Health For All

What if no one
was left behind?

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Thank you to all of our contributors who have supported us on this journey and who are continuing to help us create better work.

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Foreword

When we began working on this project, we knew we were at the start of our journey.

We knew going in we would have to face difficult conversations and honest truths about our own privilege, mistakes we have made, and about the things we didn't know or understand. Chances are, despite our best intentions, we will misstep or misunderstand again in the future. For this, we are truly sorry.

It's not appropriate for us to hold ourselves up as authorities in this field. Our intention is to start an honest dialogue about the impact that poor equity, diversity, and inclusivity has across all aspects of healthcare – from early-stage research, to diagnosis, disease management, and ongoing support – and how healthcare communications can play a role in helping to redress that imbalance. We strongly believe healthcare communications and advertising can help: not just our industry, but across healthcare, and across society as a whole.

Looking for solutions and opportunities to progress is critical. But, initiatives that aim to increase equity, diversity, and inclusivity are meaningless if they are not by and for those with lived experiences.

So we're using this platform to amplify their voices, and highlight the relentless work that they're doing to help drive change.

The more we have spoken to committed people who invest so much of their time addressing some of the inequalities in healthcare – doctors, patients, caregivers, researchers, students, charities, marketeers, and beyond – the more we have realised it will take all of us, working together, to create lasting change.

From the experts we have engaged with to shape this piece, to the writers and creative talent who have helped bring it to life, we have worked with as many different people as possible with lived experiences to create a more diverse, more inclusive, and more human product.

Thank you to everyone who agreed to be involved with this project and who has been so generous in sharing their perspectives, their stories, their passion, and their talent.

We hope you stick with us as we continue to learn and grow.

> **“Nobody’s starting in the same place when you’re talking about diversity and inclusion. It depends on your personal life experiences where you’re starting on that journey.”**

– Jeevan Virk,
Advanced Accelerator Applications,
a Novartis Company

Stories matter.

They bind people together, create a sense of connection, and engage our thoughts, emotions, and imagination all at once. They show us other people's perspectives and let us imagine what it is to live other people's lives.[1,2]

The more we researched the facts and data around equity, diversity, and inclusivity in healthcare, the more impossible it became to separate them from the stories they represented. In healthcare, a lack of equity, diversity, and inclusivity (ED&I) exposes real vulnerability.

Everyone knows what it feels like to sit in a doctor's office or waiting room, worried about what is going to happen next.

As human beings, we are all either consciously or unconsciously biased. Our bias is shaped by our own experiences and perspectives, and affects how we interpret the world around us.[3,4]

Working in healthcare doesn't prevent this – everyone has implicit bias, no matter how well-intentioned they are or how much they try to avoid it. A systematic review of 42 studies of implicit bias among healthcare professionals (HCPs) found doctors and nurses manifest biases to the same extent as the general public – in response to characteristics as varied as race/ethnicity, gender, socioeconomic status, age, mental illness, weight, disability, drug use, and social circumstances.[5]

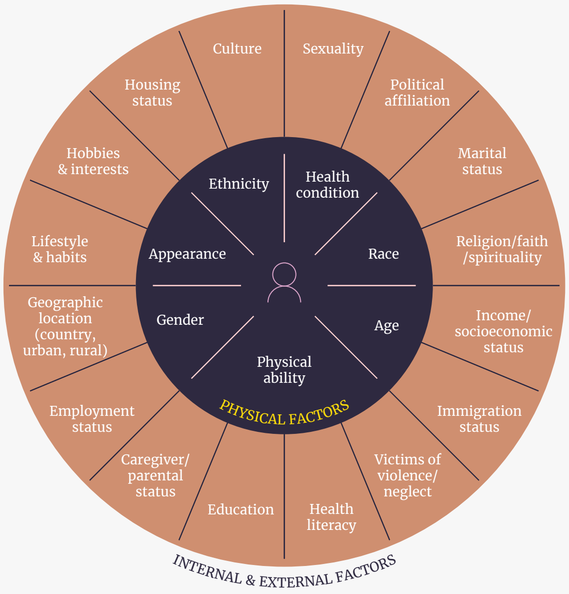
The World Health Organization (WHO) has set 'leave no one behind' as its guiding principle for the 2030 Sustainable Development Agenda,[6] and more and more companies are making ED&I a priority.[7–13]

Interweaving systems and intersectionality

There are multiple systems and structures at play globally, such as power, economics, politics, and legislation – shaping policies, culture, education, access, available funding, and technology, which can lead to biases on an individual level. This results in a lack of ED&I within healthcare, and ultimately poorer outcomes for patients.[13–17]

Many of the categorisations that shape society and lead to marginalisation or oppression are complex and interconnected and need to be considered together – this is why taking an intersectional approach is so important. For example, there is a close relationship between inequality and poverty. While economic growth is an essential factor for poverty reduction, inequality can significantly limit this process. Inequality impairs the quality of relations in the public and political spheres of life and impairs the sense of realisation and self–esteem of people.[18]

The Intersectionality Wheel: external, internal, and physical factors intrinsically connected with ED&I



> **“Intersectionality is key: politics influence all, we can’t do it alone.”**
>
> – Dr Hannah Barham-Brown

Yet, inequalities associated with social, cultural, education, gender, ethnicity, religion, and age persist within healthcare.

From the 50% greater risk of adverse drug reactions seen in women compared to men,[19] to the huge and unacceptable discrepancies seen in COVID-19 deaths in ethnic and racial minority groups in the UK and US,[20] to the reluctance to collect data on sexual and gender identity even when it could have a direct relevance to patient outcomes;[21] inequalities in treatment and care are part of the landscape facing those working in the healthcare space.

While we may not be able to fully overcome our personal biases, we can strive to be aware of them and limit their impact on our work and on others.[22] As we move from a patient-centric to a person-centred approach to care, human connection is fundamental to ensure that fewer patients are left behind.[23]

The people we have spoken to for this project show that by entwining humanity and healthcare together more closely, it is possible to reach more people, bring effective medicines to market, support more patients, and improve both commercial and clinical outcomes.[24]

> **“Don’t just look at me as a transaction, but see where there is an opportunity for the brand to build a relationship, an understanding, and trust. There is a tremendous opportunity for healthcare brands right now.”**
>
> – Aurora Archer, Bellatrix Group

One of the first people we discussed this project with told us that if the industry strove to make ED&I a priority, it had the potential to “deliver results beyond the imaginable”.

We agree.

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**Health
For All**

Dr Christine Ekechi

Dan Hett

What if no one
was left behind?

Dr Christine Ekechi

Dr Christine Ekechi is a consultant obstetrician, gynaecologist, and co-chair of The Royal College of Obstetricians and Gynaecologists' (RCOG) Race Equality Taskforce. The Taskforce addresses the ongoing disparities in health outcomes experienced by Black, Asian, and minority ethnic girls and women within the UK.[1]

> "Being a doctor should include supporting the patient as an individual,"

says Dr Ekechi. "Regardless of race, gender, or sexual orientation, the best doctors connect with the individual in front of them to deliver the best care. Although I think it's ridiculous that in 2021 we still have to recognise that differences in how individuals are treated in society and in medicine exists."

Through her work, Dr Ekechi is striving to address the gender and racial data gap within healthcare, which in her words has "terrifying implications on the care some people receive".[2]

Systemic bias and inequalities run throughout the pharmaceutical and healthcare industries, informing and reflecting each other, and reducing the quality of care that patients experience – these disparities don't just exist in niche conditions and rare diseases.[3]

Heart disease is the leading cause of death for men and women globally.[4] It effects both sexes equally, and despite common misconceptions, key heart attack symptoms do not differ between men and women.[5] Yet, women are 50% more likely than men to be misdiagnosed following a heart attack,[6,7] and were found to make-up just 34% of participants across trials for 36 drugs to treat cardiovascular disease.[8]

Dr Ekechi notes that in a recent investigation, "women were three times more likely to die from a heart attack within the first year of the study, compared to men in the same study". This discrepancy was due to bias in the way that female patients were being treated.[2]

"Researchers discovered that women were not receiving the same recommended treatment as men, in part because of the incorrect assessment of the severity of their symptoms. More often, chest pains in women were deemed not as severe as the symptoms experienced by men, and less likely to represent a heart attack."[2]

> "Clearly the doctors were wrong."[2]

It is clear there are many spaces in healthcare today where we need to champion humanity and compassion. "Through increased awareness and education of the need for cultural sensitivity and competency in healthcare, we can better understand our patients and provide better patient-centric care", explains Dr Ekechi.

When patient concerns go unheard, it has a detrimental effect on our understanding of adverse outcomes and our ability to follow up long-term. More critically, having their worries dismissed can leave patients feeling abandoned or ignored by the health services that should be designed to serve them.

Women’s pain reports are taken less seriously, they are less likely to receive an escalation in treatment, and they are more likely to have their pain reports discounted as ‘emotional’ or ‘psychogenic’, and therefore, ‘not real’ compared to men.[9] An inquiry into the use of three interventions (sodium valproate, pelvic mesh implants, and hormone pregnancy tests) found that patients’ suffering and complaints were ignored by clinicians due to the widespread labelling of many symptoms as ‘normal’ or ‘women’s problems’.[10]

This bias and trivialisation of women’s experiences fuels the gender gap in care provided, and widens further when racial bias is also involved. Black women are five times more likely to die in pregnancy, childbirth, or in the six-month postpartum period compared to White women – with Asian women facing twice the risk.[1]

This is just one example of the inequalities that Dr Ekechi and Race Equality Taskforce are hoping to address – ethnic disparities in mortality are also seen in breast cancer and cervical cancer, worse outcomes are noted following fertility treatments in Black women,[11] and there are countless other examples from multiple fields of research.[1] As a first step, the Taskforce has released a campaign called ‘five steps for healthcare professionals’, with five simple actions that healthcare professionals (HCPs) can take to end these inequalities.[12]

“We’re working to address inequality in healthcare and within our policy and processes in the Royal College of Obstetricians & Gynaecologists.” Through her work, Dr Ekechi seeks to create a platform for women’s experiences, from which gender and racial gaps can be addressed.

> “We want to help a new generation of doctors think more widely and diversely, to be more inclusive. Through teaching and increased awareness, we can reduce inequality not only as it pertains to maternal mortality, but throughout a woman’s life arc. From young adolescent girls to post-menopausal life. We shouldn’t forget women after the menopause who have been left out of the conversation for a long time.”

These changes need to occur for patients throughout their treatment journeys – and even starting with clinical trials, there is more that can be done to close these gaps.

> “Through teaching and increased awareness, we can reduce inequality. Not only as it pertains to maternal mortality, but throughout a woman’s life arc. From young adolescent girls to post-menopausal life. We shouldn’t forget women after the menopause who have been left out of the conversation for a long time.”

