Earning trust:
a foundation for health equity

July 2024

The following organisations endorse this report:

Contents

Foreword

The past decades have seen a growing awareness of disparities in a number of health outcomes across our populations. The source of these inequities is complex: existing social and economic inequalities linked to people's housing, income, education level, and geographical location invariably translate into inequities in health and well-being. Health systems can also create or exacerbate inequities through barriers to access, a lack of inclusive information, or practices that disadvantage or exclude people with certain characteristics or needs. Many discriminatory practices stem from long-standing structural barriers, institutionalized behaviors, and belief systems that permeate our health systems just as they do other aspects of society. The gradual shift toward digital and data-based approaches may be experienced differently by different people, improving engagement for some while creating additional barriers for others. Throughout all of this, people's experience of health and healthcare is individual; it is shaped by their personal beliefs, experiences, social context, relationships within the system, and observations of others.

Against this landscape, people's trust in health systems is held by a fragile thread. An individual's trust in their healthcare providers and the health system is the keystone in all aspects of healthcare; it provides the bedrock for bilateral collaboration and open communication between those seeking care and those who can provide it, yielding better access and health outcomes. It also enables different healthcare professionals to work together and motivates governing bodies to give health systems and healthcare professionals appropriate resources and autonomy, while implementing the necessary safeguards and regulations to ensure that people using health systems are always protected.

While building trust should be a concern for us all, it is especially important for people in traditionally under-represented groups, as they are most at risk of facing specific barriers or discrimination. They are also disproportionately likely to be negatively impacted by the social and economic determinants of health and to have worse access and health outcomes. Healthcare delivery, communication materials, interventions, and research rarely reflect the diverse tapestry that makes up our societies. What's more, the way healthcare is designed and delivered, including the composition of the healthcare workforce, is often not reflective of the diverse needs of the communities it serves. It is perhaps unsurprising that many members of traditionally under-represented groups find it difficult to trust health systems that do not represent or serve them.

Reshaping our health systems to nurture trust will pave the way for voices of people who have historically been denied a platform to express their needs, showcase their strengths, and contribute to building equitable and sustainable health systems. Actions in healthcare can feed into, and build on, broader actions that address the underlying causes of health inequities. Through this work, we call for governments to enact national policy and provide funding to build trust; we call for education providers to ensure that the concept of trust is included in all curricula; and we call for healthcare professionals to provide care that is appropriate and supportive for all those receiving it.

We call on system leaders, regardless of where they sit in the health system, to set an example in catalyzing change, recognizing that for real change to happen, every one of us should take responsibility and accountability for our own actions contributing to a more equitable tomorrow, today.

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International Advisory Group for A Million Conversations

About this report

This report was developed to highlight the policy principles that need to be implemented to build trust between under-represented groups and health systems. For reasons of feasibility, we have focused on four traditionally under-represented groups (people from racial and ethnic minorities, women, members of the LGBTQ+ community,[i] and people with disabilities) in five countries (Brazil, France, Japan, the UK, and the US) where recent global survey data have indicated worrying trends of mistrust in health systems.[1–3] This report built on conceptual frameworks of trust in health systems presented in the published literature, a review of policies on health equity from the aforementioned five countries as they relate to these four under-represented groups, and discussions among our Advisory Group. Our wish in putting together this report has been not just to highlight deficiencies in trust, but to propose concrete, evidence-based policy actions that, if locally co-implemented, will help build trustworthy health systems.

We recognize that other regions and countries will have different barriers to equity and pertinent solutions to build trust. While efforts have been made to develop policy principles that transcend national barriers, the report remains bound to the selected geographical scope. Moreover, although the research focused on four groups to provide a defined scope, some of the principles and concrete actions will be relevant to other groups who are under-represented in health systems.

This report was initiated and funded by Sanofi. For full details on authorship and acknowledgements, please see pages 30–31.

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i   The term used to describe individuals who identify as lesbian, gay, bisexual, transgender, queer or questioning is LGBTQ+. However, different acronyms are used throughout the report to reflect the terms used in the source material.

1 Understanding the importance of trust for equitable healthcare

What is trust in a healthcare context?

