and engagement agency with expertise in health, technology and social challenges. The focus groups were semi-structured and included between five and eight individuals to support sharing and discussion. WHO's role was to listen and learn, and when requested, and provide answers to any technical questions. WHO also provided opening and closing remarks, including context of how gathered information will be used and outlining next steps.

In each group, participants shared individual perspectives and experiences and often challenged existing perceptions on what meaningful engagement is and what it should be, notably for those living with intersectional NCDs, mental health conditions and neurological conditions. The discussions also highlighted the need to explore individual experiences in more depth, recognizing that the current body of evidence on meaningful engagement is limited. After reviewing and consolidating all discussion points from all focus groups, six key themes emerged:

1. **Advocacy and human rights**
2. **Community engagement across broader health networks and health systems**
3. **Exclusion and the importance of involvingmarginalized groups**
4. **Informed decision-making and health literacy**
5. **Lived experience as evidence and expertise**
6. **Power dynamics and power reorientation towards individuals with lived experience**

The focus groups also showed how exploring individual perspectives, experiences and stories could impart valuable learning, through which these key themes could be further explored – not least because the current limited body of evidence on meaningful engagement lacks individual perspectives.

Based on this approach, seven individuals from the focus groups and five individuals from the WHO Global Coordination Mechanism on NCDs (GCM/NCDs) lived experience network were then selected and invited to speak on these thematic areas. Using a dyadic interview process (whereby two participants shared individual perspectives on similar themes in different contexts) and facilitated by The Social Kinetic, the individuals were selected based on geographic representation (including equal representation across low-, middle- and high-income countries) as well as their lived experiences. The five individuals selected from the broader GCM/NCD network were identified based on their interest in supporting this work through previous WHO lived experience engagement activities.

In the 1.5-hour dyadic interviews, these individuals – paired in an inter-regional manner, with geographic representation across the six WHO regions – shared deep reflections (see Fig. 2).

While each theme was explored independently, learnings and findings overlapped and repeated across the six case studies. Taken together they can spark learning and action both locally and, potentially, on a larger scale by highlighting diversity in lived experiences, showcasing best practices and sharing challenges. These powerful narratives also provide evidence of why including the voices of those with lived experience is critical in the co-creation of relevant policies, programmes and services.

**Figure 1. Focus group participants' lived experiences and geographies**

| Diabetes | Mental Health | Cardiovascular Disease | Others |
|---|---|---|---|
| Type 1 | Anxiety | Acute myocardial infarction | Blood disorders |
| Type 2 | Attention deficit hyperactivity disorder | Aortic valve disease | Breast cancer |
|  | Autism spectrum disorder | Aphasia | Chronic kidney disease |
|  | Bipolar or related disorders | Cardiac arrhythmia | Chronic lymphocytic leukaemia |
|  | Depression | Congenital heart disease | Chronic obstructive pulmonary disease |
|  | Post-traumatic stress disorder | Congestive heart failure | Gout |
|  | Restrictive eating | Hypertension | Kidney failure |
|  | Schizophrenia | Mitral valve disease | Lung cancer |
|  | Substance use disorder | Obstructive hypertrophic cardiomyopathy | Obesity |
|  |  | Rheumatic heart disease | Primary immunodeficiencies |
|  |  | Stroke |  |

**Countries**

Australia, Bosnia and Herzegovina, Botswana, Brazil, Canada, Georgia, Germany, India, Italy, Kenya, Kuwait, Mexico, Nepal, Netherlands (Kingdom of the), Nigeria, Romania, Singapore, South Africa, Uganda, United Kingdom of Great Britain and Northern Ireland (United Kingdom), United States of America (USA).

Figure 2. Case study participants, thematic areas and geographies

# About the contributors

## Kwanele Asante-Shongwe, South Africa

Building on her previous training as a lawyer, Kwanele is an African bioethicist, cancer equity activist, health advocacy mentor and peer supporter. She was diagnosed with breast cancer in 2006 aged 37 years and sustained chemotherapy-induced heart muscle damage in 2007, which later led to congestive heart failure. In 2014, Kwanele was also diagnosed with bipolar disorder. Kwanele was elected to The Ministerial Cancer Advisory Committee, serving as Deputy Chairperson in her first term, before being elected as Chairperson in 2021. Kwanele is an active member of the WHO Civil Society Working Group on NCDs, the African Organization of Research and Training in Cancer, and is an independent member of the South African Noncommunicable Diseases Alliance. Kwanele is also a member of the South African Medical Research Council Bioethics Advisory Panel and the British Medical Journal Patient Panel.

## Patrick Boruett, Kenya

Patrick originally trained as a pharmacist and was diagnosed with bipolar disorder in 2011. He has now retrained based on his lived experience and since 2019 has been the Director of Preventive and Promotive Health in the County Government of Baringo, Kenya. Patrick holds a Masters degree in Health Promotion and is the Executive Director of the Bipolar Heroes Foundation, a non-profit organization which he founded in 2019. He is also a member of the larger patient-led organizations affiliated with the Noncommunicable Disease Alliance Kenya (NCDAK) and works as a peer educator for the Our Views Our Voices programme. He is also a leader at The Stability Network and a fellow of the Sitawa Wafula Mental Health Academy.

## Phil Collis, United Kingdom

At the age of 17 years and without warning, Phil suffered a subarachnoid brain haemorrhage which caused a stroke. He sits on the British Heart Foundation's Patient Advisory Group and the European Heart Network's Patient Forum. He has also worked as a patient advisor with The European Innovation and Technology Health Programme, NHS England and The European Stroke Organization. As part of his role as a Patient Partner for the International Centre for Patient Reported Outcomes, Phil has co-authored several research papers and was involved in the development of the *Ethical Guidelines for the use of Patient Reported Outcomes in the Medical Device Regulatory Research Process*, published in 2022. He has also worked with The International Consortium for Health Outcomes Measurement (ICHOM) developing the *COVID-19 Standard Sets*.

## Paul T Conway, USA

Paul started his career in the US Department of Education under the administration of President Ronald Reagan and has served under four US presidents, including roles as Chief of Staff of the American Civil Service, the Department of Labor and the Department of Homeland Security. Paul has applied his 41 years of lived experience as a kidney patient and his significant political knowledge to the goal of health advocacy and patient inclusion. Paul is Chair of Policy and Global Affairs for The American Association of Kidney Patients and continues federal government service as Chair of The Food and Drug Administration Patient Engagement Advisory Committee, which informs regulatory decisions with patient insight data. He also serves in roles for the National Institutes of Health (NIH), The US Centers for Disease Control and Prevention (CDC), The Department of Defense and other federal agencies in the ecosystem of chronic disease.

## Anu Gomanju, Nepal

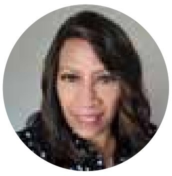
Anu lives with rheumatic heart disease and is a registered public health professional following completion of her Masters in Sociology. She is currently pursuing a Masters of Public Health in Global Health at Thammasat University, Thailand. In 2021, Anu was awarded the Partners in Health "Voices of NCDI Poverty Advocacy Fellowship", representing the South Asian Region. Anu now works closely with The NCDI Poverty Network and the Nepal NCDI Poverty Commission, and the Kathmandu Institute of Child Health (KIOCH), which hopes to re-frame NCDs for the poorest people who live in the Global South. Anu is also a steering committee member of the NCDI Poverty Network and an active member in the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH).

## Mariana Gómez, Mexico

Mariana is a psychologist and diabetes educator, and is currently the Vice President of International Markets at Beyond Type 1. She was diagnosed with type 1 diabetes more than 30 years ago and is the mother of a teenager. She sat on the Scientific Council for The Mexican Diabetes Federation from 2016 to 2019 and also volunteers for different organizations as a peer supporter and translator. She has been an advocate for people living with type 1 diabetes since 2006.

## Pei Yan Heng, Singapore

Pei Yan Heng's advocacy work is inspired by her own lived experience of type 2 diabetes and mainly focuses on diabetes awareness. Pei Yan is an Executive Member of Beta Change, an organization that supports and empowers individuals who are passionate about creating positive change within the diabetes community. She is also a core member and advisor to SugarRush, a peer support group for teenagers living with diabetes.



## Allison Ibrahim, Kuwait

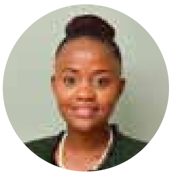
Allison Ibrahim was born in the USA but has lived in Kuwait for the past 30 years, with her husband and three children. She worked as a school principal before retiring in 2019 to spend more time with her ageing parents in the USA. She was diagnosed with type 2 diabetes in 2012, and also lives with anxiety and obesity. Allison has been an outspoken advocate for her health for many years.

## Matt Jackman, Australia

Matt was diagnosed with bipolar disorder and complex post-traumatic stress disorder in 2016. After completing their undergraduate degree and honors in social work, Matt is awaiting their Masters in Advanced Social Work in Melbourne, Australia. They have been a teaching focused academic and researcher across various universities for the past 5 years in trauma, mental health and Mad studies. Matt has published in human rights, lived experience and co-production in mental health. They are the Founder and CEO of The Australian Centre for Living (TACLE) and have represented the inaugural Western Pacific Regional Representative for the Global Mental Health Peer Network. Matt has written for Harvard Global Mental Health and WHO on key services and alternatives to the biomedical model and community mental health services. Matt was awarded the National Mental Health Advocate of the Year by the Mental Health Foundation of Australia and was listed as one of Deloitte's Top 50 Queer Leaders in Australia in 2020.

## Olga Kalina, Georgia

Olga was diagnosed with paranoid schizophrenia in 2005 at the age of 21. Olga is currently chair of the European Network of (Ex)Users and Survivors of Psychiatry (ENUSP) and the Georgian Network of (Ex)Users and Survivors of Psychiatry (GNUSP), board member of the Union Partnership for Equal Rights (PER) and co-founder and board member of the Platform for the New Opportunities (PNO), a Georgian organization for women with disabilities. She offers consultation services contributing to policy and legislation, such as the Strategic Plan of Georgia on Mental Health Care 2020–2030. Olga also lectures Masters students at Ilia State University. In 2021, she facilitated 15 online lectures for a course on mental health, disability and human rights.