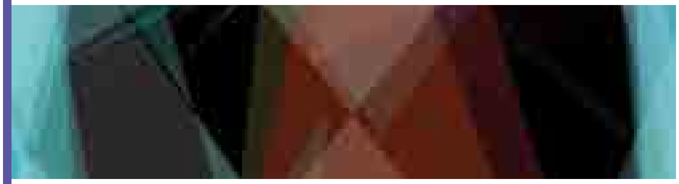
– Dr Christine Ekechi

There are signs that things may be improving. More and more companies are starting to take steps to improve diversity within their research and beyond. AstraZeneca have identified the need to improve diversity in clinical trials as imperative to driving ‘equitable access’.[13] Johnson & Johnson pledged $100 million to address racial and social injustice in public health, including initiatives on increasing access and participation in trials.[14] Eli Lilly and Company set out criteria to ensure their goals to improve diversity in clinical trials were being met, and reported recently that the proportion of minority patients enrolled in the US is close to reflecting the US population.[15]

Some companies are even taking things a step further. Despite facing challenging timelines and competition, Moderna, Inc. slowed recruitment for a Phase III trial for their experimental COVID-19 vaccine to ensure the COVE study recruited a diverse population. At the end of the study, the proportion of Hispanic or Latinx and Black or African American participants enrolled was similar to the proportion captured in the US census – so more of the public could identify with, and hopefully trust, the results.[16]

Governments and regulatory bodies are also starting to act. In March 2021, the UK Government launched a call for evidence to improve the health and wellbeing of women,[17] while in the US the FDA has published guidance on how to enhance diversity in clinical trials. The guidance emphasises enrolling broad, clinically relevant populations without exclusions based on age, gender, sex, race, and ethnicity.[18]

With HCPs, the pharmaceutical industry, and governments working together, we can build healthcare systems that are more effective for everyone.



> **“The solutions to preventing unnecessary harm require a committed collaborative effort between clinicians, government, and women to ensure that the gap in health outcomes is eradicated.”**
>
> **– Dr Christine Ekechi**

Key considerations

1. **When defining patient populations, do you see disparities in diagnosis or treatment escalation?**
   - What proportion of patient populations are being marginalised or missed?
   - What role can pharma play in supporting HCPs to identify, acknowledge, and act on bias?
2. **Patient centricity guides everything that we do in healthcare, so how can we better support each and all patient populations?**
   - How can we work towards creating a space where every patient population’s concerns and worries are heard?
   - How can we encourage a more open patient-HCP dialogue, one where individuals feel empowered to drive for earlier diagnosis or treatment escalation?

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Health
For All

Professor Andrew Biankin

Lewis Khan

Professor Andrew Biankin

Professor Andrew Biankin is the Regius Chair of Surgery and the Director of the Wolfson Wohl Cancer Research Centre, which is focused on precision oncology. He has leadership roles in national and international consortia in cancer genomics and therapeutic development. His work is currently focused on implementing Precision Oncology Practice in Health Systems internationally.

> "We now understand that diversity on a genetic level can impact on how therapeutics affect patients, whether through toxicity and side effects, or whether through efficacy,"

explains Professor Biankin, "and now we're getting closer to understanding those differences from a biological level, it will help advance the next wave of treatments and how we administer them."

20% of the drugs approved between the years 2009–2015 showed differences in exposure and/or response across racial or ethnic groups, leading to special guidance on prescribing for certain populations.[1] For example, in non-small cell lung cancer, tyrosine kinase inhibitor EGFR mutations are more common in the Asian population.

Around 30–40% of Asian people with non-small cell lung cancer have an EGFR mutation making them eligible for targeted treatment with EGFR inhibitors, compared with just 10–15% of Caucasian people.[2,3]

But, 'race' is an imprecise term and this can pose a problem. In the clinic, race may be used as a 'diagnostic shortcut' for stratification purposes.[4] Grouping people along the lines of geography, language, and self-identified faiths can produce equally significant associations on a genetic level.[4] It is the influence of genetic factors on a multitude of characteristics that accounts for 20–95% of the variability seen in response to individual drugs.[5,6]

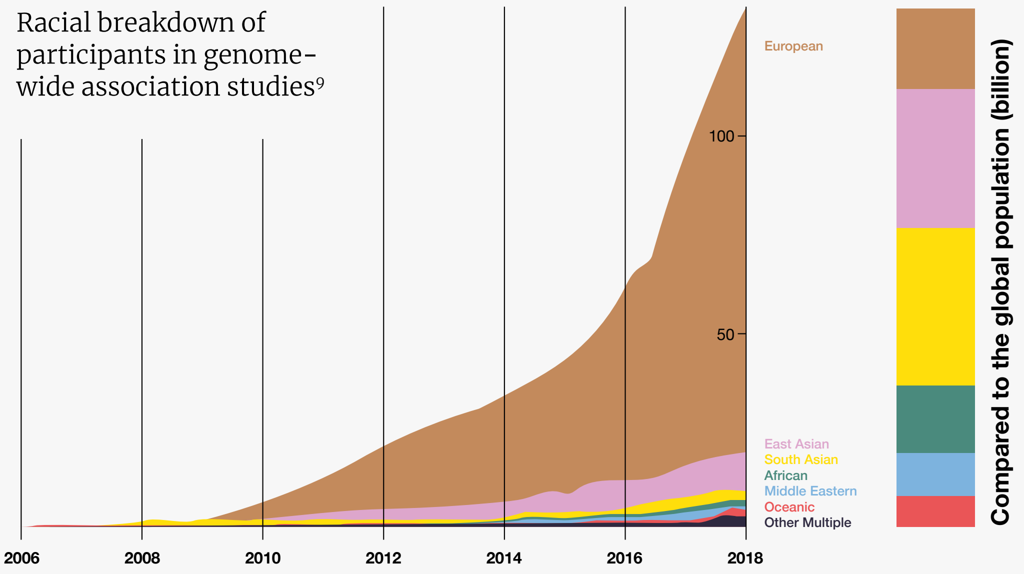
For Professor Biankin, diversity is essential for ensuring that we understand what is happening within the individuals we are trying to treat. "On one hand, as scientists, we see diversity and inequalities causing us issues. But when we are trying to enact precision medicine, we're looking straight towards diversity and we want to see all those differences between individuals and what they mean."

Precision medicine uses differences in genetic factors to maximise efficacy and mitigate the risks of pharmacotherapy – essentially enabling the selection of the right drug, at the right dose, for each patient.[7] It has the potential to improve outcomes and reduce wastage caused by a lack of efficacy and has been the source of considerable investment over the last decade. Spending on precision medicine has increased 30% yearly between 2008–2018 compared to a 1–2% increase for traditional drugs.[8]

If precision-based medicine was more widely available, it could free healthcare professionals (HCPs) from making ‘diagnostic shortcuts’ based on race.[4]

Precision medicine is powered by data. “When we look at toxicities in a clinical trial, you might get one severe set of toxicity that’s related to a variation in the genome. But these are the sorts of questions we’re not going to address easily with the range of cancers that we’re seeing. It’s only where we have a significant chunk of the population that are similar that we can detect those signals. Otherwise, without enough people, we don’t see them”, explains Professor Biankin.

However, although people of European descent make-up 16% of the global population, they make-up an incredible 79% of the participants in the genome-wide association studies used to inform disease risk and precision medicine.[9]


Racial breakdown of participants in genome-wide association studies[9]

Adapted from Martin AR et al. 2018.[9]

Part of the appeal of precision medicine is that it allows treatments to be tailored to individuals. To become a clinical reality, however, differences between people must be factored in. “If you are looking at a population where you’ve got no idea what’s happening, and you’ve got all these differences going on everywhere, you might get it right every so often, but in general it’s not going to work”, explains Professor Biankin.

Looking at the woeful diversity in genome-wide association studies, it’s apparent that widening participation in research could not only improve access to treatments among underserved groups, it could also improve the quality of the research outputs.[9]

This is something that Professor Biankin is considering within his work: “Through organisations like International Cancer Genome Consortium, we’re starting to disseminate information in multiple different languages, because if we’re not looking at a whole population we can’t understand which populations it is impactful in or not.”

> “The elephant in the room is the socioeconomic pieces. One of the key drivers is about democratising access to precision medicine.”

– Professor Andrew Biankin

Diversity in clinical research means thinking about more than language. It requires an understanding of patient mindsets within a larger context of culture, gender, ethnicity, religion, and socioeconomic realities. It's an obstacle for drug development and clinical trial recruitment. Bristol-Myers Squibb invested $150m to extend the reach of clinical trials to underserved populations in the US, by training trial investigations and medical students, and working within communities to build trust and participation.[10] So far, $11m has been awarded, with 16 grants dedicated to increasing diversity among clinical trial participants and research fellowships.[11]

"If nobody in your family or nobody in your community participates in clinical trials for cancer or any disease, any treatments that are developed may be biased against you – and that's an important thing to understand", says Professor Biankin.

Strategies for widening participation in clinical trials are starting to gain traction. Perhaps the most fundamental is to engage participant advisory groups to represent patients of different demographics involved, and thinking beyond traditional trial sites and locations. Beyond community outreach, people from marginalised communities should have opportunities to act as study staff and clinical trial investigators.[12,13]

Relationships between study staff and participants require a certain level of trust – so good communication, transparency, and simplicity are key. Running virtual – or partly virtual – trials can make participation easier for patients with limited access to tertiary care, while advances in telemedicine can free up staff to focus on relationship building. Putting the patient experience front and centre in clinical trials could revolutionise trial design, retention, and recruitment, and transcend historic barriers to participation (see www.patientcentricityontrial.com for more information).

> **"Working in oncology, that's something that affects everybody. Cancer doesn't discriminate. And going back to defining diversity, there are so many different factors, groups, and items that could be considered diverse."**
>
> **– Ryan Billings, GSK**

As well as the ethical and economic arguments for widening participation in trials to include underserved or marginalised populations, there is also a practical reason: to reflect the make-up of patients in the real-world. This is where real-world evidence can complement clinical trials.

"The question is, how do you harness that real-world data rather than doing it in a Phase IV clinical setting, which is going to add to the cost of therapeutic development? How could you do that in the real-world? It would save money and allow more people to have access to the drug." This exciting development is something that Professor Biankin sees starting to take shape in multiple organisations: "Roche has a real-world data team. Novartis has a real-world data team. IQVIA has a real-world data team. All the big players in the world are all over it."

The proof of concept for precision medicine is in place, but to advance further health disparities and data gaps across populations must be addressed.

> **“If you look at a system where you understand all this diversity as it flows, then we might have some chance of answering these questions.”**
>
> – Professor Andrew Biankin

Key considerations

1. **How can the work we do recruiting for research impact the make-up of future clinical trials? What impact does this have on access to treatment following approval and launch?**
   - Are there tools, materials, or partnerships that could support pharma and HCPs in reaching larger, and more diverse, patient groups?
   - What part can we play in making healthcare and participation in research more accessible to underserved groups?
2. **Are your studies representative of the population living with the condition you’re interested in?**
   - Are there data gaps or clinical questions that real-world evidence can help address?
   - Are there opportunities to capture and visualise real-world data to create a more complete picture of patients, conditions, and treatments that are more representative of the global population?
   - How could this data be leveraged to benefit teams like commercial, access, or medical?

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Professor Eleanor Stride

Marylou Faure

Professor Eleanor Stride

Professor Eleanor Stride is Statutory Professor of Biomaterials at the University of Oxford's Institute of Biomedical Engineering. Her research focus is on drug delivery systems engineering and biomedical ultrasonics, and her new projects have applications in women's health. She was awarded an OBE in 2021 for services to Engineering.

> "There is really good evidence that accommodating greater diversity and the needs of women is beneficial for everyone,"

says Professor Stride. "Not only from an ethical and moral standpoint – but there's huge commercial potential too."

'Women's health' has traditionally been preoccupied with sexual and reproductive health – but most death and disability among women is caused by non-communicable diseases.[1]

Professor Stride believes addressing conditions in 'women's health' (a broad term that covers both female-specific health issues and diseases that impact women more severely) is in everybody's interest: "If you think about the impact these diseases have on women as individuals, and also on the working population and the economy, why wouldn't you try to address them? There are strong financial drivers."