Trust is the foundation of relationships between people, healthcare professionals and the health system. It is built on the intangible understanding that health systems, and the professionals within them, will act in a way that serves the interests of the people seeking care (*Box 1*). When a person enters and navigates the health system, they are putting themselves in the hands of another, making themselves vulnerable by virtue of their need to ask for care and get better. This vulnerability is enhanced by the asymmetry of information between an individual and their treating healthcare professional, whereby the latter has considerable power over the former's access to care.[4][5]

Box 1. Types of trust in health systems

Trust can operate in relationships between people, and among people and the health system and its institutions; these include hospitals/care centers, public health organizations, and many others.[6][7] In each of these circumstances, trust can be defined as:

- a set of expectations that health service users have for the health system and healthcare professionals to help them heal, including: making the best decisions regarding diagnosis and treatment; putting their best interests forward; and transparently disclosing information,[8] and/or
- a psychological state that determines a person's willingness to be vulnerable under conditions of risk/uncertainty and interdependence.[9][10]

A person's trust in healthcare professionals and in the health system as an institution are not always linked.[6] Public trust in health systems may rise and fall in light of people's overall views of the government's or public sector's trustworthiness and accountability; this can be significantly affected by the political climate, or the occurrence of scandals or breaches of trust (e.g., a cyberattack on the health service). However, even when their trust in institutions is low, people often continue to have high levels of trust in their personal healthcare providers.[6]

What is the relationship between trust and health equity?

Lack of trust may be a rational response to inequities in healthcare and health outcomes. The Racism and Health Framework[11] explains that medical mistrust is a natural response to exposure to racism, discrimination, maltreatment, and general hostile social landscapes that many people from under-represented groups have traditionally faced, and continue to face, in the health system.[12] People from traditionally under-represented groups – including racial and ethnic minorities, women, people from the LGBTQ+ community, and people with disabilities – often face particular barriers when it comes to accessing health information and care, interacting with healthcare professionals, and having optimal disease management options. They are also disproportionately likely to be negatively affected by social determinants of health, which impact their underlying well-being.[12–14] This combination of factors contributes to inequities in health outcomes (*Box 2*).

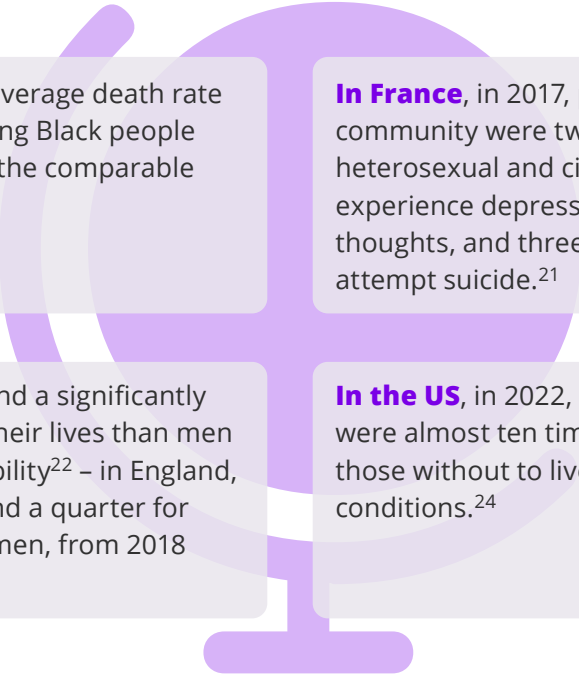## Box 2. Defining health equity, inequality and inequity, and disparities

The World Health Organization defines health equity as "the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically."[15] The term "equity" recognizes that each person has different circumstances and allocates appropriate resources and opportunities needed to help achieve equal outcomes.[16]

"Structural inequality" describes disparities in wealth, resources, and other outcomes that result from macro-level and institutional discrimination, such as those found in legal, educational, business, government, and health systems.[17]

Inequalities and inequities may contribute to health disparities – the differences in risk, incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific populations.[18]

Given that some inequalities in health outcomes are the result of preventable circumstances and discrimination, health equity can be understood as a social justice issue.[19]