## Odireleng Kasale, Botswana

Odireleng is the founder and Chief Executive officer of the Sesha Recovery Center which provides drug and alcohol addiction support services. She also uses her love of writing to share her experiences of being in long-term recovery after suffering a period of substance and alcohol misuse. Odireleng believes in the power of creating communities among those with collective narratives. She is a member of the International Society for Substance Use Professionals and Executive Country Representative for Botswana with the Global Mental Health Peer Network.

## Prachi Kathuria, India

Prachi has been living with asthma and chronic bronchitis for over 20 years. She is currently a Capacity Development Consultant at NCD Alliance. She was the National Coordinator of the Healthy India Alliance (HIA or India NCD Alliance) between 2015 and 2021, a coalition of 18 multidisciplinary CSOs working across NCDs and their risk factors in India. She is a member of the National Network of People Living with NCDs and is an NCD Alliance-certified *Our Views, Our Voices* trainer. She is an active advocate for those with NCDs, particularly "invisible" chronic diseases, such as her own. A firm believer in lived experience as evidence, Prachi is a leader in setting up networks and conducting training for those living with NCDs in India.

# 1

# Case Study 1: Advocacy and individual rights

Kwanele Asante-Shongwe, South Africa and Pei Yan Heng, Singapore

In this case study, Kwanele and Pei Yan share their personal experiences and perspectives on the theme of *advocacy and individual rights*, including how inequalities, access to health care and the ability and right to participate in decisions that impact themselves and others affects health outcomes.

WHO's Constitution states that "*the highest attainable standard of health as a fundamental right of every human being*" *(15)* – a vision that implies a clear obligation for WHO Member States to ensure appropriate conditions are met for quality standards of health for all people.

Through Kwanele and Pei Yan, we learn that there is much work to be done to make this a reality. As a citizen of Singapore and a person living with type 2 diabetes, Pei Yan shares her experience and observations of global inequalities in access to essential medicines for people living with diabetes. Kwanele's story demonstrates how health inequalities impact black women experiencing breast cancer across South Africa.

Often driven by social and economic disparities, there are significant inequalities in NCD prevention and control rooted at local, national and international levels that result in vastly different lived experiences of the same health conditions. Where inequalities exist, there is often a lack of opportunity for advocacy, education and inclusion in informed decision-making. Kwanele and Pei Yan's testimonies also highlight that those impacted by such inequalities often feel powerless, which can be driven by a fear of losing access to the care that is available or by a lack of knowledge and advocacy skills.

Both experiences show the tragic impact such inequalities cause – be it the children left behind by the women in Kwanele's story or the lives lost without access to life-saving insulin in Pei Yan's story. Both case studies demonstrate why advocacy and individual rights are essential components of the meaningful engagement of people with lived experience.

# Kwanele’s story

> “We need socially and culturally appropriate treatment services that are influenced and shaped by the expressed health needs of people living with noncommunicable diseases. Patients and caregivers’ right to participate is a fundamental component of the right to health.
>
> **Kwanele Asante-Shongwe, South Africa**

Born in South Africa in 1969, Kwanele is in remission for breast cancer. She was diagnosed in 2006 aged 37 years, and sustained chemotherapy-induced heart muscle damage in 2007 which later led to congestive heart failure. In 2014, Kwanele was also diagnosed with bipolar disorder.

Kwanele was treated in the South African private health sector, which benefits from access to higher quality services even though it only treats a small minority of the country’s population. Witnessing this disparity first-hand, she quickly realized that poor women with breast cancer were dying as a result of structural health inequalities. Prevented from accessing treatment by economic, social and structural barriers, women like Kwanele were dying far too young. When she finished treatment, Kwanele was keen to investigate this further.

*“So here I was being treated in the private health sector, totally unaware of the disparities in my country. I asked my oncologist, ‘Where do black people in this country go to get treated for breast cancer? Surely, I’m not the first one...Where do they go?’ I met three women who were aged between 33 and 34 years. Like me, they had developed heart damage from their breast cancer chemotherapy treatment. But there was a huge difference. I was able to access world-class treatments and services in a country where my compatriots didn’t enjoy the same level of affordable and accessible treatments.”*

The women Kwanele met were all suffering from advanced breast cancer. All three were single mothers and the sole caregivers of very young children. Limited by their socioeconomic position, the only treatment available to them was that provided by the public health-care system.

*“The public health sector breast cancer clinic sees 80 to 140 people who come every week, with three attending doctors. By contrast, my private health sector breast clinic sees at most 30 patients, yet still there are three doctors.”*

Each of the women travelled several hours a week to access these services. Hampered by financial concerns and limited public transport, it often took 2 hours to travel the 30-minute distance to the hospital where they would frequently be met with long waits and broken diagnostic and treatment machinery. All three women also suffered from cardiomyopathy as a result of their treatment. However, none felt safe mentioning the side effects to their oncology nurses, fearing that if they did, they might be taken off the only affordable life-saving chemotherapy and other new treatments available to them.

Kwanele took on the role of chaperone for the women, attending appointments with them, outlining what questions to ask and showing them how to advocate for themselves. All three quickly became confident and articulate at expressing their needs, enabling them to engage fully in their treatment. Fuelled by the harsh realities of the inequalities she had observed, Kwanele set out to change the narrative around breast cancer treatment. She now focuses on the intersecting barriers that prevent others from accessing treatment and aims to drive recognition of the diversity of lived experience.

*"We need to change this idea that diseases are experienced the same way by all people. Different people experience their diseases differently – geography, social circumstances, financial circumstances, stage of disease – we need to emphasize the need for diverse voices to be involved in conversations, because we experience diseases differently."*

Kwanele believes passionately that people with lived experience should be involved in all decisions that affect their lives, from the early stages of research and clinical trials to government level decision-making and public health policy-making. Kwanele now works as a health and human rights activist, ensuring that those most in need of treatment are able to access it, regardless of economic background.

*"It is crucial that patients are included as substantive partners in health. The right to participate is an integral part of the right to health. Patient groups from Netherlands (Kingdom of the), the United Kingdom and the USA are equal participants from the moment of inception. I would like to see more of this in lower-income countries... I think we should frame it holistically, with the right to health as a fundamental human right of every person everywhere in the world, regardless of any other factors, just the fact that they were born human. The sad end of the story is that all three women I talk about here died by the age of 35. And I'm still sitting here at 53, advocating for black health justice and equal access to essential treatments to all who need them."*

# Pei Yan’s story

> Every citizen should have equal access, and rights to medication and health care. We should not be subjected to challenges, hoops and obstacles that we must jump through to obtain the necessary care we need. It should be a basic right.
>
> **Pei Yan Heng, Singapore**

Pei Yan is a secondary school teacher living in Singapore. She was diagnosed with type 2 diabetes in 1996, at the age of 10 years. Unusually for type 2 diabetes, Pei Yan requires the regular use of an insulin pump. As a citizen of Singapore, Pei Yan recognizes that she is privileged to live in a country with universal health care, with to access a well-resourced system that offers quality care services and essential medicines for people living with NCDs.

The treatments and medicines she requires are readily available, which is not the case for many people living with diabetes around the world. Through her advocacy work and global diabetes community, Pei Yan is concerned about people living with diabetes that are struggling to access live-saving insulin and treatment due to local factors. This disparity fuels her advocacy efforts around global diabetes awareness, particularly on access and affordability issues related to living with the condition.

For many people with diabetes, insulin is a life-sustaining medicine as essential for survival as air and water. Due to multi-faceted global affordability and access challenges, many people are forced to ration insulin, risking their health by living for long periods with high glucose levels, resulting in dangerous health outcomes and even death. Although 2021 marked the centennial of the development of insulin for human use, progress with affordability and access to this life-saving medicine remains slow.

*"There are still countries facing limited access to health care and limited access to medication. I hear stories of patients having to walk for hours or travel long distances just to get a shot of insulin, or of people rationing their medication because it is really too costly for them… Someone I know passed on because he did not have enough access to medication. He was running on high glucose levels for a long period of time, which led to serious consequences."*

A Canadian scientist involved in selling the insulin patent to the University of Toronto for US$ 1 notably said, "Insulin does not belong to me, it belongs to the world". This principle is highlighted through various advocacy organizations that Pei Yan supports, such as T1 International, an organization that teaches people living with diabetes how to advocate for their rights to obtain affordable and quality diabetes treatments, care and essential medicines.

Pei Yan passionately argues that everyone should have equal access to the care they need. She uses her lived experience and platform as a diabetes advocate to raise awareness of the global health inequalities experienced by the diabetes community. She also recognizes that not all health systems around the world are equally positioned to facilitate equal access and that there is still much work to be done.

*"What equality means to me is everyone having an equal chance of voicing their opinion. Equality is not just restricted to certain people. We need a wide diversity of voices of different ethnicities, genders, religions and backgrounds... We cannot just imply that health inequalities are the government's fault or the health-care system's fault. Every part of the equation plays an important role in increasing equal access. The government has to be stable, you have to have a country that has enough cash flow to support health care, as well as support from pharmaceutical companies. Every part in the equation needs to work together."*

## A vision for the future

Kwanele and Pei Yan shared their visions for the future of people living with NCDs, mental health conditions and neurological conditions around the world.

> Now we have come to truly understand the personal, economic, but also the national impact of NCDs. We've come to understand the impact on people's livelihoods and on countries' economies. As a result, we have decided to mainstream NCDs by allocating substantive budgets to their prevention and control around the world. Access and equity and the whole notion of the fundamental human right to health care means that people do not suffer adverse health outcomes because of where they live. There is absolute equity.
>
> We don't talk much about meaningful engagement anymore. Instead, we talk about engagement as a fundamental human right. It is absolutely foreign to have a group, be it a technical advisory committee or any other policy implementation group, that does not include patients. Inclusion is a matter of right.