One area of growing interest in Professor Stride's work is urinary tract infections (UTIs). UTIs affect only 14% of men, but up to 60% of women in their lifetime, and disproportionally affect post-menopausal women.[2–5] Despite being one of the most common bacterial infections occurring globally, affecting approximately 150 million people each year,[6] UTIs can be challenging to assess and difficult to treat.[7]

Failing to invest in understanding and treating this 'women's issue' is a missed opportunity for many reasons. UTIs are not only one of the most common infections in women, they are also the second most common trigger for antibiotic prescription (after respiratory tract infections), contributing to the ticking time bomb of antibiotic resistance.[8]

"UTIs cause a miserable existence at best, and at worst cause sepsis and contribute to the antibiotic resistance crisis," says Professor Stride. "We've submitted a grant application on antibiotic resistance in UTIs because it's a huge problem, especially in South East Asia and Africa"

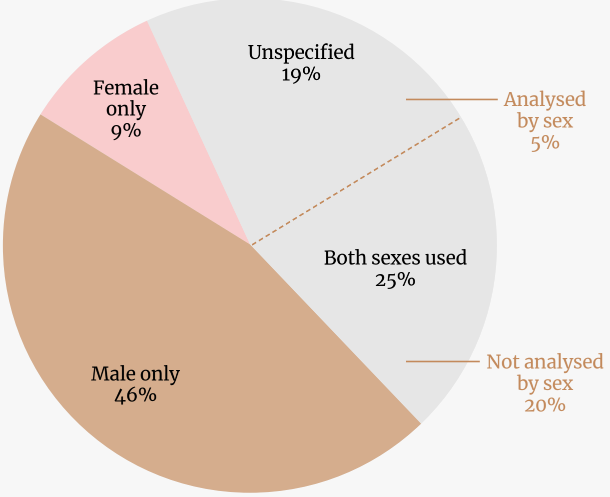
> "'Ignored' is an understatement."

This apathy has manifested as difficulties in securing funding for her innovative research. "My team has struggled to get funding for our research on UTIs, and a male urologist surgeon I work with said, "You know why this is? It's because it's a 'women's disease'." And he's persuaded me, unfortunately, that's the case, which is shocking."

Women are not a minority demographic. They make-up 49.6% of the world's population, and 38.9% of the world's labour force, but many conditions that primarily affect women lack research funding and investment.[9–12] Less than 2.5% of publicly funded research in the UK is dedicated solely to reproductive health, despite 1 in 3 women suffering from a reproductive or gynaecological health problem.[10] Women also consume 80% of the pharmaceuticals in the US – so ignoring their needs,[11] or the importance of sex as a biological variable,[13] doesn't make sense.

Gender bias in medical research begins before a drug is ever tested in human subjects. The majority of animal studies are conducted using all male mice – in neuroscience, studies of males outnumber studies of females 5:1, and only 20% of studies used both sexes.[14]

Inclusion of male and female subjects in animal research



Adapted from Beery. 2018.[14]

The assumption is that female mice are too 'variable' due to hormonal fluctuations, and including them would render study results uninterpretable.[15] As a result, even disorders that are twice as prevalent in women as men (like depression), have animal models developed for male mice, often with the justification of simplifying the research, and avoiding unnecessary costs.[14]

While the logic of reliance on male-mice-dominant medical research is easily refuted[14] (in fact, male mice show greater hormonal variability than females[16]), it could also be argued that not including females in preclinical or early phase research is a false economy. When trials are not powered to analyse sex differences, disparities can be missed.

From 1997–2000, 8 of the 10 drugs withdrawn from market were pulled because they posed greater health risks for women

– risks only identified after they had gone to market, as a result of surprising adverse events or harmful trends in prescribing.[17] The 'female Viagra', flibanserin, was initially tested in 23 men and 2 women. It became apparent, following the drug's release, that taking it while consuming alcohol could increase the risk of losing consciousness – but only in women.[18]

Given that the cost of developing a new medicine is nearly $4 billion, and can even exceed $10 billion, withdrawals on this scale represent not only a substantial health risk, but potentially wasted investments of between $32–$80 billion.[19] And, for every withdrawal, there are countless lives impacted – women fighting against dismissive attitudes, feelings of guilt, or hopelessness and family disruption.[20]

> **“I’m also a nurse, and I’ve been in pharma a really long time. It’s always been predominantly male. It’s always been skewed and male driven. It was always the good old boys and eventually that has started to change.”**
>
> – Jennifer Yessaian,
> Advanced Accelerator Applications,
> a Novartis Company

A review of 43,135 published articles and 13,165 clinical trial records identified female underrepresentation in 7 of 11 disease categories – including HIV/AIDS, kidney diseases, cardiovascular diseases, neoplasms, digestive diseases, neurological disorders, and hepatitis.[21] One explanation for this disparity is that healthcare providers may not always take women's symptoms as seriously as men's – so they may not be viewed as 'sick enough' to participate in a clinical trial.[22]

For Professor Stride, there is potential to increase our understanding of women's health generally, opening up avenues of research and commercial opportunities that have been closed until now.[22]

> **"We hear 'oh, it's one of those things' – it really isn't! There are ways of dealing with it and as a society we need to do more."**
>
> **– Professor Eleanor Stride**

Key considerations

1. **What are the gender differences in the therapy areas you work within? When focusing on a specific disease, do you know if the level of incidence is higher amongst women vs. men?**
   - Are there opportunities to develop bespoke communications that engage with each group based on their specific needs?
   - How can we use HCP training or patient education to help tackle gender-specific barriers to prescribing?

2. **How can we better understand the impact of hormones on drug development and treatments?**
   - What impact could the inclusion of women in the early stages of research have on greater drug efficacy and safety across wider population groups?
   - How can pharma and HCPs work together to move from the generic 'women's health'/ 'women's issues' terms to a language that focuses on each disease individually?

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Rainbow Café: Jacob Bayliss & John Hammond

Jacob Bayliss & John Hammond

The Rainbow Café is an initiative from Switchboard, a well-established charity in Brighton and Hove. Jacob Bayliss is the charity's Chief Executive Officer and oversees Switchboard's activities.

John Hammond oversees the Rainbow Café, a project for the LGBTQ+ community affected by dementia or memory loss and their caregivers.

> "My experience of dementia began because my mum was diagnosed with Alzheimer's disease; from 2015 to the end of 2018, I was her caregiver,"

explains John. Like a lot of other caregivers, he wasn't making a choice but took on that responsibility by default.

"I saw the whole process – from prior to the diagnosis maze itself and the complications it can entail. When she was formally diagnosed with Alzheimer's disease, there was always a question mark over the accuracy of this diagnosis. By the time it was possible to do more exploration, she wasn't well enough to go through the diagnosis process again."

Alzheimer's disease is the most common subtype of dementia, but diagnosing it can be notoriously difficult.[1] It has an insidious onset that may be mistaken for memory loss due to 'normal' ageing, along with a range of other presenting symptoms (such as finding words or making decisions), and the absence of a widely available 'cure' for dementia may slow the drive to diagnose further.[1]

The World Health Organization (WHO) estimates that there are some 50 million people around the world with dementia. Every year there are nearly 10 million new cases, with ageing populations creating a global dementia epidemic.[2] Dementia research is now considered a public health priority.[3]

For families, dementia can cause considerable disruption and distress.[2] In John's mum's case, one of the ways this manifested was frequent falls and trips to the accident and emergency department (A&E).[4]

"She hit her head at one point and fractured her elbow at another. So she had to go to A&E. If you're living with cognitive impairment and you're sat in A&E for 10 hours while you're waiting for somebody to help you, 10 hours feels like a lifetime. For caregivers, trying to comfort someone for hours and hours in waiting rooms can be devastating."

John started volunteering with the Alzheimer's Society to give back and became passionate about ensuring the voices of diverse groups were heard.

> "But if you're living with cognitive impairment and you're sat in A&E for 10 hours while you're waiting for somebody to help you, 10 hours feels like a lifetime."

> “I found the research didn’t really investigate the inequity and the diversity of different communities, and as a gay man who was a caregiver for my mum, I experienced bias and discrimination. It sparked a passion in me to understand that and start to redress it within my own local community.”

Estimates suggest there are around 25,000 LGBTQ+ people in the UK currently living with dementia.[5–8] Given the reluctance that people can feel disclosing their sexual gender identity, the true number is likely to be higher.[9]

For Switchboard, Jacob Bayliss believes that recognising and understanding the needs of the older members of the community and providing appropriate services, such as the Rainbow Café, is critical. Even well-intentioned activities can have the potential to cause pain and stress.[10] Reminiscence therapies are often done in a group or in residential settings and aim to improve memory by evoking events from the past.[11] “We’ve found for a lot of LGBTQ+ people, that reminiscence doesn’t chime with them,” explains Jacob. “For example – remembering the dance halls, guys on one side of the room, girls on the other side, and going to ask someone to dance. It’s lovely, but for LGBTQ+ people those memories may not be positive – taking them back to a time when they would be keeping this big secret or maybe didn’t feel safe, or if they are trans they may have been struggling with dysphoria. It can be distressing.”

“For a lot of older people, they almost feel like they’ve had to go back in the closet, particularly using some of the more mainstream services. So we try and break the mould. We take our older people’s project out for cocktails, brunch, and things like that because we got a lot of feedback such as,

‘Please don’t take us to the village hall for biscuits and tea. Please take us to a drag night. Please take us for cocktails.’

And we are more than happy to do so because it helps people feel seen and feel queer.”

Dementia places considerable stress on families, as well as the people living with the condition. The progressive nature of the disease means that decisions and advanced care planning should happen in the early stages of the disease.[1] However, this may not always happen as frequently as it should.[12] In Jacob’s experiences, family structures can look different for a lot of older LGBTQ+ people:

“There are very few people we work with who have children or maybe they haven’t gotten married because that wasn’t available to them for a long time. So we help people think about who is your logical family, who’s your chosen family, and how do you care plan with that structure instead of the nuclear or extended family structure people assume is the default?”

Recognising that these family structures and other nuances demand cultural competency and sensitivity from healthcare providers.

“People living with chronic degenerative conditions are going to be touching health services at lots of different points and requiring hospital admission.” But John believes more needs to be considered to create a positive experience for the LGBTQ+ community. “Going into A&E can be a very different experience for someone who is maybe trans and living with dementia, and having to decide which ward to access.”

For John, acting as a touchpoint for people as they navigate memory clinics and hospital visits is one of the benefits of running a service like the Rainbow Café.

> “Unlike other chronic conditions, you don’t have one designated person to see you through your journey. Over the years we probably saw around 15 different social workers, plus neurologists, GPs, occupational therapists, physios, but no one person to see someone through their entire experience. That’s one of the Rainbow Café’s central aims: to offer a source of support.”

– John Hammond

Although there is no cure for dementia, increasing evidence shows that it may be preventable. Earlier recognition of and intervention for modifiable risk factors can reduce the number of people developing dementia in later life.[1]

Some of these risk factors – such as depression, isolation, and stress – can disproportionally affect the LGBTQ+ community. But they are modifiable risk factors. Looking only at the variables, social isolation and stress have the potential to reduce the risk of dementia in later life by around 8%.[13]

A final factor that may contribute to the risk of dementia among sexual and gender minorities in later life is the impact of lifelong minority stress. Although its full impact is not yet fully understood, prolonged exposure to the stress hormone cortisol is thought to be associated with damage to dementia-sensitive neural networks.[14] Minority stress and its links to dementia can be seen further in discrepancies between Black and White people exposed to midlife stressors.[15]

Discrimination and internalised heterosexism predict poor general health for older members of the LGBTQ+ population and can increase the risk of angina, arthritis, congestive heart failure, diabetes, heart attack, high cholesterol, hypertension, osteoporosis, and stroke experienced over the age of 50.[14] Yet patient support or educational programmes almost never consider sexual orientation or gender identity.