Inequitable outcomes are experienced, to varying degrees, by different populations around the world. Evidence of this includes:

In Brazil, in 2019, the average death rate in public hospitals among Black people was more than double the comparable national average.[20]

In France, in 2017, people in the LGBTI+ community were twice as likely as heterosexual and cisgender people to experience depression and suicidal thoughts, and three times as likely to attempt suicide.[21]
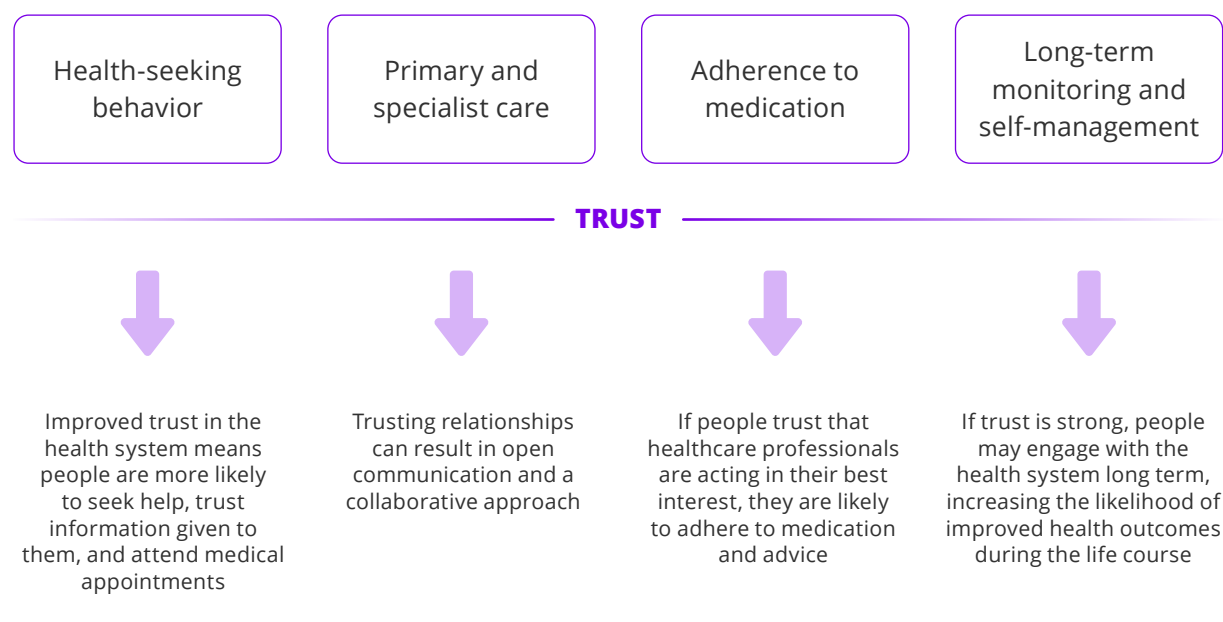
In the UK, women spend a significantly greater proportion of their lives than men with ill health and disability[22] – in England, this amounted to around a quarter for women and a fifth for men, from 2018 to 2020.[23]

In the US, in 2022, people with disabilities were almost ten times more likely than those without to live with multiple chronic conditions.[24]

Why is trust so important?

Lack of trust in health systems can have significant consequences. Within health systems, mutual trust is fundamental to the relationship between people and healthcare professionals.[25] Trust is built over time, and will eventually foster a partnership where people feel empowered in their own care, and work with healthcare professionals to manage their own health.[25 26] At this personal level, trusting relationships yield open communication, improved adherence to medical advice and, ultimately, better health outcomes (*Figure 1*).[27–29] When people do not trust healthcare professionals or official sources of information, they may not engage with the health system, forgoing care and looking for alternative sources of information.[12 30 31]

Figure 1. The role of trust at different stages of interacting with the health system

Health-seeking behavior	Primary and specialist care	Adherence to medication	Long-term monitoring and self-management