**Kwanele**

> Everybody has an improved awareness about what diabetes is. It comes down to education and creating and providing the correct content and materials to tell people about diabetes – whether it is educational materials published in school textbooks, or talked about in some simple literature. People will no longer predominantly associate food with diabetes. There will be a universal understanding of diabetes around the world, together with an understanding of the differences individuals experience and how they deal with it.

**Pei Yan**

# 2

# Case Study 2: Community engagement and networks

Mariana Gómez, Mexico and Phil Collis, United Kingdom

In this case study, Mariana and Phil share their personal experiences and perspectives on the theme of *community engagement and networks*, including how peer groups and communities become critical – often life-saving – pillars for people living with diverse health conditions.

Engaging with community networks benefits individuals and health systems alike. For individuals, peer groups provide access to clear and relatable knowledge, guidance and other resources. Networks can advocate for individuals with lived experience who might identify as marginalized, either due to their health condition, social circumstances or experience with stigma. Community engagement can also mitigate education equality gaps by providing accurate and relevant information in a supportive and protective environment. Individuals, peer groups and community organizations can provide valuable lived experience input for research, policy, programme and service design based on the needs of specific communities.

Peer education, particularly through online communication channels such as social media, is an effective mechanism to engage those that are vulnerable and hard to reach. However, limitations remain in the digital age for those with limited Internet accessibility, lower media and health literacy, or with specific language barriers.

Mariana describes how her community saved her life by providing access to the medicines and resources that were otherwise unavailable to her given the timing of her type 1 diabetes diagnosis in Mexico. Through Phil's experience with stroke at the age of 17, we learn how local support groups in his hometown in the United Kingdom fuelled his desire to pay it forward and build supportive networks for stroke survivors. Both experiences illustrate how communities provide urgently needed guidance and resources to address not just the clinical, but also the holistic and personal needs of individuals. Both are essential components to the meaningful engagement of people with lived experience.

# Mariana’s story

> “Community engagement is wonderful because we see this ripple effect. We educate someone and that person will replicate this effort and help new people. We are constantly translating information and requesting personal stories so that they can empower someone else. The community keeps growing. We are now trying to build an international community of people helping each other.  Community engagement is not only a couple of voices, it includes everyone.
>
> **Mariana Gómez, Mexico**

Mariana was born and raised in Mexico. In 1984, at the age of 6 years, she was diagnosed with type 1 diabetes after falling into a coma for nearly a week. At the time, doctors in Mexico had a limited understanding of type 1 diabetes and Mariana was only diagnosed due to the chance presence of a military health care professional who recognized her symptoms.

At that time, the type 1 diabetes diagnosis came with a poor prognosis, as services and treatments were expensive and hard to access. The expected life span for children with type 1 diabetes was short. There were no tools for diagnosing diabetes and no access to insulin or support. To this day, Mariana, now aged 43 years, is one of a small number of people in her age range in Mexico that continue to survive with the condition.

Following her diagnosis there was not enough information about diabetes available to Mariana and her family and before the advent of the Internet she lacked connections with others experiencing the same condition. As a child, Mariana’s parents became her diabetes educators, sourcing information through her father’s connections as a scientist and, years later, finding information online and translating it from English to Spanish. As a university professor, her father was well-connected in the international scientific community and could access resources that were not available in Mexico. Her family’s economic status meant that they could afford diabetes services and treatment. Most people living with type 1 diabetes were less fortunate at the time.

*“My family and I didn’t know anyone living with type 1 diabetes. We didn’t know doctors who knew how to treat it and we didn’t have the tools to manage it. We didn’t have access to different types of insulins nor disposable syringes. There were no blood glucose meters, and no other devices. We relied on peer support. It was really our own community, friends and family members who helped me to survive. I realized, as I grew up, that I was extremely privileged to be born into a family who had access to diabetes resources. I soon realized there were others dying because they had no access to information, to medicines or services.”*

Motivated by her own experience, Mariana was determined to share her story and represent others in Latin America who face similar challenges. By 1995, Mariana had access to the Internet and found it a transformational experience to discover people in online communities who were living with diabetes. She went on to create *Dulcesitosparami*, one of the first online spaces for people with type 1 diabetes in Mexico. Based on her own experience, Mariana understood that scarcity of resources, skills and information costs lives and she became a peer educator, traveling regularly to under-resourced rural areas in Mexico to provide diabetes education.

*"I had this drive and this anxiety to help other people survive, the same way that I had received support and had been given the tools I needed to survive. So, I decided to become a diabetes educator myself. Now I am a translator, a diabetes educator, a psychologist, and an active member of the diabetes community in Latin America."*

# Phil’s story

> “ The way that stroke affects individuals may differ, but there are similarities in the way we have to learn to cope. Learning from other people’s experiences can give the little bit of extra education you need to live a better life with your stroke.
>
> **Phil Collis, United Kingdom**

Phil was born in a small village in the United Kingdom. In 1975, at the age of 17 years and without warning, he suffered a subarachnoid brain haemorrhage which caused a stroke. This was a hugely traumatic experience which left him temporarily paralyzed, changing his life forever. He still suffers the consequences to this day.

Following Phil’s stroke, he became reliant on a team of clinicians and was extremely vulnerable. He had dreams of becoming a rock star and the situation made that future hard to imagine. It was deeply traumatic for a young adult.

*“I couldn’t talk properly. I wasn’t able to move, to sit up, to roll in bed or even use the toilet by myself.”*

Upon returning home after 4 months in hospital, Phil recognized the critical value of having a supportive local community. Later, as an adult, this spirit motivated him to set up community stroke services in the East End of London.

*“When I returned home there were queues outside the front door waiting to see me.”*

One of the first groups he set up was in Hackney, a diverse, multicultural area with a high number of stroke survivors. Phil ran this group for 10 years, empowering the community with knowledge, skills and confidence. He prioritized the things that really mattered in people’s lives and that also impacted their well-being, such as finding healthy ways to prepare a variety of cultural cuisines.

*“We invited physio students, speech and language students, and some already qualified professionals, to come in and talk with us. We also ran classes on nutrition with trained dietitians from the community.”*

A second group, in Thurrock, was designed to provide regular physical exercise and was open to anyone affected by stroke, including caregivers and family members. Simple, enjoyable exercise routines were facilitated with fun music so that members could connect in an informal environment.

*“What we were doing was improving people, not just physically but also psychologically. Through being able to talk about their condition and share their experiences, they built their own little community within the exercise group.”*

The power of networks and communities means that Phil, and others like him, benefit from and maintain a constant cycle of learning, education and support for others. Phil is connected to both his local and international lived experience communities and uses that collective knowledge to inform consultations, health service reviews and to support organizations with which he is involved.

Phil is a passionate believer in the value of learning from community wisdom. He knows that sometimes it takes a peer to look at your situation with empathy and suggest a simple solution that you might not have considered.

*"I will always remember one of the wives saying to me "Phil, this is great. This is the first time I've ever been able to do anything with my husband since he had his stroke. We can't even share a bed anymore, because he can't get up the stairs," and I said "well, we need to get that bed downstairs, don't we?". It's those simple things, just small things, that can have a huge effect on people's lives."*

## A vision for the future

Mariana and Phil provide a vision for the future of people living with NCDs, mental health conditions and neurological conditions around the world.

> Everyone would be diagnosed on time, so there would be fewer people dying and less need for community-based education. Everyone would have access to diagnostic tools and the treatments they need to survive. I would come back to Mexico because I am able to receive the treatment that I need to keep living here in my own country and there is no guilt.
>
> 'Nothing about us, without us' would be a reality. People living with health conditions, such as diabetes, would be included in policy decisions and paid to participate in conferences and in seminars.

**Mariana**

> Patients and those with living experience will have a say in stroke research, because that is the way to influence change. In an ideal world there would be an international platform of patient voices. A network that ensures those with lived experience are involved at every stage; in research, in prevention and in education.
>
> We will understand which population groups are at risk. We will understand what we can do to eliminate that risk. We will have what we need to support people with those risks should they happen. Then we will prevent it from happening again in the future. To do that, the voice needs to be inclusive.
>
> There is greater investment in communities and in empowering the voice of those with lived experience. A global effort, with global patients and a global patient platform to address the key issues that aren't going away and to share experiences, knowledge and understanding.

**Phil**

# 3

# Case Study 3: Exclusion and the importance of involving groups that are marginalized

Olga Kalina, Georgia and Matt Jackman, Australia

Groups that are marginalized are often those most in need of support related to health and well-being. Despite this vulnerability, individuals that are marginalized are often dependent on environments that are entrenched in systemic power imbalances. They are therefore not included in decisions related to their wellness, resulting in a lack of representation and advocacy for themselves.

This case study features two individuals living with mental health conditions. Through Olga, we learn how stigma and a lack of meaningful engagement by her health care providers can lead to disempowerment. Through Matt, we learn how social structures and trauma can lead to mental health challenges and deepen the experience of marginalization. Both Olga and Matt highlight how stigma, exclusion and lack of respect for human rights can have negative consequences for individuals experiencing mental distress.

They also explore the complex social, structural and systemic drivers of mental health experiences that are rarely taken into account by health-care providers through traditional biomedical approaches, which often neglect wider individual experiences and perspectives. In Matt's case, the trauma they experienced because of the loss of their mother, being taken into foster care as a child, and the experience of poverty and the stigma associated with homophobia and sanism, have all contributed to their mental distress. With Olga, the experience of being institutionalized without informed consent and being excluded from discussions and decisions about her care has fuelled her tireless and influential advocacy efforts to help ensure that others do not go through the same experience.

Matt and Olga also demonstrate that the inclusion and involvement of individuals that are marginalized and groups can result in actionable evidence for the redesign of mental health services and to ensure individuals receive the care they need to manage their well-being and realize their full potential. Most notably, Matt and Olga do not perceive their mental health conditions as problems to be solved but rather as strengths that provide them with unique skills and mindsets. This perspective demonstrates why the meaningful engagement and inclusion of individuals that are marginalized has the potential to bring invaluable learning to health systems around the world.