> “Healthcare is set up for the majority, but the minority are still entitled to the best possible quality care.”

Changing this is something that John believes is critical for creating a more inclusive society.

"What will often happen is people will talk about 'them' meaning 'those people living with dementia' and lump people together. But all of them are living very individual lives and from all parts of our society. There's a kind of new momentum gathering. And while it's gathering, it can also gather parts of the community that are living with dementia. And I think the work of the Rainbow Café does that."

> **"Dementia is a very human story, as all chronic conditions are, and I think that's what healthcare can sometimes lose sight of… it's a human story."**
>
> **– John Hammond**

Key considerations

1. **How can pharma and HCPs work together to provide a positive healthcare experience for the LGBTQ+ community?**
   - What services and tools can be used to connect all healthcare touchpoints and provide a holistic approach to care?
   - What training and content can be developed for caregivers to better support them?

2. **When thinking about patient support strategies and materials, do you know what the needs are of the LGBTQ+ community you're trying to serve?**
   - Can we gather feedback from the community to evolve the established support systems operating today? Are there opportunities for partnership with patient advocacy groups to make this a reality?
   - How can communications help empower patients to adopt intervention strategies for modifiable risk factors? Are there opportunities for educational materials to help promote awareness and prevention?

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Health
For All

Shiron Rajendran & Samrah Ahmed

Hawwa Alam

Shiron Rajendran

Shiron Rajendran, when we spoke, was a second year medical student at the University of Southampton. When the UK went into lockdown in March 2020, he was alarmed at the vast amount of misinformation that was being spread about COVID-19 on social media, particularly amongst non-English speaking communities. Together with doctors and volunteers, he created the COVID-19 Infographics Project, to summarise government guidance into an accessible and reliable format to support his own Tamil-speaking community.

> “
> A huge proportion of the UK’s population speaks an additional language and for a lot of the population, English isn’t their first language. Our mother tongue is Tamil, so we would often get random social media messages regarding COVID-19 in our own language, and most of the time it would be fake news.”

Explains Shiron.

The global pandemic has provided a stark illustration of how language barriers can cause significant challenges to providing effective and high-quality healthcare. People are desperate for information to help them better understand more about COVID-19 and this led to a rapid spread of false, and sometimes dangerous information on social media, particularly in non-English speaking communities.

In September 2020, WHO, UN, UNICEF, UNDP, UNESCO, UNAIDS, ITU, UN Global Pulse, and IFRC issued a joint statement highlighting the need to limit the spread of misinformation (the ‘info-demic’), because ultimately, it was costing lives.[1]

As the pandemic developed, it became apparent to Shiron and his team that the spread of misinformation was dangerous: “At first, the messages seemed almost comical, and we thought surely no one believes this. But the more messages we received, the more worried we became. We knew this misinformation was negatively impacting the opinions of community members and shaping their view of the pandemic.”

This is a huge concern given the diversity of the languages found worldwide. In the UK alone, approximately 4.2 million people speak a language other than English when at home.[2] In the US, over 67 million residents do not speak English at home;[3] this number varies across states, with 44.5% of California’s population using a language other than English.[4]

When it comes to medical information, English is the international language of education and research.[5] For non-English speakers, medical terminology is often considered one of the most difficult specialised languages to learn, involving complicated terms which seem difficult to sound, spell, remember, and even understand.[6]

The COVID-19 Infographics Project was established to help overcome these language barriers, minimise the spread of misinformation, and support the UK's multilingual community with reliable, highly visual, translated resources about COVID-19. The voluntary group made up of doctors, students, and translators have produced resources in more than 35 languages about numerous topics including self-care, face coverings, shielding, and vaccines.

"We didn't want to add to the massive pile of misinformation that's out there. It's easy to create content. However, if we got one thing wrong, then that would jeopardise the credibility that we have worked so hard to earn. We take official government guidance and summarise it, so there is little room for interpretation and less chance of making errors."

Information for these resources is taken directly from reliable sources such as government guidance documents, NHS, and Public Health England websites. The translated resources undergo strict quality assurance processes from both healthcare professionals (HCPs) and members of the public to ensure that information is represented in an easy-to-understand format. This feedback loop has allowed the team to gain invaluable insights which have helped them to refine their resources. By working closely with community organisations, the team were able to tailor their resources to specific community needs.

The translated material was checked by doctors and specialists to ensure that it was still medically correct, and shared at a public question and answer session for further feedback. This allowed the team to gain insights into how successfully they were conveying the messages so that they could refine the process.

The demand for the infographics grew beyond the Tamil-speaking community. "It really went from us providing resources in Tamil for our community in London, to getting messages from family and friends asking whether we could create things in Punjabi or Gujarati, or Hebrew or Arabic? We started with one translation and now produce materials in more than 35 different languages."

The project placed a real emphasis on building strong relationships with community organisations and leaders, who people trust and interact with on a daily basis. This collaborative approach proved to be a real asset when addressing some of the popular misconceptions around vaccine hesitancy.

> "Individuals from minority communities, especially from Black and Asian communities, have been disproportionately affected by the pandemic. Vaccine hesitancy has been a real concern for some people from these communities. At the root of the problem are mistrust and misinformation. People have very genuine concerns about the vaccine which must be addressed. People had heard stories that the vaccines were not halal or kosher and that it wasn't suitable for vegetarians. To address these concerns, it is really important to work with trusted and respected community leaders. Organisations such as the British Islamic Medical Association and the Muslim Council of Britain, have been working really hard to verify that these claims are not true, to support and improve vaccine uptake amongst their communities."

> “A warden at an assisted living accommodation told us how older members of the residence had come across a Gujarati version of our self-care graphic. It had helped them better understand what COVID-19 is and how to best look after themselves during the pandemic. We receive these kinds of messages and realise what we’re doing is really worthwhile.”

– Shiron Rajendran

Key considerations

1. **Are the patient populations you’re engaging with non-native speakers? How can we improve communications and reduce language barriers to avoid misinformation?**
   - When developing materials for patients, have you considered what language they prefer to communicate in?
   - What channels can be used to gain feedback from different communities? How can we better understand what works best for them, so that we can develop and adapt materials accordingly?

2. **Are there opportunities to make information more accessible for all patient groups?**
   - Can tools and services help improve health literacy and adherence amongst these groups?
   - Based on the therapy areas you work in, have you identified the communities, and community leaders, you could be reaching out to?

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Samrah Ahmed

Samrah Ahmed is a Medical Writer at Havas Lynx Group, and one of several writers involved with this project. She has worked in industry and has built extensive knowledge across several therapy areas. She wrote this story about her own experiences as a person with a second language inspired by, and in response to, Shiron's interview.

"It's a warm Autumn afternoon. Mum has just got back home from her doctor's appointment and has her newly prescribed medicine in her hand. I ask her how her appointment went. She says it was fine and hands me the medicine carton. She then walks over to her drawer to get her pen and notepad. She needs help understanding what medicine she has been given and how to take it.

Like a lot of the people living in the UK, English is not the first spoken language in our home.

I pick up the new medicine, open it, and take out the patient information leaflet.

I start to translate each section of the leaflet from English to Urdu. I see Mum scribbling away in her notepad, making sure she has correctly noted everything I have said on paper. This is her personalised patient information leaflet which she can easily understand.

She marks the indication of the medicine on the label of the carton so that she knows what it is used for.

With a warm smile, she takes out the piece of paper from her notepad, folds it up, and slots it inside the carton along with the medication and leaflet supplied. She is now confident on how and when to take her medicine.

> "
> This is a normal scenario in my home. Luckily, I am there to support my mum, but I do wonder just how many people are really struggling with their health simply because they don't understand how to take their medications properly?

And what impact does this lack of accessible healthcare information have on non-English speaking communities as a whole?"

Health
For All

Matt Eagles

Sebastian Curi

Matt Eagles

Matt Eagles has lived with Parkinson's since he was eight years old. A self-named positivity activist, he is Head of Patient Voice at Havas Lynx Group where he provides patient insight and ensures the patient voice is heard and represented across the healthcare ecosystem. He is a trustee for Spotlight Young Onset Parkinson's Disease, a small charity designed to help those diagnosed with Parkinson's under the age of 50 and is also one of the founders and the frontman of Parkylife, a platform initiated to challenge the unrealistic stereotypes of the disease. Matt is famed for not letting his Parkinson's get in the way of his life – he's jumped out of aeroplanes, abseiled from town halls, is an accomplished photographer, and completed a remarkable wing walk. He's a one-man Parkinson's myth-buster.

> "People automatically assume Parkinson's is a disease of old men,"

explains Matt. "And it isn't. It can affect any gender, any age, any ethnicity. Yes, it changes your life, but it certainly doesn't mean life is over. And yet we still have the stereotypical image of an old, hunched man with a cardigan and walking stick on Google, which is over 150 years old. And that has to change."

Matt knows first-hand that healthcare and healthcare communications need to reflect the world we are in today. Not only from a diversity angle but also from an equity angle.

"James Parkinson's 'An Essay on the Shaking Palsy' was written well over 200 years ago. It's outdated and the imagery we see online and on Parkinson's materials needs to reflect real people and real situations, otherwise the stereotypes continue to perpetuate. We all need deeper understanding or at least a more open mind of individual situations."

After all these years, we are still stuck in a one-size-fits-all approach to managing Parkinson's – and Matt thinks he knows why. "I think one of the big issues is we have a lot of history to try and change. There are a lot of institutionalised views and biases that have been formed over the years and have been normalised into society. This is why we created Parkylife."

> “The people with the condition have to be at the forefront moving things forward.”
>
> – Matt Eagles

Contrary to the cardigan-wearing old man who sits at the top of a Google search, the Parky community is a diverse bunch of people who have their own tips and coping mechanisms to overcome symptoms. They also have a uniquely positive and often humorous outlook on life, and for people who lack the 'happy hormone' dopamine, that can only be a good thing.

Parkylife is all about sharing that positivity, reversing that negative imagery, and celebrating the amazing people with Parkinson's who come from all walks of life. As Matt points out, when depression is twice as likely in the newly diagnosed, the need for a window of optimism is absolutely vital. And Matt certainly has an astonishingly positive mindset when it comes to managing his Parkinson's.

"There are good days and bad days of course, and I feel pain every day, and there are days when my legs just don't work. But there is no reason why we can't laugh about it all occasionally," grins Matt, "because symptoms can be so unpredictable and hard to control, you can end up in the most ridiculous situations. People see me staggering and wobbling around in the street, and quite frankly it looks like I'm blind drunk. So of course, they'll make assumptions and jump to conclusions, it's human nature. But rather than getting angry about it, I wear a t-shirt that says 'I'm not pissed, I've got Parkinson's'. It certainly gets plenty of laughs."

And that's exactly what Parkylife is all about. Not just seeing the funny side, but providing little slices of optimism, and to truly challenge the perception that people with Parkinson's are just elderly patients rather than people who still have lives to live. Doing this is critical if we are to tackle the agism and discrimination that people living with Parkinson's face, and step away from the 'one-size-fits-all' approach to care.[1]

And Matt says the response has been incredible.

> "People love Parkylife, and many have thanked us for totally reframing Parkinson's with humour and colour without ever diminishing the serious nature of the disease. And that's exactly what we wanted to achieve."

But Parkylife is not just about Parky People themselves. There have been contributions from healthcare professionals (HCPs), speech therapists, specialists, and Parkinson's nurses. In fact, it seems Parkylife is also a lifeline for carers too. Matt told us about a Parkinson's nurse who contributed to Parkylife, who had a particularly transformative experience: "She was actually considering leaving nursing until she came across this project – it inspired her to continue in the profession. That is incredible."

The warm insights at the heart of Parkylife, coupled with the bright positive artwork, seem to draw people in and encourage conversations. So much so, the Parkylife team receive constant requests to be 'Parky-fied' – people want to appear in the pack and on the website. As Matt points out, "Parkylife celebrates the positives in people. So everything is as bespoke as them. And that's a beautiful thing. There's no definition, no handbook. It's based on what somebody can read and how they interpret that."

> "
> A lady in Denmark burst into tears when she saw her card because it depicted her as a person who likes table tennis and works to help other people, and this is how she wants to be seen. She wanted to be seen as Elizabeth, not a Parky Patient. It's not about detracting from the serious nature of the disease, but simply showing the world who Parky People really are."

By lumping everyone into the same category, we not only miss vital insights that make creative work really shine, we also miss the personal perspectives of both patients and HCPs. In Matt's experience, celebrating these perspectives can help bring patients and their doctors closer together.

"It definitely works both ways," Matt explains,

> "
> Patients also have to listen, not demand. It's easy to expect too much of your healthcare professional."

Matt believes that levelling the playing field between patients and their HCPs can work wonders. "I think this is why I get on well with my neurologist. He was actually a registrar when I first met him and now he's a professor. But I respect him as a person first and foremost, and respect the fact he has other things to do in his life in exactly the same way that being a patient isn't necessarily my permanent state of mind. In fact, I only feel like a patient when I'm in a hospital. When I'm at home, I don't think of myself as a patient. I'm just me, having my tea."

Projects like Parkylife show us how we can communicate more effectively by focusing on what makes us people first, and 'typical patients' second. Strategies like this can help move patients, particularly older patients, towards an engaged and active approach to managing their disease and the broader ageing process.[1] However, coming face-to-face with reservations around person-centred care isn't unusual, and can be difficult to navigate.

As Matt explains, "It's often a stumbling point, but looking at Parkylife I do believe we can be open to anybody." This doesn't mean that there isn't a way forward. "For me it doesn't matter how you approach people, what matters is that point of realisation."

> **"We need to recognise that by making these changes, we can change peoples' lives for the better and help them feel better within themselves. That in itself should be motivating enough."**
>
> – Matt Eagles

Key considerations

1. **Are healthcare communications truly reflecting the world we live in today? Or are they helping reinforce stereotypes and biases?**
   - What have you learned from the people affected by the disease? Do insights match what the category is saying? Can you do something different that captures people's realities in an honest and human way?
   - How can patient support programmes go beyond a one-size-fits-all approach and adapt to individuals' needs? Are there opportunities for collaboration with patient advocacy groups or even friends and families of those affected by a disease?

2. **How can healthcare communications help connect HCPs with patients for an improved person-centred approach to care?**
   - What new forms of communication can be created with patients for them to feel engaged and driven to actively manage their disease? What should be the tone of these messages for them to be effective?

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Industry Insiders

Industry Insiders

We spoke to some of the pharmaceutical industry's key players and marketeers to understand how thinking more inclusively has shaped the way that they operate – and how it should continue to shape things in the future.

Aurora Archer, CEO of Bellatrix Group, a consultancy for the health and wellness industry, co-founded with Pamela Raitt. Aurora's experience in leading business transformation spans 25 years, seven of which she spent in healthcare. In 2015, Aurora led a team to win a Cannes Lions Grand Prix, with the first healthcare campaign to do so.

Pamela Raitt, an executive strategist with decades of design and digital transformation experience, who has lead teams across the US as well as in EMEA (Europe, the Middle East and Africa) and APAC (Asia-Pacific) to create centres of innovation.

Ryan Billings is a passionate customer experience leader in the healthcare space. He currently works at GlaxoSmithKline (GSK), where his focus is on oncology. He was voted one of PharmaVoice's 100 Most Inspiring People of 2020.

Florent Edouard, Global Head of Commercial Excellence at Grünenthal. After multiple local and global commercial roles, including four years in Japan at AstraZeneca, during which he led the Respiratory/GI franchise and achieved market leadership, Florent joined Grünenthal to implement their new commercial framework and strategy.

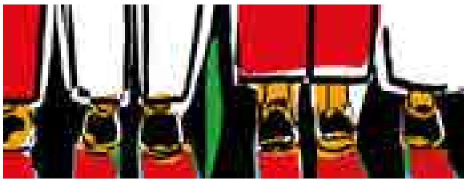
And Jeevan Virk, a Global Franchise Head at Advanced Accelerator Applications, a Novartis Company, where he oversees Neuroendocrine Cancer treatments.

> "This industry isn't like other industries in that change doesn't happen as easily."

Jeevan Virk says when we ask him about equity, diversity, and inclusivity (ED&I).

> "It's a really challenging topic. Nobody wants to say the wrong thing. But nobody is going to progress if they feel like they can't have a conversation about diversity and inclusivity."

Someone who is happy to have these conversations is Aurora Archer. She has been a vocal spokesperson for racial inclusion for the past 30 years. Before co-founding Bellatrix Group, a consultancy with ED&I at its centre, Aurora successfully built an inclusive digital transformation team at AstraZeneca, recognising that conscious efforts to become more inclusive reap great rewards.



"My role was to transfer my insights and my learnings to open people's hearts and minds, so that we could fundamentally make this world a better place. Where all of us could have an opportunity at that table." Aurora says. "I firmly believed that when you create a team that is multicultural and diverse, the performance, the insights, the empathy, and the outputs are much richer."

Striving to create more inclusive work, and inclusive work environments, can be motivation for some but it can also bring broader benefits. Research indicates that inclusive teams were found to be nine times more likely to innovate and succeed, ten times more likely to be 'highly effective', and five times more likely to provide excellent client or customer service.[1] In corporate settings, diversity within a workforce means it better understands the diverse consumer population and can create products and services tailored to them, leading to increased returns.[2]

For Florent Edouard, a global commercial leader, how companies approach diversity determines the size of the improvements they can make.

> "When it comes to making the big jumps you need to focus relentlessly on one fight at a time, make it super tangible for all, and give it your best shot. Then you need to build diverse groups of team members and run them through this deeply disruptive idea that they will be better if they are more diverse and inclusive."

It was this mindset that allowed Florent to champion diversity within his own team.

"When I came to Japan, I took a team that was 9% female with zero female managers." He explains. "I set ourselves an objective to reach a ratio of 50% females in the team, with at least 25% female managers." When we spoke to Florent, he told us before he left AstraZeneca females made up 50% of his team, as were 30% of his managers.

> "Things change only if managers are taking strong personal positions, put a stick in the ground, and commit to deliver tangible, measurable, diversity reinforcements. It then becomes easier to progress on other diversity challenges, like racial or LGBTQ+, in the specific case of Japan."

> **“The leaders of our future will understand how critical it is that we are all aware, from a moral and a commercial perspective.”**

– Pamela Raitt, Bellatrix Group

In the EU alone, health inequalities are thought to result in economic losses of €980 billion per year.[3]

> “This is a huge opportunity to turn transactional relationships into value exchange relationships that build trust.”

Says Pamela Raitt, who co-founded Bellatrix group with Aurora. “Even if we think about it purely from a product-launch perspective. The product will be launched for people, so we need to know who they are and what they need.”

Increasing understanding of important social and cultural issues, beyond differences between social and ethnic groups, is to increase cultural competency and acknowledging the bias that may happen while patients are being assessed and treated.[4] In response, there are calls for medical schools to educate around health equity and combating racism that teach trainees about the social determinants of health, policy, and advocacy. This would need to be provided alongside ongoing training on implicit bias and how disparities can be eliminated.[5]

For the pharmaceutical industry, this is an opportunity to provide more literacy, transparency, and education. As Jeevan Virk sees it:

> “That’s really taking a leadership position in a disease area, which adds tremendous brand equity.”

This brand equity can then be leveraged through brand planning and to sustain life-cycle management efforts.

Within branded healthcare communications, there are great opportunities to shape markets and shape the treatment landscape for the better. Through advertising, marketeers choose who they will promote – by digging into target patient profiles, potential pitfalls can be uncovered, opportunities discovered, and more nuanced understanding built.

Ryan Billings believes that technology could be a means to providing content that resonates more deeply.

> “I don’t think we’re ever going to be able to represent everybody, which is a shame because with targeting and technology today, you could essentially have custom content to anybody, including photos and messaging – so it’s possible to try.”

Claire Knapp, CEO of Havas Lynx Group explains: "If we as an industry are just showing a particular type of patient, a particular type of person, we are guiding doctors to the type of person they should be looking for. We need to think about real representative types of patients and how to reach them.

> "I think in healthcare, we shy away from showing sick people, from showing real people, from showing elderly people, which is crazy."

As we have heard time and time again, human connection is at the heart of healthcare, and critical for person-centred conversations. It is key to understanding someone's preferences and needs, for the pharmaceutical industry and its brands to connect and communicate authentically.[6]

> **"It comes back to authenticity. What are people with this condition doing or how do they live their lives? What do they look like? Let's have it be more representative."**
>
> **– Ryan Billings, GSK**

Key considerations

1. **How can we make our marketing communications materials more inclusive? What can be done to truly represent all patients who are affected by a specific disease?**
   - Can you help create educational materials for HCPs explaining how a disease's symptoms may vary across different patient groups?
   - Are there opportunities to incorporate true patient demographics into your photography selection process when developing brand assets?

2. **How can marketing teams create an environment of open collaboration? How can we consider and bring in multiple perspectives?**
   - Are responsibilities and opportunities for progression clearly defined and fairly established across teams?
   - What can be done in terms of recruitment and training to ensure your teams are diverse?