# Olga’s story

> “Some psychologists in my country say to me ‘We don’t know, maybe what you experience is true.’ I like this attitude – when your doctor says ‘I have no idea what is real, but if this creates discomfort, I should try to intervene and advise you on how to better get out of this painful experience’.
>
> **Olga Kalina, Georgia**

Olga was diagnosed with paranoid schizophrenia in 2005 at the age of 21 years. On three separate occasions she was involuntarily hospitalized in a psychiatric facility. During her first period of psychosis, Olga lost touch with reality. She stopped communicating with her family and engaging with the world around her. Confused and afraid, Olga’s family sought medical help at a psychiatric institution. Despite being calm due to her psychosis, she was excluded from discussions about her care and gave no informed consent for her hospitalization.

*“They are recording everything my family says while I’m there in the room. But they’re completely ignoring me like I’m not there, like I’m an object. After that, without having made any attempt to explain or listen to me, they just offered me a paper and ordered me to sign it.”*

Despite no explanation about what she was signing, her records show that she was admitted voluntarily. Olga has since learned that this is a common experience within Georgian psychiatric facilities. She was taken to a secure unit, in a state of psychosis, with no understanding of what was happening – an experience she describes as terrifying.

*“I started to ask questions, ‘Why am I here? What is happening? Why is the door locked?’ in quite an agitated voice, which I think is logical… In response to my questions the nurses applied physical force, they restrained me against my will, gave me an injection and left me.”*

There was little regard for Olga’s human rights and the effect of the sedation lasted for 3 days. Olga’s mother sought her release, determined she would receive better care at home. In response, the doctors demanded that she pay a fee, although the institution was state-run with no costs for the individual with lived experience or the family.

*“Much later my mother learned, from me, that my menstrual cycle had been interrupted for over half a year. She insisted on investigating the reason. I went through some tests in a somatic health care facility, but they found no cause for the problem. Eventually, my mother complained about this additional health problem to my psychiatrist and he very calmly explained that it can be a side effect of neuroleptics. My mother was shocked by the lack of seriousness he attached to this problem. But, after all, the doctor was a man and he said, ‘She’s ill, she should take this medication, it’s obligatory, otherwise she will not be well.’ He didn’t specify when I could stop taking medication, neither did he suggest any alternative. The impression from his tone was that I should be taking the medication until the end of my life. For all of this he was talking to my mother. I was not talking. I was there in the room, but he was not talking with me.”*

Later as Olga was working towards her master’s degree in biology, she did not disclose her condition to the university, afraid that stigma and lack of understanding would preclude her from continuing with her courses. The heavy doses of neuroleptics she was prescribed impacted her energy levels and focus, making it difficult for her to study. This was disregarded by the doctors, who were focused on eradicating her symptoms rather than listening to what she needed and wanted.

**"***Schizophrenia has a direct connection with abstract thinking. I have the maximum level of abstract thinking as a norm and it actually helps me. My thinking is already jumping from one topic to another, but that's exactly what I regarded as my strength when I was a biologist, because I could find the connection between topics."*

At one point, Olga approached her doctor for advice regarding her anxieties about a presentation she was preparing in another language. In response her doctor doubled her dose of neuroleptics.

*"It was a turning point, because up until then I had belief in the system, that the doctors were right, that they could not make such big mistakes. But after he doubled my dosage, I learned that he had no idea what he was doing. On the higher dosage I wouldn't be able to leave my house. I wouldn't be able to function at all, let alone give a presentation. But he wasn't interested in that. I was not sure that I was a person anymore because that was the attitude that I received in the service. That I was an object or an animal or a lower being. I decided to stop listening to the system because systems are not interested in me."*

In 2007, Olga experienced another episode of psychosis. Instead of seeking treatment in a state-run institution, she was treated at a non-governmental rehabilitation centre. She found that there was a radical difference in her treatment and the way that staff interacted with her.

*"They were not judging people for their unusual views, but were trying to help people express themselves, stressing that all people may have problems and this is not the end of the world, you just keep going. I strongly suspect some of them had living experience of mental health issues because they were not talking like people who did not understand."*

Fuelled by her experiences, Olga began to involve herself in advocacy, first as a volunteer and later as a member of the monitoring team for the National Prevention Mechanism of Georgia. She conducts surveillance of closed state-run institutions, including psychiatric hospitals, retirement homes, prisons and detention centres. This role has allowed her to gain new insight into closed institutions in Georgia and to identify human rights violations.

*"In my role, I saw people who were held in these institutions for 10 or 15 years based on one signature, and they were recorded as voluntary patients. Eighty per cent of patients in this situation sign the papers without even remembering later what it was and without being given the chance to read it. I always thought that science can change the world and that's why I chose biology to study. But after I learned that such an awful system of psychiatry still exists in the 21st century and despite the knowledge collected by science, they still fail to apply even primitive knowledge. So I switched my life path to civil rights activism."*

# Matt’s story

> Like queer, ‘mad’ has also been used in a derogatory way to pathologize and to discriminate and ‘other’ our community. I see madness as not just a celebration but also pride. It’s acknowledging that there are some amazing things to come out of my madness. I use mad really to reclaim that shame that has been put upon me in society and gain great empowerment in subverting people’s consciousness, to help realize that we’re all human beings. I would not want to be anything but me. My bipolar is a part of who I am. It is a spiritual gift that has been brought about through interpersonal, family, community and societal trauma. It is a special gift in the face of consistent adversity and constant hypervigilance. A gift that requires harnessing.
>
> **Matt Jackman, Australia**

After experiencing major clinical depression and anxiety disorders throughout their upbringing as a result of family and childhood abuse, neglect and abandonment, Matt was diagnosed with bipolar disorder and complex post-traumatic stress disorder (PTSD) in 2016. The onset of a stressful work environment and ongoing bullying led to their first serious episode and hospitalization. They have struggled with eating issues and recurrent suicidal episodes throughout their life. Matt has a family history of mental distress, with both their mother and two younger siblings also experiencing periods of unusual beliefs and suicidal thoughts. They believe that this history of mental distress is representative of the social and systemic trauma they and their family have experienced.

Matt’s story begins with their grandmother, who they describe as being forced by societal pressures into having children.

*“She ended up telling my mom that she never wanted children. I think it was that which resulted in my mother’s trauma and disorganized attachment style which she then passed down to me.”*

By the age of 24, Matt’s mother had three children.

*“She had my younger brother when I was 3 and I was very jealous because at that time she had a severe lapse in her mental health. She had a psychosis related postnatal depression, due to her family not being there to support her, as well not having any real community and being in a relationship with my father who at times was domestically abusive.”*

Cut off from her family, and dealing with an abusive partner, Matt’s mother faced social and structural issues that caused her mental health to deteriorate.

*"I became a parent from the age of 3 to 9 years. I looked after her and I looked after my two younger siblings while my dad and mum would fight all the time. They divorced a few years later, and my mum was in and out of psychiatric hospitals. She was diagnosed with borderline personality disorder, which is a shocking label. It was really just complex trauma issues from very unsupportive parents and an abusive partner. She had major clinical depression which turned into psychosis or unusual beliefs, as we call it in the Hearing Voices Network, which is a more humanistic way of understanding that experience rather than pathologizing it as a problem. Our family was isolated in poverty. Poor access to community mental health after deinstitutionalization and lack of family involvement were significant contributing factors to my mother's mental health risk."*

In 1999, Matt's mother took her own life and Matt and their siblings were taken into foster care for another period of time while awaiting child welfare outcomes. While in care, still battling grief and trauma, Matt was faced with an additional challenge as they began to realize they didn't fit into a heteronormative world. Matt now openly identifies as non-binary, agender and pansexual, however at the time their feelings towards gender and sexuality were a source of shame.

"*I learned to disguise and avoid because I was an effeminate child. I was told that it was not okay to be gay. That developed into very severe anxiety and depression and having to live my life of shame during my adolescence. Again, a very human response to oppression, not an illness, not a brain disorder, but trauma – societal, structural, systemic institutional trauma."*

At 19, Matt tried to take their own life for the first time. At the time, they were extremely isolated, living in a rural area, and had no access or contact with mental health services and no supportive community.

*"I was suffocated by shame and I didn't want to live anymore... I didn't want to make any friends because I was so scared of coming out and engaging with people on a deeper level."*

In their mid 20s, Matt experienced their first hypomanic episode. Over the next few years they would experience fluctuating moods, defined by periods of deep depression and elevated mood. Matt spent a total of 10 months institutionalized, including three public and five private hospital admissions, depending on whether they could afford access to private health insurance at the time.

They were shocked by the treatment they received in the hospital. Patients were given sedatives in the evenings for sleep, resulting in missing their morning meals and being given insufficient food.

"*When I went to complain, not just for me but on the behalf of patients who couldn't speak, the nurse said there's no place for collective advocacy here. If you have an issue you can come to me individually*."

Matt's hospitalization experiences have been characterized by a belief in profit-driven corruption in private health facilities, with poor staff engagement and a complete under-resourcing of public hospitals resulting in poor institutional care.

*"In the private system, they don't do any discharge planning, because they want people there paying $ 1200 [Australian dollars] a night, and they don't provide any community follow up so*

*you see the same people cycling in and out. In the public system they can't wait to get you out due to the pressure or demand and people are often left feeling unprepared and poorly transitioned back home, leading to readmissions."*

Matt worked as a social worker, advocate and peer worker, supporting service users with mental health conditions. Matt left due to the overly relied upon biomedical approach alongside human rights violations they witnessed, believing there was a lack of consideration of the wider needs of service users and the social and structural issues that impact them. Believing mental health starts in the community, Matt has become a vocal and passionate advocate for the "Mad movement". Matt spent 3 years working in forensic mental health in contemporary asylums and prisons, as a living experience consultant, and volunteers with several charities, peer support groups and lived experience services.