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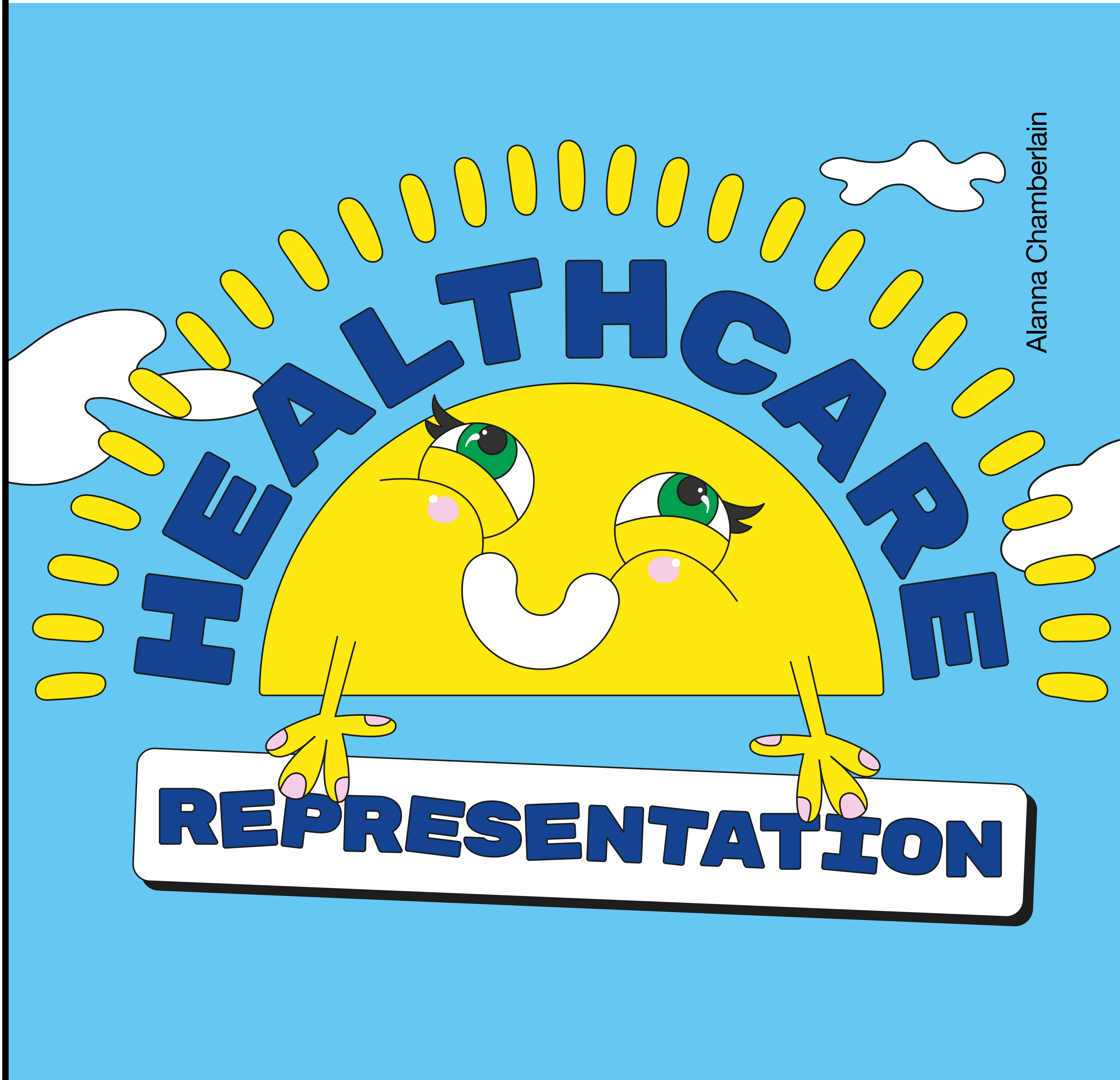
Health
For All

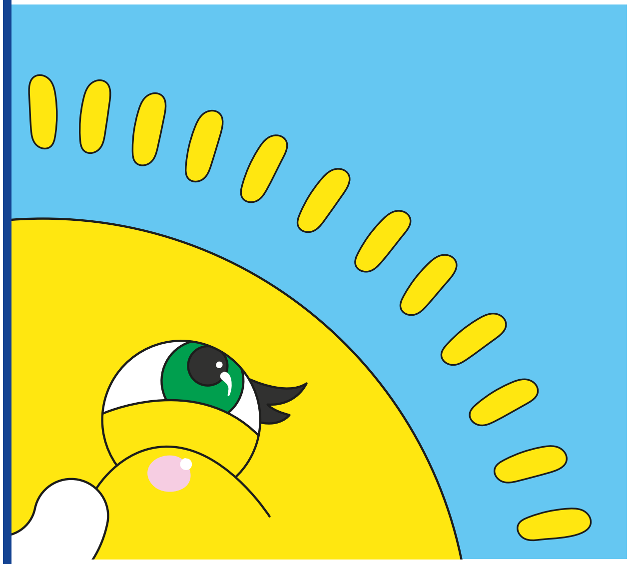
Pride in Practice



Pride in Practice

LGBT Foundation is a national charity delivering advice, support, and information services to lesbian, gay, bisexual, and trans (LGBTQ+) communities. They are based in Manchester's Gay Village, and since they were founded in 1975, they have become the UK's largest health and community charity for LGBTQ+ people. We spoke to them about Pride in Practice, an initiative which has been working to strengthen the link between primary care providers and LGBTQ+ people within the local community.

"There is an example I always like to give when we talk about Pride in Practice, and the difference it can make," Joe, from the LGBT Foundation, tells us.



> "We had someone called Martin write to us about seeing a poster promoting our helpline in his GP's surgery. He was afraid to talk to anyone else and was thinking about ending his life. It made him feel like he was able to speak to his GP, and get the help he needed. So just the act of being able to see something like a poster allows somebody to have a conversation and potentially save this person's life."

The poster that features in Joe's story was put up as part of a pilot scheme, to raise awareness of the foundation in primary care services across Greater Manchester. That was 10 years ago. Since then, the pilot scheme has grown into Pride in Practice, reaching over 573 primary care services, and training more than 7,000 healthcare professionals (HCPs) across 10 boroughs in Greater Manchester.[1]

According to the 2017 National LGBT survey of over 108,000 LGBTQ+ adults that examined the care they received within the NHS, many LGBTQ+ patients have poor healthcare experiences and outcomes. The survey showed that large numbers of respondents had difficulty accessing healthcare services, such as gender identity clinics, or faced inappropriate questioning and curiosity from healthcare staff. At least 16% of survey respondents who accessed or tried to access public health services had a negative experience because of their sexual orientation, and at least 38% had a negative experience because of their gender identity.[2]

Katie says:

> "There's a lot of fear with this subject, unfortunately – a lot of anxiety about saying the wrong thing. How do I ask somebody about their pronouns? How do I ask them personal questions? Of course, it's not that personal if you're trying to give somebody adequate healthcare. But there's still this stigma about sexuality and identity being a personal question, even in this context."

For many facing any kind of health problem or question, primary care is the first place they turn – and can be the first step to accessing specialist care. But a lack of confidence by GPs when discussing LGBTQ+ issues, plus fear of causing offence by asking personal or probing questions, means that patients may not receive care that is suited to their needs.

Looking at oncology, in 2019 a study concluded that those in sexual and/or gender minorities face cancer-related healthcare disparities, including low rates of cancer screening and higher rates of certain cancers.[3] Their survival outcomes may even be compromised by these inequalities; for example, lesbian women with breast cancer have greater disease-specific mortality.[4] One qualitative study of 39 women with breast cancer observed that healthcare providers rarely or never inquired about their sexual minority status.[5]

For the doctor or healthcare practitioner, being aware of their patient's LGBTQ+ status gives them a deeper understanding of their patient, and a more rounded view that enables them to provide holistic and personalised care. But many may still hesitate, possibly due to a fear of causing offense.[6,7]

To help counteract this, Pride in Practice now provides awareness training for doctors, receptionists, support staff, and nurses. The scheme has gone beyond general practice to optometry, community pharmacy, and dentistry – and beyond Greater Manchester to other cities around the country. 97% of trainees who take part in the scheme report increased confidence in supporting LGBTQ+ people's healthcare.[1]

> **"It makes sense for LGBTQ+ people to 'come out' to enable them to receive holistic care, but it is easier to do this if the provider is committed to Pride in Practice."**
>
> **– Owen, patient from Salford, UK**

"It's not just about the doctors because it's about a patient journey," says Katie. "A patient walking in might have an amazing experience with the receptionist who doesn't misgender them, then goes in to see the doctor and has a terrible experience. They're never going to come out again. So, the training makes sure that everyone, every step of the way, is providing that same level of care."

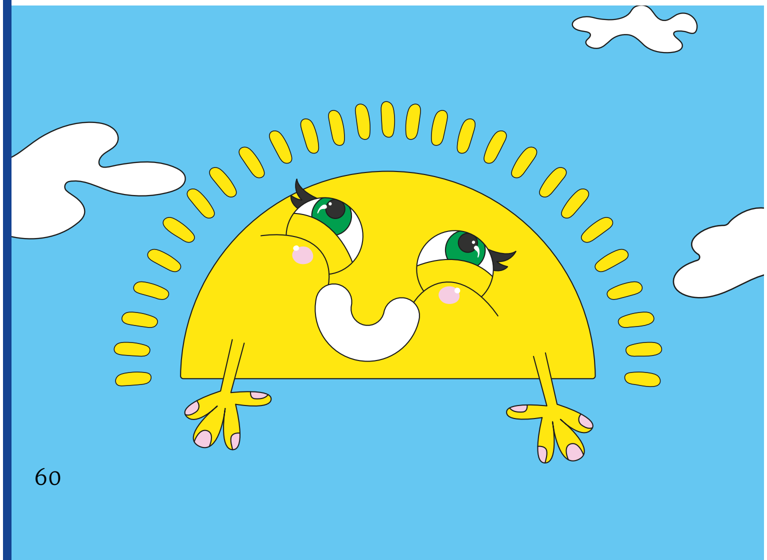
It has resonated so well with HCPs that the LGBT Foundation is now extending its training beyond healthcare to any organisation, company, or charity as all organisations could benefit from LGBTQ+ awareness training. It also offers bronze, silver, or gold accreditation awards, enabling primary care services to promote their equality credentials, and demonstrate their commitment to ensuring a fully inclusive, patient-centred service.

> “It makes sense for LGBTQ+ people to ‘come out’ to enable them to receive holistic care, but it is easier to do this if the provider is committed to Pride in Practice.”
>
> – Owen, patient from Salford, UK

At primary care level, capturing data about LGBTQ+ patients can broaden their understanding of the community a practice is serving. For Joe, having this baseline data is critical to ensuring the services they are providing are sufficient. “Getting adequate monitoring of sexual orientation and trans status is absolutely one of the core fundamental parts of Pride in Practice, because without having that knowledge and that data about the demographics of who’s accessing the services, practices are never able to say that ‘we do have adequate access or equal access of services.’”

> **“To see practices get that passion and make all the changes because they want to is really amazing. They’re genuinely so proud if they achieve it.”**
>
> – Katie, LGBT Foundation

Katie says it’s exciting to see how the Pride in Practice accreditation can trigger a ripple effect, inspiring practices to do more: “The really nice thing about the program is it ignites passion as well. People who really didn’t necessarily think about LGBTQ+ awareness before, not only care about it now and are implementing the changes, but they become really passionate about it. That’s where the award system works really well, because you see practices really, really wanting to go for gold. But, of course, to go for gold, you have to implement all the changes.”



> **“I’ve never had an issue with my own sexual orientation, but being out to my GP means that I can be myself and help them understand more about my individual health needs.”**
>
> – Patrick, patient from Manchester, UK

Key considerations

1. **Thinking about a patient’s journey through assessment to diagnosis to treatment, are there external cues that could prime their interaction with their healthcare provider?**
   - What implications does this have for your patient pathway?
   - How can you arm them to have open and constructive discussions?
2. **Are there at-risk populations who could be overlooked if an HCP doesn’t feel comfortable asking the right questions?**
   - What would this mean for your potential pool of patients?
   - How can you support or encourage patients to advocate for themselves?
   - How can we generate more accurate baseline data?

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Dr Aquiles Salas

Daniel Ido

Dr Aquiles Salas

Dr Aquiles Salas is Director of the Medical School at the Central University of Venezuela and Fellow of the American College of Physicians, with a Masters in Public Health from Harvard University. We spoke to him about his work as a founding member of the 10/66 Dementia Research Group, a group that has been working to understand dementia and its impact in low and middle-income countries for the last two decades. This led to collaborations with Alzheimer's Disease International, and the Pan American Health Organization, to help develop public policies for the elderly on an international scale.

> "When we first met to start the project in India in 2000, we didn't imagine how far it would go, and how helpful it would be."

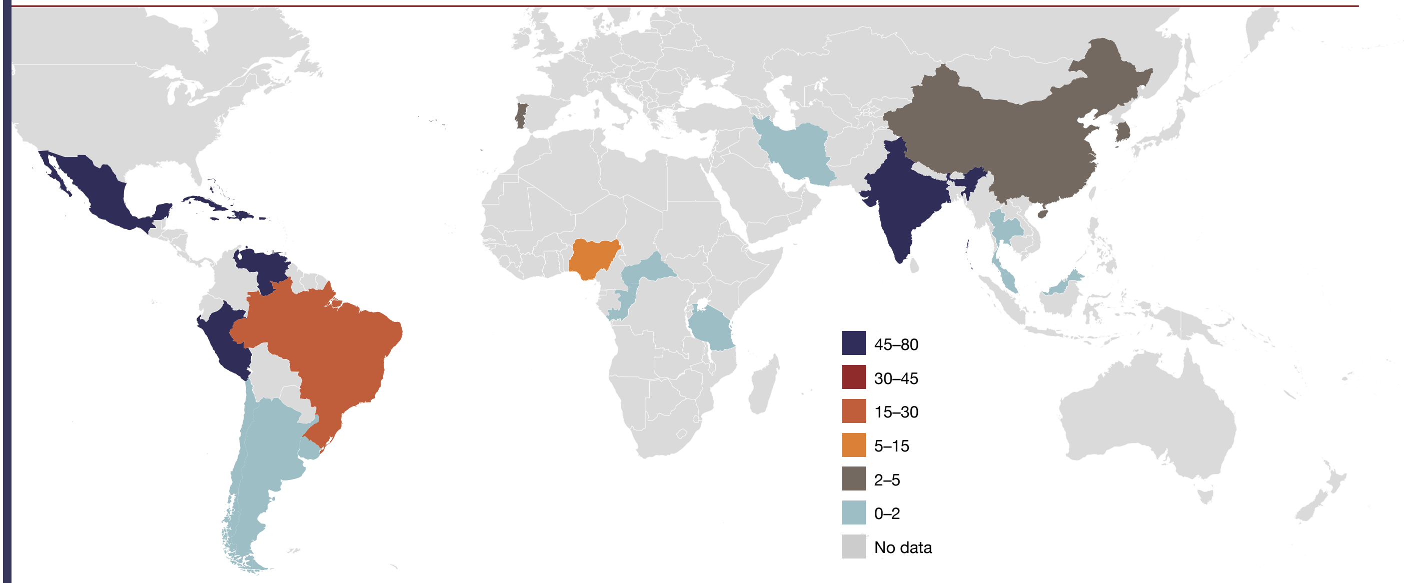
Dr Aquiles Salas is one of the lead investigators in the 10/66 Dementia Research Group, a collective which seeks to understand dementia, non-communicable diseases, and ageing in low and middle-income countries (LMICs) around the world, using population-based research.[1]

"Just 10% of the money invested in dementia research was going to developing countries, where 66%[2] of the population were living" Dr Salas explains.

> "In the scientific world, we didn't know what was happening in those countries – we thought that there was a lower proportion of the population living with dementia. We were wrong."

The work of the group was critical in demonstrating the global impact of dementia, along with other chronic diseases – including hypertension, heart disease, diabetes, chronic obstructive pulmonary disease, and arthritis. This rich data set allowed the link between these diseases and dementia, and their contribution to disability and dependency, to be more fully understood.[3]

Publications of the 10/66 Dementia Research Group 1998–2019[4]



The group is part of Alzheimer's Disease International and is coordinated by Professor Martin Prince, from the Institute of Psychiatry, Psychology, and Neurosciences at King's College London.

Dr Salas is the primary investigator for 10/66 in Venezuela, one of the first countries to become involved with the network, which aimed to develop high quality evidence about dementia in LMICs.

To start with, the instrument the team created to conduct the research had to be standardised and calibrated across countries and cultures, to ensure the results could be trusted on a global scale.[4] From the first set of prevalence data published, involving 14,960 assessments, it was apparent that existing estimates relying on the DSM-IV may be underestimating the scale of the problem.[5] The new instrument was not only more consistent across regions, it reflected the high levels of disability seen.[5]

For Dr Salas, one strength of the research is the clearer picture it painted of the other chronic conditions affecting elderly people's health and social welfare.

> "We found that dementia was not the main disease in our subjects – it was also diabetes, hypertension, cardiac problems, and respiratory problems."

When the teams in the Latin American sites looked at the blood tests conducted, they found that although three-quarters of cases had already been diagnosed, only 40–61% of diagnosed subjects had their diabetes under control.[6] "They don't have access to medication." Explains Dr Salas. "Some of them didn't know that they had these conditions… And these conditions, diabetes and hypertension, feed into the dementia problem." For many study subjects, their involvement in this research may have been the first time that they had any type of blood test done.

> “The world is not equal – and that’s a shame, but we can dream. And we keep working together. Because this is what we can offer to the world, and we do what we can.”

- Dr Aquiles Salas

In addition to sharing clinical findings, Dr Salas and the other investigators also worked with caregivers in households where there was someone with dementia, to understand the demands placed on caregivers.[7] 95% of those with dementia living in LMICs live at home.[8] Dementia was the largest contributor to dependence in Venezuela, and half (50.3%) of the people with dementia included in the original study needed care.[9]

This care and attention are provided by families, people who are physically and emotionally close to them, despite having no prior training or financial compensation.[10]

"When the elderly are in the worst part of their disease, and they lose their dependency and everything has to be done for them, this is the worst part for the family, because the caregiver doesn't have all the skills to do it." Explains Dr Salas. "They spend 8–10 active hours during the day with the person they are caring for. Even when they are resting, they are worried the person is at risk, and it creates huge psychological strain. It's stressful."

For Dr Salas and the rest of the investigators, this was a chance to trial interventions that could help more broadly. "We trained the caregiver. We gave them eight sessions twice a week. At the end, we could see how things changed, how they were feeling, and how things were working better at home. And so, the following month people sent me a message to say, 'well, when are you coming back?'"

In countries where social security is not reliable, and the elderly struggle to regularly access medication,[11] interventions like this represent a scalable way to help people live a better quality of life.

> "This was one of the better moments because we were doing something for them. Unfortunately, we don't have pills. We don't have food. But when we teach and train people to work with individuals living with dementia, we can make a difference that we can see and measure."

Dr Salas' findings have been taken up in other countries in Latin America and beyond, particularly thanks to his work with the Pan American Health Organization, a specialised international health agency for the Americas. Together they created a roadmap so these results could be put into place as widely as possible. "It was called the national geriatric plan. Countries like Costa Rica, Mexico, Cuba, and other countries outside America, are building these results into their planning." Work is still ongoing at a policy level to ensure that findings from the 10/66 network ultimately improve service delivery for people and their families.

The increasing number of people living with dementia means the need to plan effectively for ageing populations is more pressing than ever. "By the time we finished our prevalence study in Venezuela in 2008, we found that around 7–8% of the elderly in my country had dementia,[5] around 100,000 people. The year after in 2009, after staying with the same prevalence and we have almost 200,000 people living with dementia."

Since it began, 10/66 has grown to span 30 research groups in 20 countries in Latin America, the Caribbean, India, Russia, China, and South East Asia.[4] 10/66 tools and methodologies have been employed in countries around the world. The findings from the group have formed a key part of the evidence base for the World Alzheimer report (2009–2016), World Health Organization (WHO) reports, and subsequent global action plans to tackle dementia.[4]

Ultimately, there is hope that more countries and policymakers will use the results from the 10/66 research to build a better life for the elderly worldwide.[4]

> **"We started exploring the issue almost 20 years ago, and the group keeps going further in every country. I'm very proud to be the PI here in Venezuela. There is still more work to be done. It really is a shame that it is not equal across all countries. Well, the war is inequality, and we will keep fighting for funding because it helps people."**
>
> – Dr Aquiles Salas

Key considerations

1. **How much do you understand about country-specific environments and how it impacts the diseases that you're working on?**
   - Are countries' public policies affecting how diseases are diagnosed and treated? Are there pragmatic, low-cost tools that can be implemented to help bridge this gap?
   - What services can be provided to improve access to treatment when this is being impacted by income? Are there any opportunities for partnerships or sponsorships?

2. **What intervention strategies can be put in place to help people live as healthy as possible?**
   - Are there educational resources to help HCPs and patients manage a disease in a more holistic way (including comorbidities)?
   - Considering the prominent role that caregivers usually undertake to help patients manage their chronic conditions, is there any training or further support that can be offered to them?

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Dr Elad Yom-Tov

Dr Elad Yom-Tov

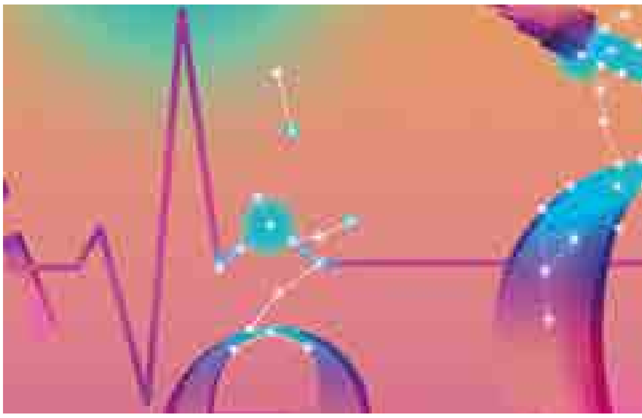
Dr Elad Yom-Tov is a Senior Principal Researcher at Microsoft Research and a Research Associate at The Technion, Israel. Before this, he worked with Yahoo Research, and IBM Research. His work centres on how machine learning can improve health and medicine, and is the focus of his book, Crowdsourced Health: How What You Do on the Internet Will Improve Medicine.

“Internet data may be a type of equaliser,”

says Dr Elad Yom-Tov about one of his ad campaigns to help people who suspected they had cancer, understand whether they should seek medical attention based on their symptoms.

“When we looked at who was engaging with the campaign, we saw that it was people in countries with very good access to the internet and significant barriers to accessing medical care.”

Some of the most common barriers of access to healthcare are geographic and transportation related,[1] so provision of access to the medical system through the internet is important to reduce the inequality between people in different locations.



“You could be in a country with excellent medical care, but if it’s a big country and you live somewhere in the middle, you may want to use the internet first to figure out if what you have is serious enough to warrant taking a few hours off work and possibly not get paid to visit the doctor.”

Recent research has shown the efficacy of screening for serious medical conditions from data collected while people interact with online services. In particular, queries to search engines and the interactions with them were shown to be advantageous for screening a range of conditions including diabetes, several forms of cancer, eating disorders, and depression, and reflecting a broad stratum of the society, including people in underserved populations and with poor access to medical services.[2]

Nonfinancial barriers to healthcare are also well documented and include race, gender, LGBTQ+ identity, disability, age, religion, and access to information.[3] Healthcare professionals (HCPs) exhibit the same levels of implicit bias as the wider population, and these biases can impact diagnosis and treatment decisions in many different fields including:[4] women receiving worse treatment for heart attacks than men[5] or Black patients being deemed less eligible for kidney transplants.[6]

The wide impact of these biases highlight the need for new ways to create equity in healthcare. One approach may be harnessing the power of artificial intelligence (AI) and data-driven technologies. In principle, these new technologies may be useful tools for addressing racial and ethnic disparities in health.[7]

> “There’s a language gap between clinicians and patients that I think machine learning could help bridge, in many cases.”

Machine learning can be used to uncover and treat diseases more effectively with personalised care and pin-point accuracy, and its applications are growing throughout the healthcare industry.

One use is to assist with the assessment of toddlers who are suspected of being on the autism spectrum based on their parents’ answers to an online autism-specific screener. Using machine learning, the algorithm, by choosing and asking parents an additional question, overcomes the language gap and significantly improved the accuracy of risk prediction.[8]

“Using that kind of setup, we could train the machine learning module to decide on what was the most important question to ask of every individual parent. So, it was not a generic question, it was tailor-made to add the most information to the child’s description.”