*"I just do what I love and what I'm passionate about. My brother and sister still live in public housing with significant psychosocial diverse abilities. I still live with $ 3000 [Australian dollars] in my bank account and no inheritance, so it's very stressful when I do all this work and I don't get paid for anything. I still live my experience every day. I called our national suicide crisis hotline only last week. I'm a living breathing human being and my mood fluctuates."*

## A vision for the future

Olga and Matt share their visions for the future of people living with NCDs, mental health conditions and neurological conditions around the world.

> Closed institutions should not exist, because of the power imbalance they create and as they are the source of numerous human rights violations. Acute care should be switched to alternative services that are either crisis intervention alternatives, like Soteria houses or respite houses, or open departments within the general hospital. These new services should also have a good connection with lawyers and peer supporters who visit the service regularly. Where doors are locked all sorts of mistreatment is possible.
>
> [We need] services oriented towards the real needs of the person and their real experiences. Services that pay attention to the whole person, rather than regarding only the diagnosis and the supporting symptoms.
>
> Better services contribute to early interventions and therefore better treatment… When people have trust in the services, they go for treatment early and do not wait until [things have] deteriorated to the last point, which leads to less chronic conditions later and less suffering.

**Olga**

> What we really need is natural healers in our communities, we need peer support, we need strong families, strong communities. We need social justice, allied health, non-diagnostic ways and methods to support us Mad folk in distress.
>
> We are the data, we are the science, people with lived experience... I can't stand it when people say 'there's data and there's lived experience'...There's no binary.
>
> The reality of the mental health system is that it's colonized and patriarchal and it's designed to entrench those that are oppressed, in oppressive conditions. Everything is blamed easily on the individual, 'they're depressed, they're suicidal, they've got bipolar, they're schizophrenic', when the reality is that for many it's actually unjust conditions that we live in that results in a lot of the distress and expression of distress that we experience.
>
> We need a whole government, whole society response, including sustainable economic models and systems that move away from hierarchy to inclusivity and partnership. We need empathy, love, compassion, culturally-led, community driven, social justice-based communities that talk about power and how to share power.

**Matt**

# 4

# Case Study 4: Informed decision making and health literacy

Patrick Boruett, Kenya and Allison Ibrahim, Kuwait

Informed decision-making and health literacy are deeply connected. Health literacy represents the personal knowledge and competencies that accumulate through daily activities and social interactions and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them *(16)*. Informed decision-making implies an understanding of a health system, how to access services and resources, navigating power dynamics, and participation in decision-making processes.

In this case study, Allison and Patrick share how health literacy and informed decision-making impacted the critical, early stages of their diagnoses in distinctly different ways. For Patrick, a lack of understanding and internalized stigma at the point of his bipolar diagnosis in Kenya resulted in delayed acceptance of his condition. This subsequently impacted his well-being, relationships, the ability to trust health-care providers and the willingness to engage with his condition. The opposite was true for Allison, whose clinician in Kuwait ensured that she was informed and equipped to manage her type 2 diabetes diagnosis and advocate for herself.

Both experiences demonstrate the critical need for people living with NCDs, mental health conditions and neurological conditions to be meaningfully engaged in informed decision-making through access to contextually relevant and clear information; appropriate guidance from clinicians and health-care teams; as well as education for family members and respect for decisions made by those with lived experience. Without these components, people with lived experience might find it difficult to make the best decisions for themselves, impacting the trajectory of their relationship to and care for their condition in the future.

# Patrick's story

> “At my turning point, it became so easy to access resources, books, and educational materials, something that was very difficult when I was in denial, because I was only looking for materials that would reinforce my position. It is like learning to ride a bicycle, initially you fall several times, but over time it becomes an automatic process and that is only possible if you are able to get access to reliable information.
>
> **Patrick Boruett, Kenya**

Patrick was diagnosed with bipolar disorder in 2011 and describes himself as having lived in denial for 4 years. The diagnosis was a huge personal shock to him. Despite his background in pharmacy, his knowledge of mental health was limited. His health-care provider took very little time and attention to build Patrick’s understanding of his condition. After being hospitalized against his wishes in the very hospital where he worked as a pharmacist, he was firmly in denial about the validity of his diagnosis. This prevented him from playing an active role in its management.

*“Now when I look back, if I had been taken through the process of the diagnosis in a different way, maybe I would’ve done things differently. But I was just told, ‘this is your diagnosis.’”*

Following a severe manic episode in 2015, two extensive hospitalizations in 2 months and a dangerous car accident, Patrick experienced his darkest moments. He began to acknowledge the severity of his situation. He felt isolated, ashamed and believed he had let down his community of family, friends, and colleagues. He began to access online resources such as the Bipolar Hope Magazine, Depression and Bipolar Support Alliance (DBSA) and the NAMI Athens Ohio recordings, which he describes as “*a candle in the dark*”.

Despite his new-found acceptance, Patrick felt his lived experience was not taken seriously by those close to him because of the lack of understanding and stigma related to his mental health condition. His family would worry and advocate for his hospitalization, believing that was in his best interest. His perspective and experience were ignored by both his family and doctors. He recalls how his doctors would often rather listen to his family members than him, even though they would recount things differently to how Patrick was experiencing them. This led to friction between him, his family and the doctors. The perception was that his mental health condition made him less reliable and accountable. Even later, when engaging meaningfully in his own treatment, Patrick recounts experiences where his viewpoint was not taken seriously.

*“I remember a time when I was given a prescription that was very similar to the one I had previously had and which had not worked well for me. I explained this, but the doctor was insistent that I go back on it. I had a training programme where I needed to report very early and the medication made it difficult to wake up in the morning. So I said to the doctor ‘this medication does not work for me in this situation’ but he was hesitant to make changes though he eventually obliged.”*

Upon diagnosis, Patrick did not have the health literacy to fully comprehend his condition. The doctor at the walk-in clinic had long queues of patients and had minimal time to listen, answer his questions and explain things to him.

"*From the beginning there was an assumption that I knew certain things given my health background, but at that time you are just absorbing the shock of the diagnosis.*"

This changed when he visited a different doctor who saw individuals by appointment and had time to listen.

*"The first interaction just made me switch because he was able to talk to me and we had a conversation that was very meaningful and I found it very informative. And it was just because he cleared that space to listen, and I was able to ask questions."*

By supporting the development of Patrick's health literacy and providing space for discussion, this doctor gave Patrick the skills and knowledge to participate in an informed dialogue about his condition. The power imbalance in health literacy that had prevented Patrick from engaging in the initial years of his diagnosis ultimately shifted to a collaborative partnership through this meaningful engagement.

Although valuable, the information and resources Patrick was able to find were mostly written in and targeted at the Global North. Patrick was keen to connect with others in Kenya and to be part of a local mental health movement.

*"I began to read articles about people living with bipolar disorder, mainly from Europe, Australia and North America. I longed to hear from people in Africa, too. I started looking out for people who had spoken out about their mental health conditions and I came across a few Kenyans who had shared their experience in blogs... We needed a safe space to share our stories and act as a source of reliable information, so in 2019 I founded the Bipolar Heroes Foundation. Our vision is a world where people living with bipolar achieve their full potential and are treated with dignity. Through the use of storytelling, support groups and advocacy to promote the NCD agenda in Africa, we are helping to raise awareness and improve access to mental health resources."*

"*It's not easy, but it's a journey. Everyone's journey is unique, but if we are able to support one another by sharing our experiences, it makes the journey lighter.*"

# Allison’s story

> “Health literacy is a piece of empowerment that brings the patient to the forefront, in the same way that health advocacy gets patient voices out there. Informed decision-making leads to a better outcome – and for me to take better care of myself.
>
> **Allison Ibrahim, Kuwait**

Allison’s journey into advocacy began with her type 2 diabetes diagnosis in 2012. She received support from what she describes as a wonderful endocrinologist in Kuwait who introduced her to the power and potential of advocacy. Allison’s doctor walked her through the practical process of monitoring herself, and simultaneously introduced her to the steps of inquiry and what to consider in the critical early stages of her diagnosis. She found this hugely empowering.

*“My amazing endocrinologist saved my life and I really mean that. She really did bring me to an understanding of what it meant for me to advocate for myself, to be involved and to be an informed decision-maker. She empowered me to take back control of my health. As I became more experienced in the steps that would help me, I developed those skills and we could move onto the next stage, for example monitoring my bloodwork.”*

Once Allison felt empowered and informed, she became actively engaged in managing her condition and her well-being.

*“It was an awakening. After that I made appointments with other health-care professionals in Kuwait, with specialists and nutritionists. Until then, I had never heard of people living with noncommunicable diseases advocating for themselves.”*

Allison describes the ideal relationship between doctor and patient as a trusted partnership.

*“Informed decision-making to me means that I’m going to be partnering with the health-care professionals. It means that I am able to come prepared with specific questions, to dive deeper and therefore benefit more from the treatment.”*

Allison returned to the USA to support her ageing father and terminally ill sister, both of whom were experiencing palliative care and hospice-level in-home care without support. She suddenly felt disempowered as she struggled to understand the complex health system in the USA and felt unable to make informed decisions about her medical care as well her family’s care. Without knowing how to navigate the health system, Allison could not be as proactive as she would have liked and found it difficult to advocate on her family’s behalf or access the information and care she needed for herself.

*“I didn’t have anywhere to go to figure out what the alternatives might be. I wasn’t in a position to challenge the primary doctor or to challenge the specialist. I didn’t know how to get to the next specialist in a timely manner.”*

Navigating the very different health systems in Kuwait and the USA, and the vast differences related to informed decision-making in both contexts has given Allison invaluable insight and perspective. Lack of understanding of the complex health system in the USA made for a very difficult period in her life – including the passing of her mother, father and sister – that much harder.

*"I am desperate for more focus on patient involvement from medical teams here in the USA. Of course, there are health-care professionals with the same perspective of a collaborative and interactive care model. However, the idea that the doctor is the only expert, and addressing health-care as a one-way interaction is far too prevalent. I really would like to see more of an interactive system like I have often experienced in Kuwait."*

## A vision for the future

Allison and Patrick share their visions for the future of people living with NCDs, mental health conditions and neurological conditions around the world.