Virtual support groups allow people to share personal experiences and feelings, coping strategies, or first-hand information about diseases or treatments they have had or are experiencing.

“In terms of socioeconomic status or access to healthcare, patient groups are wonderful because you can be anywhere in the world and you can ask for help, and you’re then likely to receive that help. No one knows who you are, so you’re likely to be treated just like anybody else.” Explains Dr Yom-Tov. “Of course, you should always be careful because the advice you get on a patient group is not the same as what you would get from a medical provider.”

Such groups may fill a gap between medical treatment and the need for emotional support, which is not always provided by the healthcare system, as well as disseminate information on economic and social resources.[9]

Online search data can also be used to develop complementary public health surveillance methods and have helped inform Public Health England on COVID-19 cases. By using online search queries to gain insights about the prevalence of COVID-19 in multiple countries, Dr Yom-Tov’s work indicated that online searches precede the reported confirmed cases and deaths by 16.7 and 22.1 days, respectively.[10]

> “If we understand what people are experiencing, or what is of interest to them at each phase, we can think about how to access that, or how do we serve that kind of interest?”

> **“There’s a language gap between clinicians and patients that I think machine learning could help bridge, in many cases.”**
>
> – Dr Elad Yom-Tov

Patient recruitment remains a significant roadblock to clinical trial development and success, and an area where AI could offer solutions through campaigns with targeting of audiences based on the apps they use, the online communities they join, other ads they've clicked on in the past, and purchasing behaviour.

"An interesting new direction that Microsoft presented at the White House was this chat bot that you could interact with in plain language to describe yourself, your condition, your location, and how far you'd be willing to travel, and it would ask a few questions for clarification and then give you a small set of clinical trials that would be appropriate for you to try."

There is great promise associated with the use of AI in healthcare. However, when this promise is internet-dependent, it applies to 19% and 47% of the population with internet access in the least developed and developing countries, respectively compared with 87% of people in industrialised countries.[11]

Privacy issues and concerns about biases and the quality and diversity of data are provoking major concerns. Companies seeking to ask the right questions and set the right course on AI ethics have a growing number of sources for inspiration and guidance, such as the EU guide that establishes seven key requirements, including transparency, diversity, non-discrimination and fairness, environmental and societal wellbeing, and accountability.

However, if ethical and practical concerns about AI are addressed so that enthusiasm about its benefits does not turn to dread over potential adverse effects, few industries will stand to benefit from AI as much as healthcare.

> "If you look at what people express online on social media or on search engines, you really get a good picture of what is happening."

Key considerations

1. **How can pharma and tech companies maximise inclusion, diversity, and equality in future virtual campaigns, studies, and resources?**
   - What tools can be designed and deployed to ensure future technologies are not affected by structural racism and do not perpetuate inequalities for minority groups?
   - What educational support can be developed and distributed to address inequality biases at their roots?
2. **What is the best way to ensure the public's trust and engagement with AI?**
   - How can companies guarantee personal data protection and anonymity in a tangible way that the public can believe in?
   - What strategies can be put in place for individuals to feel included and valued when taking part in AI-driven activities?

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Dr Samira Hassan

Anshika Khullar

Dr Samira Hassan

Dr Samira Hassan is a GP in Leicester and one of the founders of the British Somali Medical Association, where she heads up the community outreach arm of their activities. Dr Hassan grew up in the Somali community in the UK and observed the discrepancy between the services available within the NHS and the needs of the Somali community. Her aim now is to raise awareness, improve health literacy, advocate for the community, and empower people to take charge of their health and ask for what they need.

> “Not a lot of questions are asked about medications or how conditions come about, and a lot of people in my family and in my community are not really empowered to take charge of their health.”

Language barriers can be challenging for patients and clinicians, leading to non-adherence and poor outcomes in conditions including asthma and diabetes.[1,2]

This is something Dr Hassan has experienced first-hand:

> “The amount of times I have random aunties who call me and say: ‘I have had this letter, I want you to help me understand it. I had a conversation with my GP this morning.’”

‘So what does the GP say?’
‘I don’t know.’
‘Well, did you tell her about this specific topic?’
‘No – she didn’t ask, so I didn’t tell her.’

> “And when I hear that I think: ‘you have a little more power in this relationship than that!’”

Time is often limited in consultations, and if cultural barriers exist patients may feel defeated from the outset – which can be costly for patients and the healthcare system. In one US study, a lack of local language proficiency was linked to adverse events causing detectable harm for 1 in 2 patients surveyed.[3]

Language or cultural differences can lead to barriers with understanding medical situations, correct medication use,[3] or even seeking medical help if they feared they would not understand their healthcare provider.[4] Other reports highlight increased length of hospital stays, longer hospitalisation as a result of adverse events, and drug complications.[5]

The responsibility to address this lies with both clinicians and patients, and there is much more the healthcare communications industry could do to help facilitate better understanding. Doctors can provide more optimal interactions by focusing on basic things such as listening to patients (through a translator if needed), observing their body language, giving them time to air their concerns, acknowledging them, and offering support and explanations.[6]

Not feeling listened to is a major source of patient dissatisfaction,[7] and patients will go to great lengths to ensure their concerns are heard.

Members of the Somali community often travel to Germany for diagnosis and treatment – not just from the UK, but also from Sweden and the Netherlands.[8] German doctors have advertised on Somali television and this has developed as the main medical tourism route. “Patients will pay for tests, consultations, and treatments that may help occasionally, but more often than not are the same as they have been receiving in the UK,” Dr Hassan points out.

> “But it doesn’t matter to them that this is the case. Patients feel ‘They have listened to me, and I know that this medication is right for me because they have actually processed what I have to say. I feel better.’ That’s health psychology.”

> “Part of the medicine is the therapeutic relationship and that additional support. ‘Does this doctor even care, do I feel listened to, do I feel like my anxiety has been addressed?’”

The patient-clinician relationship is critical and has been shown to have a significant impact on improving patient outcomes.[9]

> “You have to look into the patient’s world. You have to think about the social, psychological, financial, physical aspects, mental and emotional needs, not just the physical symptoms – there is a life beyond that.”
>
> – Dr Samira Hassan

For treatment to be effective, the patient must understand it from several angles – including personal, religious, and cultural; if a treatment is not culturally acceptable, it won't be accepted by patients.[10] If there is a cultural or religious stigma surrounding diagnosis and treatment, it can shape how patients think about their disease. For example, in the Somali community, the causes of mental illness are seen as spiritual, coming from God or evil spirits.[10] Rather than seeking help for depression, patients may seek help for physical symptoms that accompany depression such as low appetite, low energy, or pain. Treatment should then be framed in terms of its impact on the symptoms as well as the diagnosis as a whole.

Dr Hassan has taken the importance of culture into account when developing videos to educate the Somali community about COVID-19. "In the Somali community, and in most ethnic communities, a lot of what happens in health is rooted in faith, religion, destiny, and God's plan. And it helps sometimes when I can bring that in. Towards the end of my COVID video, I talked about how we don't know what the future holds, but it is important to do your best in searching for the information, satisfying yourself with the information we have, and then having faith."

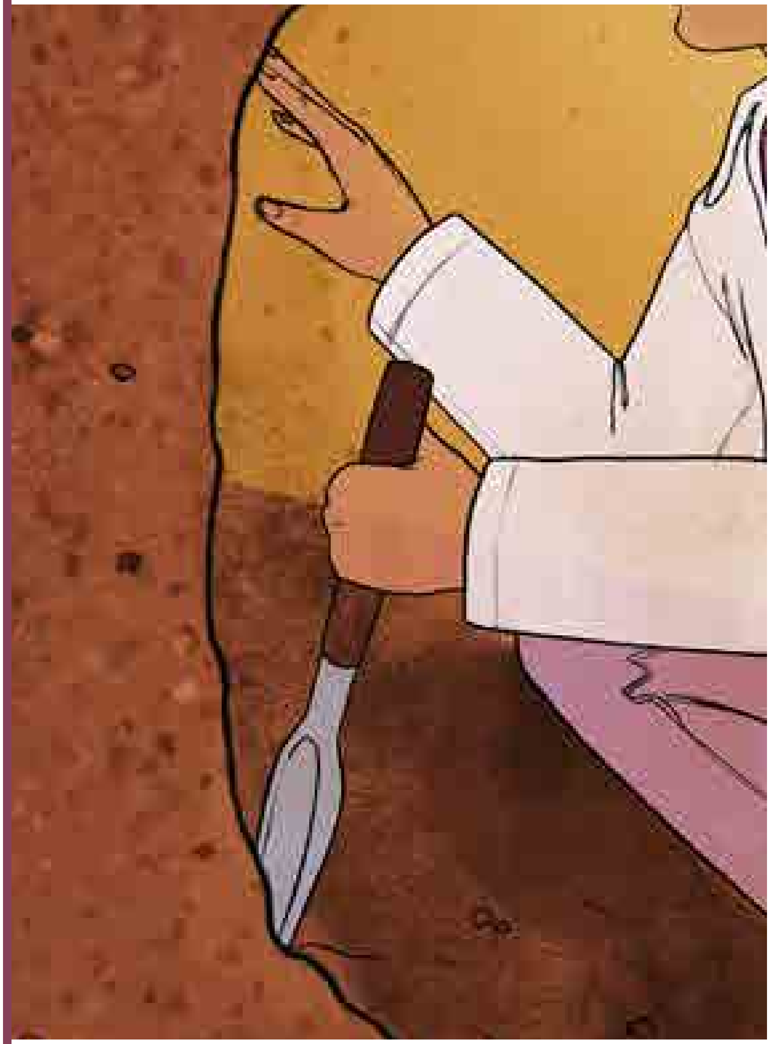
The video achieved 13,000 views within a week, which Dr Hassan attributes to the relatable content, the incorporation of cultural nuances alongside the facts, and the medical information about the disease.

> "
> The mentality of 'I think I know what you want, and therefore I will produce it, and you will buy it' does not work."

Doctors can do a lot to bridge the gap between patients and the healthcare system, but so can companies and organisations. "If you go out of your way to come into the community, you'll find we have a lot to say and we want you to hear it."

Dr Hassan believes there are a number of ways to do this: "It is important to have focus groups, offer webinars, collect feedback, ensure there is some way to have a two-way dialogue. Then you can create products that meet the needs of the community. They don't care about criteria or your goals – they care about whether or not it meets their needs."

> **"People say we are 'hard-to-reach' – we are not 'hard-to-reach', we are 'hardly reached'. There is a difference."**
>
> – Dr Samira Hassan



Key considerations

1. **How can we encourage a more culturally aware HCP-patient dialogue? Where would this improve the quality of the conversations that are happening across the treatment pathway?**
   - Are there opportunities to develop practical guidance and patient-focused content that raises awareness and empowers patients to drive their conversations with HCPs?
   - Can we forge relationships with community doctors (and not just key opinion leaders), working together to gather insights and develop materials that truly respond to each group's needs?
   - Where can we help bridge cultural or personal divides between patients and their doctors?

2. **How can we better support patients within different communities to adhere to medication?**
   - Do you have a holistic view and understanding of your patients beyond their clinical symptoms? When working within a therapy area, have you built patient profiles that take into consideration the intersectionality of factors?
   - Do you have a patient support programme in place with beyond-the-pill capabilities and services? Are there translation services or community partners that can be leveraged to build trust and increase patients' understanding of their treatment plan?

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