> We need to make mental health information available to the people in the patient's life, including caregivers, family or friends. After my diagnosis there was a lot of friction between me and my family as they had a different understanding of situations to me. At my turning point, after I started valuing the need to educate myself, I also realized the importance of educating my family. It took time, but with information, my family became allies in managing my condition.
>
> To encourage informed decision-making, it is crucial to create an environment where you can easily access information. This information needs to be accurate and in simple language. To have a relationship where you can be heard. If you have that relationship, when there are issues you are able to smooth them out, and that builds trust in the doctor and the system.

**Patrick**

> I would like to see more of an interactive system, maybe even to add an expanded health literacy and advocacy component to all hospital systems. A Department of Patient Advocacy and Health Literacy that can act as a collaborative component between patient advocacy and informed decision-making with health literacy and health education. To shift gears from the hospital setting, to a community support setting.

**Allison**

# 5

# Case Study 5: Living experience as evidence

Odireleng Kasale, Botswana and Prachi Kathuria, India

The lived experience of people living with NCDs, mental health conditions and neurological conditions is often undervalued as a form of insight and expertise by traditional powerbrokers such as policy-makers and health-care actors. Individual perspectives and experiences can be perceived as anecdotal, with long-standing scientific approaches often tipping the evidence scale towards quantitative data.

When lived experience is ignored, or not fully taken into account, it significantly impacts the individual and the health system as a whole. At the individual level, it can affect early diagnosis, reduce opportunities to engage in care-related decisions and negatively influence self-management approaches. A lack of meaningful engagement also leads to mental distress, disappointment and frustration at not being heard. At the systems level, it can lead to chronic mistrust between individuals and care providers, potentially leading to negative health outcomes.

In this case study, Odireleng and Prachi show how they, as strong, living and breathing sources of valuable evidence, can provide tremendous learning to others, including health-care providers and employers. In Botswana, Odireleng experiences stigma on account of her substance and alcohol misuse, which unfairly impacts her credibility when advocating for the wellness of others experiencing similar challenges. In Prachi's experience of chronic respiratory challenges in India, the lack of understanding by health-care providers over many years not only impacted her diagnosis, but eventually led to an ongoing mistrust of medical systems – even when she developed endometriosis and polycystic ovarian disease.

In both cases, local context, gender constructs and societal hierarchies downplay the rich understanding and evidence individuals have and can offer as a result of their complex health journeys. Prachi and Odireleng show us that those with lived experience have far greater understanding of their conditions, including the barriers, challenges, opportunities and ideal services and treatments that can help themselves and others, including health-care providers and systems of care.

# Odireleng’s story

> “When I got into recovery there were very few resources for people looking for help, like myself. I found my healing; I needed my mission so I was very determined. Now that I’ve found there is a way to get better, I wanted to share it.
>
> **Odireleng Kasale, Botswana**

Odireleng is in long term recovery after suffering a period of substance and alcohol misuse. Having found it difficult to find the right support in Botswana, it was at a rehabilitation centre in South Africa where she had the breakthrough that set her on the road to recovery.

Inspired by the care and support she had received, which transformed her life, she decided to train as an addiction counsellor and share her learning to help others. She got in touch with the only local public centre for addiction and mental health treatment in Botswana. Odireleng was keen to use her lived experience to help others.

*“I had found what worked for me was a mixed approach. I had the benefit of group therapy through Narcotics Anonymous. So, in my proposal I said, as there is nowhere that people can detox, that we introduce group therapy as part of the programme. Particularly for people who are in early recovery, because when you are trying to find a new way of living it can be very lonely. They had the space. I had envisioned a spot outside where it is nice and breezy and there is a beautiful big tree. We could get the resources from the Narcotics Anonymous from South Africa and do groups in the evenings and movies and hikes at the weekend. It was something that I was so invested in.”*

Yet, Odireleng found her ideas were dismissed and her lived experience was not valued. She believes that the cultural context where women defer to hierarchy and do not speak up was one of the issues at the heart of the challenge, alongside the belief that health professionals know best.

*“I left crying because she just dismissed me. She used some very deep, painful Tswana words. She just felt that I was moving too fast. What hurt the most was the fact that I was in a place where I’m supposed to be welcomed and feel safe and feel heard and then I was dismissed. It was just like, ‘let us professionals deal with it’.”*

This inspired Odireleng to found her own organization, the Sesha Recovery Centre.

*“I found my new beginning. I felt even more sure that this was what I was supposed to be doing because I know the pain of struggling with substance use but also because I am a woman and so the stigma is even more intensified.”*

Odireleng now uses lived experience across her professional life. She works closely with universities and schools in Gaborone, providing educational resources and tools on substance abuse and recovery. Her organization also works with several groups that are marginalized, including sex workers, the LGBTQ+ community and those from lower socioeconomic backgrounds. Odireleng is passionate about using her lived experience to help others and is keen to become involved in policy-making.

*"I've been building a lot of rapport and very solid relationships with social workers, nurses, police, psychologists and psychiatrists, so I feel I could contribute a lot. I know the system – public and private – well enough because I've used it twice."*

Still, it can be a challenge for Odireleng's lived experience to be considered as evidence in the scope of her work and among some of her colleagues.

*"When I am working with my colleagues, sometimes I feel apprehension from them taking up my recommendations, which stems from them being in the health-care service provider field longer. This can lead to them disregarding the wealth of knowledge and experience my living experiences brings to the table in managing cases."*

Odireleng also uses her love of writing to share her lived experiences and stories on her blog.

*"I have a page where I write about my experiences on Facebook, about just being a person in recovery in a community where there's no support and so much fear about talking about a topic that has so much trouble. I had to take a break for a while because of all the backlash I received, because I am a woman. African culture is very conservative, but I found the courage to find my way back. It is possible to recover and it's something that should be spoken about. I still struggle with questions 'Should I tone it down? Am I exposing my family to being criticized by talking so openly about my addiction?'"*

Through her continued advocacy and work, Odireleng is reaching individuals and communities who might otherwise go unsupported.

*"There are a lot of people who want to get into recovery but all of us are just figuring it out on our own. No matter how much we want to get better we're just figuring it out individually because there is no recovery community. Once you're heard and you're safe, then it's a ripple effect. Once you get it, you pass it on to one person and that person passes it on to another and you get your strength from the community."*

# Prachi's story

> “I feel living experience for me is my life and it is my being. It is not just about a day or two – every moment of my life is decided by my lived experience. It is the foremost thing that decides what my day is going to look like. It plays a role in how the rest of my life will turn out and what sort of decisions I make, personal and professional.
>
> **Prachi Kathuria, India**

Prachi has been living with asthma and chronic bronchitis for over 20 years, which has led to other respiratory problems. When she was young, there was limited understanding among clinicians and the community which led to delayed diagnosis and challenges in managing her condition. Prachi lives in northern India, where air pollution levels regularly reach a very hazardous 500 on the Air Quality Index (AQI). Over the past few years, this has significantly affected her quality of life, particularly between October and December. During this period, she has to stay indoors using an air purifier, which she is fortunate enough to afford, and she struggles to be outside even to complete daily activities. In 2016, Prachi was also diagnosed with endometriosis, polycystic ovarian disease and multiple fibroids.

*“It might be hard to believe, but one noncommunicable disease invites many others. My asthma and respiratory problems invited chronic sinusitis and made me prone to allergies. My sinuses were so sensitive they could be triggered by food allergies, smells, dust or even temperature changes. Sinusitis then leads to formation of polyps, which grow in your sinuses and are very painful and eventually block your nasal passage completely. Then there are sleepless nights where you’re just sitting because you can’t breathe while you are lying down. So you can’t sleep and the next day it is a working day and you have to be in the office.”*

Prachi started to experience periods of breathlessness as an adolescent. These were the first signs of her asthma and chronic bronchitis. It was also the beginning of a journey of lived experience which was often ignored or dismissed. This has led her to become a firm advocate and voice for others with NCDs across India.

*“When you live with a disease or condition, it changes you. I am not talking about a temporary one here, it becomes central to your life and those around you. Honestly, you cannot plan for weeks but just the current day. You face shame when you are compelled to call-in sick at work. For those of us working with supportive employers it might be easier, but not all workplaces will understand.”*

Following a failed surgery to remove the polyps from her nose to help her breathe, she noticed no improvement. Despite numerous attempts, she could not get her doctor to listen. She was angry and upset.

*“It impacted my life so much during the years that followed. There was a time when I just couldn’t breathe through my nose even after the surgery. My nose on both sides was blocked completely and I kept mentioning this to my surgeon. I’m talking about a health system that is a) non-responsive and b) has some sort of self-imposed seniority that everyone shows. If we are telling you that there is a problem, there is a problem...”*

Eventually they listened to her, and examined her.

*"One of them said to the lead surgeon, 'You haven't done the surgery correctly, you've still left some parts of the tissue' and the doctor who had operated on me replied 'Oh you can just remove it right now.' I was conscious while I could hear their conversation. This would have been a very painful procedure, normally done under anesthetic."*

Traumatized by her experience, Prachi was afraid to go back and has since developed a deep mistrust of doctors and medical systems. She found similar attitudes when she consulted doctors about her endometriosis. There was no partnership, consideration of her lived experience inquiries into what mattered to her, including impacts on her occupation and career.

*"Once a month you have to go through a lot of pain and it affects your life and your mental health because you're so scared of those three days of pain. When you seek help from a medical professional, they tell you that nothing can be done. They suggest you start planning a family, because otherwise [eventually] you won't even be able to do that, and that's what they leave you with."*

Prachi wanted to do something so that she and others could be heard. She believes that her lived experience should be used as learning and evidence.

*"I knew that there was something called 'lived experience' and I could share my story, but I didn't know how that translates into evidence and how I could make a case for developing a public narrative."*

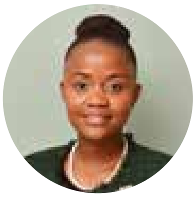
In 2019, the NCD Alliance hosted a leadership and communication training in Geneva, Switzerland. Three leaders from the Health India Alliance (HIA) attended, including Prachi. As an in-country trainer, she then conducted two training sessions for approximately 40 people living with NCDs. The trainings focused on understanding how lived experience can be used as evidence and a call to action. The training also aimed to teach advocacy and public narrative skills. The trainees were then invited to become members of the National Network of People Living with NCDs, which now guides the work of HIA around meaningful involvement.

*"I have translated my story to a national level and built a network of 40 people living with NCDs. We have since been working on various advocacy campaigns with them. We also hope to develop a formal engagement framework for civil society so that they can facilitate the inclusion of voices of people with lived experience on various decision-making bodies. We ultimately want people living with NCDs not just to have a seat at the table but a voice at the table, heard with dignity."*

## A vision for the future

Odireleng and Prachi share a vision for the future of people living with NCDs, mental health conditions and neurological conditions around the world.

> “In my vision for 2025, people are more open minded. There is a shift in perspective and a shift in mindset to be more welcoming and open minded towards those with lived experience. I want to see lived experience respected.
>
> I would like to see people with lived experience afforded more local opportunities for training and capacity building. So that they can contribute to policy and practice and engage more in service delivery. My prayer for us as a country is that we engage more people and are more open minded.



**Odireleng**

> “I want to see the narrative expanded to talk about overall noncommunicable diseases and the integration of palliative care, as an empathizing core component of delivery within the medical curriculum.
>
> The burden on medical professionals could be eased by using people with lived experience as supporting staff. Each medical professional would be supported by a person with lived experience who can provide counseling support, empathy and advice to somebody who’s coming to a doctor. I think that would be a good starting point.

**Prachi**

# 6

# Case Study 6: Power dynamics and power reorientation towards individuals with lived experience

Anu Gomanju, Nepal and Paul T Conway, USA

Reorienting power dynamics towards people with lived experience can increase individual agency, representation, and lead to the development of people-centered solutions that benefit individuals and health systems.

When people with lived experience are not considered equal and important partners, or their lived experience and unique insights are not valued as critical evidence to inform decision-making, vital health opportunities are lost. Limited knowledge or the inability to influence or ask questions can lead to failed early diagnosis and future exclusion from choices and decisions about their care. Those regarded as the power brokers, ranging from clinicians and pharmaceutical companies to insurers and policy-makers, should acknowledge the power imbalances that exist. Further they should venture to develop collaborative partnerships with people with lived experience to support care and innovation that is mutually beneficial.

In this case study, Anu and Paul show us how the impact of unequal power dynamics affects early diagnosis, stigma and representation of their lived experiences. Through Anu's experience with rheumatic heart disease and congestive heart failure in Nepal, we learn how shifting the power dynamic from her clinicians to herself eventually led to meaningful participation in her care alongside driving her future community advocacy efforts for others. Paul's experience with kidney disease and kidney failure in the USA shows how shifting power dynamics towards the voices of his peers not only elevated the value of the lived experience but also resulted in policy changes at the highest levels of government.

In both experiences, recognizing the value of people with lived experience and including them as partners, rather than peripheral characters, ultimately leads to greater opportunities for change. This further supports why reorienting power dynamics is a critical component of the meaningful engagement of people living with NCDs, mental health conditions and neurological conditions.

# Anu’s story

> “ Having the confidence to be a partner in your health and care. If patients feel inhibited to ask questions or advocate for themselves, this can affect the treatment they receive and their life thereafter. At a systems level, if the power dynamic is not orientated towards the people living with NCDs, then they are unable to advocate for themselves or others.
>
> **Anu Gomanju, Nepal**

Anu was diagnosed with rheumatic heart disease in 2001 at the age of 11 after suffering rheumatic fever caused by repeated episodes of strep throat infection. Following surgery, she lived without major physical complications for 15 years. But in 2016, she suffered congestive heart failure resulting from damage to multiple heart valves. She underwent a second open heart surgery. Although the surgery was a success, she still suffers from an abnormal heart rhythm.

Born into a family of six in a small municipality near Kathmandu in Nepal, Anu’s parents worked hard to allow all four of their children to complete higher education. The family runs a small grocery shop in their village and rely largely on farming.

*“In Nepal there is a lack of knowledge and understanding of NCDs. If my community, my family and neighbours had known what symptoms to look out for, if my parents had health literacy and access to information and services without financial hardship, I could have been prevented from having chronic problems. If health-care providers at the primary health-care centres have the knowledge, they can identify the symptoms and assist with early diagnosis.”*

At the time of Anu’s first surgery, her lack of knowledge and confidence meant that she was excluded from participating in discussions about her care.

*“At the time, I didn’t know anything about my condition. I didn’t even know where the heart was in our human body. Often, I used to be careless about taking the medicines on time as I did not know about its importance for my health, especially when I think about this now. As a child, I used to misperceive electrocardiogram (EKG) as an electric-shock giving procedure.”*

Before Anu’s second surgery for mitral valve replacement and tricuspid valve repair, she had to make a choice between a biological valve or a mechanical one. It was a difficult decision, as both had their advantages and disadvantages. In order to support her in this important decision-making process, she was interested in hearing the experiences of people who had had their mitral valve replaced. Anu worked extremely hard to inform herself about her condition and understand the options. By informing herself, Anu was able to shift the power dynamic and advocate for herself during discussions about her second surgery.

*“It was interesting comparing the experiences of my first and second surgeries. With my first surgery, I didn’t know anything about my disease and I was afraid to even ask the doctors what the problem was… But when I had my second surgery I was prepared because I knew more about my condition and I was able to talk freely, ask questions and get advice about my treatment.”*

Although Anu was able to find the information she needed, she struggled with the lack of locally contextualized resources or advice related to her condition. By working hard to inform herself and reorient the power dynamic, Anu has transformed her self-identity, life and livelihood. She also recognized the value of connecting with others in Nepal who have similar, or even more challenging, conditions. Today, Anu is using her personal platform to raise the agenda of this topic and address this gap, aiming to connect people with rheumatic heart disease in Nepal to share common experiences and provide them with locally relevant resources.

*"It was this power shift that drastically improved my quality of life, by allowing me to pursue a career in the public health sector, but also in looking at myself not as a diseased person, but as someone with resources who can do something better for others."*

Motivated by her own experience of heart disease, Anu hoped to become a cardiologist but this was not affordable. She studied public health instead, allowing her to focus on her passion for disease prevention and health promotion. Her selection to the NCDI Poverty Network and Partners in Health "Voices of NCDI Poverty Advocacy Fellowship" has been hugely empowering and has helped her to find meaning in her struggle.

*"As a Christian, I used to question why I had to have rheumatic heart disease. I didn't understand my purpose, especially when I was sick and I had to take a lot of medicine, draining me physically, mentally, emotionally and financially. But now, contemplating more about NCDs and their relationship with poverty, learning advocacy skills, applying global health learnings, and bringing my experiences together to put my voice forward so others can learn, I am happy. I feel I have found my life's purpose."*

Anu's work with The NCDI Poverty Network represents a further power shift, giving greater agency to people like her around the world. Beyond information and peer support, Anu is determined to help others participate in decisions that affect them. Her work in this fellowship also focuses on global and national advocacy for increasing commitment and investment in NCD innovation and interventions, universal health coverage, as well as meaningful involvement of people living with the conditions. In Nepal, she has begun to work on establishing a network of effective lived experience advocates in order to serve as an expert and resource on lived experience-centred policy advocacy. She is also working with her surgeon, Professor Dr Bhagawan Koirala, on an advocacy campaign in Nepal to inform the public and health professionals to encourage open and informed decision-making.

*"I think the Voices Fellowship is an example of the power shifting to people living with NCDs because it's a programme designed for people with conditions... As part of my fellowship, I am working on a campaign to build solidarity between people who have rheumatic heart disease in Nepal. I hope to publish a book of case studies, to have as an evidence base for policy in the Nepalese context. The book will also include a case study based on my experience, about a child with no knowledge, who one day comes to be working with her own doctor to create positive change."*

*"I hope that my advocacy campaign will increase public and patient interactions with health professionals and help people to build healthy relationships between doctor and patient, eventually enhancing health-related quality of life."*

# Paul's story

> “ The treatment status quo is not currently anchored on the perspectives of those who are living with a chronic disease and I firmly believe in the benefit of shifting it. Not only would quality of life for patients be improved, you may actually attract more people into the medical field if they feel they have a higher chance of making a substantive impact for people.
>
> **Paul T Conway, USA**

Paul was diagnosed with kidney disease at the age of 16, after a random urine test during a high-school sports physical examination. This was a blow for Paul who had wanted to join the military, which was a family tradition. Instead, his father encouraged him to serve his country another way through a career in politics and government.

Paul lived for 13 years with chronic kidney disease before suffering kidney failure and undergoing dialysis. At the time, he was working as the Deputy Secretary for Health in Virginia. He spent 3 years on dialysis, during which he never missed a day of work, before receiving a kidney transplant in 1997.

Paul is passionate about amplifying the voices of those with lived experience, advocating for their experience and unique insights to be treated as evidence. He pursues this through his volunteer work for The American Association of Kidney Patients, and through service on a number of patient advisory boards, including one for the US Food and Drug Administration.

In 2018, Paul was invited to speak at the UN Convention on Ageing, Ethics and Disease. While on a panel with a number of leading health professionals, he was shocked by the discriminatory and disempowering perspectives shared about people living with NCDs.

*“I was struck by how heartbreaking the dialogue was; that those with chronic disease have undue expectations about how long they should live and that chronic disease places a burden on economies. It was offensive and it was wrong.”*

Paul announced that day that his organization, The American Association of Kidney Patients, would put resources into a global advocacy effort to shift the narrative and redress this extremely imbalanced power dynamic.

*“Chronic disease often affects the most disenfranchised people. People who look at people with disease as a burden are out of date. You must recognize that every single individual has the opportunity to contribute throughout their life. People want to be creative and engaged, they might need some help, but to think that someone with a disease is a burden to society is wrong.”*

In 2019, Paul and The American Association of Kidney Patients partnered with the George Washington School of Medicine and Health Sciences. Under the leadership of the Chair of Nephrology, Dr Dominic Raj, the first Global Summit on Kidney Disease Innovation took place, with a live audience of 500, reaching a further 10 000 people online from over 20 countries.

The panels included medical professionals, students and policy-makers. Crucially, they were all led by individuals with lived experience.

*“We had world-renowned medical professionals talking about new innovations that were trying to reduce the burden of disease. But really, we did it to send a message to patients around the world and to researchers and politicians, that status quo kidney care must change and that assuming that kidney disease patients are a burden is wrong.”*

Now in its third year, the 2022 Global Summit has brought together an audience of over 23 000 individuals with lived experience of kidney disease, representing 91 countries, including researchers, companies and medical leaders from around the world. They are now putting together an international consortium of patient-led organizations to support the development of artificial kidneys to save more lives.

Within the private health-care system in the USA and parts of Europe, insurance providers choose which drugs to cover. These decisions drive clinical outcomes and quality of life for real people but they are often made based on perceived cost for the insurer, rather than what is the best medical outcome for the patient consumer.

*“A major pharmaceutical company recently announced a new drug that can slow the rate of kidney failure in people with diabetes, but a major health insurance company in the USA was refusing to make it available. We contacted them and essentially said ‘we can be nice or we can go public that you’re denying access to a therapy that can save people from kidney failure.’ They changed their policy within a short-time.”*

Paul’s work also focuses on building a network of effective patient advocates, to increase support for (or pressure on) pharmaceutical companies, insurers and governments.

*“If patients are aware of new innovations, and the only barrier to them receiving it is a pharmaceutical company, insurer or government not wanting to invest, we’re going to train those advocates on how to speak up and make it public. What has become abundantly apparent is that once you shift that dynamic, what you’ve essentially done is give greater power to the patient consumer.”*

## A vision for the future

Anu and Paul share their visions for the future of people living with NCDs, mental health conditions and neurological conditions around the world.

> “We have to respect and listen to people living with NCDs, involving them in decision-making processes, because others do not understand what it is like to live with NCDs… it will be regarded as important to take into account their thoughts and experiences.
>
> People with lived experience will hold positions of power and influence. They will be respected for their direct experience of living with their condition every moment of their lives, not just while seeking health services. As they have an understanding of the full spectrum of issues, they are able to contribute to innovation and progress for services and support for people living with NCDS.
>
> There will be resources available, making it possible for people living with NCDs to be involved in the design and implementation of programmes. This would be regarded as a priority by the government, not the exception. Policies and strategies will be reformed and redefined to enable and empower people living with NCDs and those living with mental health conditions and neurological conditions.

**Anu**

> “Patient insight data [data including lived experience] will be included in the regulatory process alongside clinical outcomes data and reimbursement policies. This will be a huge achievement because those who impact science and research determine policy.
>
> Patients will be part of the dialogue and have a seat at every decision table. Pharmaceutical companies will involve patients in the design of clinical trials. In the media, reporters will talk about disease in the context of the patient experience.
>
> In the private sector there will be increased opportunity for innovation, both to make money and to save lives. Government officials will understand the needs of those through National Hospital Care surveys and become more effective representatives of the patient interest.

**Paul**

# Key learnings

All six case studies demonstrate that individuals with lived experience are, and should further be, strategic contributors to the global response to NCDs, mental health conditions and neurological conditions. They highlight that the inclusion of people with lived experience should be comprehensive across all aspects of decision-making, and from co-creation and co-implementation to monitoring and evaluation. Individuals with lived experience should not be engaged tokenistically or as mere "representative voices", but rather as valued critical experts that communities and power brokers consult to improve health outcomes. This section summarizes key learnings for the global health community across the six explored themes.

## Advocacy and human rights

Social and economic inequalities have a profound impact on the individual experience, including access barriers to health care and life-sustaining medicines. Out-of-pocket expenditure on health services, the cost of travel to receive care as well as financial pressures of time away from income-generating activities all pose hurdles to accessing care. Structural inequalities also shape an individual's ability to participate in decisions that affect themselves and others. These structural inequalities impact every aspect of inclusion, care and outcomes, in some cases costing lives. In order to achieve a sustainable system change and ensure fair and equitable health care, people with lived experience should be meaningfully engaged and understand their rights. When individuals can confidently advocate for themselves, they are able to change the trajectory of health outcomes. Health-care systems should also be designed to respect individual rights and address issues of inequality.

## Community engagement across broader networks and health systems

Community engagement and networks play a vital role in supporting people living with NCDs, mental health conditions and neurological conditions. Peer support groups, community organizations and online communities provide individuals with access to critical information and support, and in some cases help to save lives. Peer-to-peer communities and networks can also help fill resource and knowledge gaps, in some cases providing routes and access to essential medicines and services that otherwise would not be readily available to many. Community networks also help reduce stigma and discrimination of the lived experience by supporting inclusion, equality and diversity among participants. Peer groups further support informed decision-making, empowering individual understanding and leading to greater confidence when interacting with health systems.

## Exclusion and the importance of including groups that are marginalized

Groups and individuals that are marginalized are often those most in need of support, education and involvement in decisions about their health, yet they are frequently not fully included or empowered to advocate for themselves or others. Trauma caused by complex structural and social dynamics, negative experiences, economic and social disempowerment all compound exclusion and lack of involvement in shared decision-making. Grave social injustices and human rights violations are often exponentially experienced among groups that are marginalized, particularly among individuals experiencing mental distress. Systemic power imbalances are further entrenched when the voices of those living with mental health conditions and neurological conditions are excluded, presenting serious risks to individual well-being and potential quality of life. To tackle this, a move towards the inclusion of the wider holistic, personal and social needs of individuals and their loved ones is needed. Reframing mental health 'issues' as neuro-diversity can help reduce stigma, exclusion and discrimination and potentially undo the pathologizing of communities that are marginalized. This reframing may also put an end to closed institutions and forced interventions that signify a lack of respect for the human rights of the individual, while countering the lack of will to build and integrate alternative options. A fundamental respect for the wishes and decisions of individuals by health-care providers in the mental health space must be the driving force for more meaningful engagement of people with lived experience.

## Informed decision-making and health literacy

Informed decision-making and health literacy can impact participation in different contexts. A sense of empowerment in one health system or cultural setting may not automatically translate to another, and the power to advocate for one's own health may fade. Limited health literacy and a lack of engagement pose particular challenges during the early (and often challenging) diagnosis phase. Effective decision-making also requires clinicians to be informed and up-to-date on the latest treatment options and best practices. However, by building an informed and trusted dialogue with a clinician and by forging a collaborative partnership where power is shared equally, people with lived experience can be heard, respected and take the lead in decisions that impact their health and well-being. The value of informed decision-making to individuals, society and health systems is substantial. Meaningfully engaging individuals with lived experiences through informed decision-making frames the diagnosis as the start of an advocacy journey resulting in greater engagement in and management of the condition. It also increases health literacy of the health condition among the individual, family and surrounding support networks and transforms decision-making into a collaborative partnership between those involved.

## Lived experience as evidence and expertise

Lived experience is undervalued and at times ignored by health-care providers and systems. This affects participation in diagnosis and treatment decisions and can have a detrimental impact on physical and mental well-being. People living with NCDs, mental health conditions and neurological conditions have significant learning and insight to offer but need support to ensure that their perspective is factored into shared decision-making, based on mutual respect and partnership. This is particularly important in health systems where there is a greater reliance on the individual to be their own advocate. Valuing and using lived experience as evidence is essential to bridge the gap between data, science and clinical expertise. When lived experience is considered as evidence, it can be a valuable tool to shape policies, services and build critical partnerships across health-care systems. Ultimately, this can lead to greater innovation and improved health outcomes that are needed by both the individuals and systems involved.

## Power dynamics and power reorientation towards individuals with lived experience

Shifting power dynamics towards people with lived experience is essential to making meaningful change. Low health literacy can prohibit meaningful participation in care. Reorienting the power dynamic has the potential to facilitate personal transformation and gain empowerment for individuals and communities, resulting in meaningful collaboration. Encouraging people with lived experience to participate and advocate for themselves can support collective wisdom that transcends geographic borders and redefine empowerment. This collective power dynamic can even lead to meaningful engagement with government officials and policy-makers. Amplifying the voices of people with health conditions helps shift power dynamics and elevates the value of the lived experience as evidence for decision and policy-making. It also helps build advocacy movements that ultimately hold organizations and systems accountable and ensure that quality of life is prioritized over profit.

# Conclusion

The inclusion of people with lived experience is essential to ensuring the principles of respect, value and dignity are met and to achieve health for all. When engaging with individuals with lived experience in a meaningful way, one size does not fit all. Rather, there is a diverse community of individuals, professionals, care providers, organizations, and institutions to be heard, supported and engaged.

This report highlights powerful narratives that provide evidence of why including the voices of those with lived experience is critical in the co-creation of health policies, programmes and services. The topics explored transcend lived experience and geographies, and can spark learning and action both locally and, potentially, on a larger scale. Only through listening and learning from diverse experiences, can those in power understand and address the challenges from lived experience perspectives.

At a fundamental level, all stakeholders in the NCD and mental health response should include learnings from the expertise of those with lived experience from start to finish. This includes providing sustained platforms for individuals to set decision-making tables, create opportunities for the co-creation of programmes, policies and services, and ultimately shape the things that matter most to them. Individuals with lived experience are powerful agents of change that provide support to other individuals through peer-to-peer networks, navigating complex health systems and sparking or reigniting advocacy movements.

These case studies further highlight the need for all relevant stakeholders and traditional power brokers involved in the NCD and mental health response to adjust current strategies related to planning, delivery, decision-making and co-creation opportunities with people with lived experience. As WHO works towards development and publication of the WHO Framework for Meaningful Engagement of People Living with NCDs, Mental Health Conditions and Neurological Conditions, the learning process will continue to build evidence and apply lived experience voices, perspectives and expertise.

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