TRUST

Improved trust in the health system means people are more likely to seek help, trust information given to them, and attend medical appointments	Trusting relationships can result in open communication and a collaborative approach	If people trust that healthcare professionals are acting in their best interest, they are likely to adhere to medication and advice	If trust is strong, people may engage with the health system long term, increasing the likelihood of improved health outcomes during the life course

Earning the trust of traditionally under-represented groups is central to improving health equity. Disengagement from the health system due to medical mistrust can exacerbate disparities in health outcomes.[32] Rebuilding trust among people from traditionally under-represented groups may lead them to engage in health-seeking behavior and participate in the health system,[33] increasing the likelihood of preventive care, early intervention, and more favorable outcomes. Healthcare professionals have a crucial role in demonstrating the trustworthiness of the health system; they have an obligation to "do no harm," and building trust is central to this obligation.[26 34]

> "The physician must avoid acting in such a way as to weaken public trust in the medical profession."
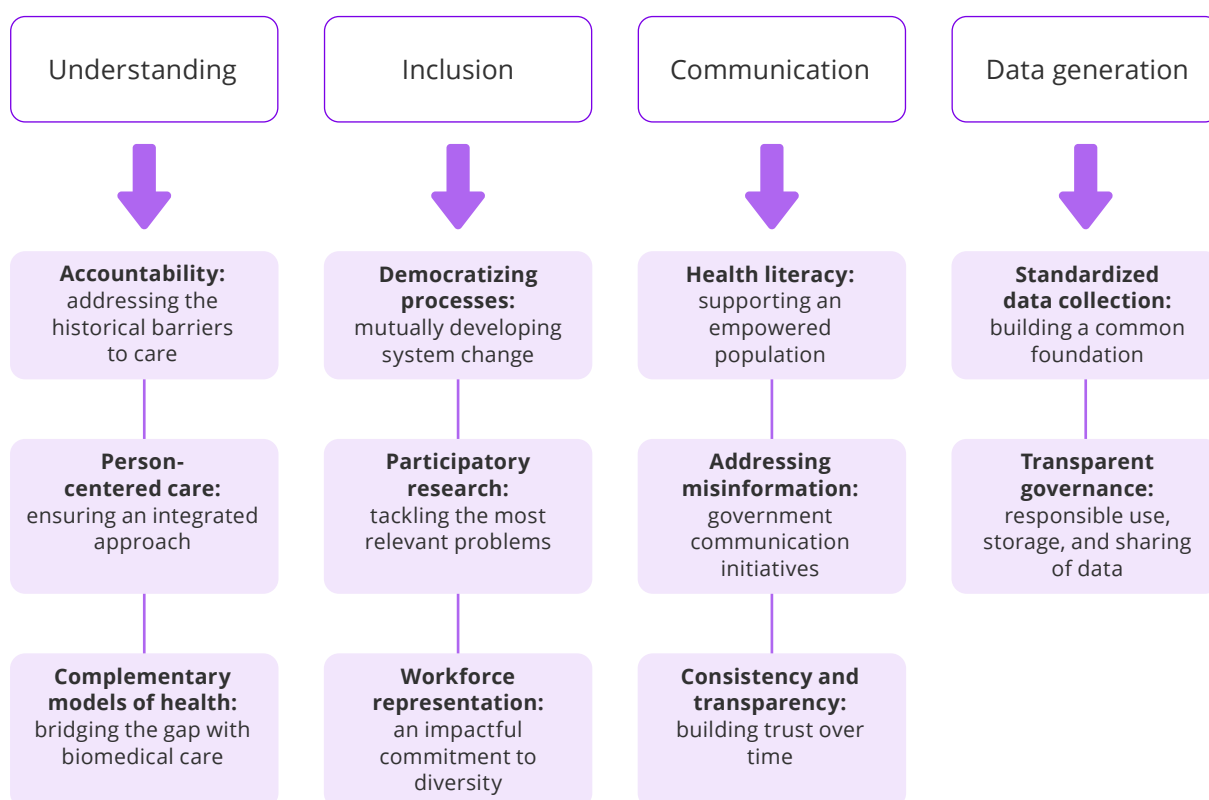
World Medical Association[34]

2 How can health systems earn trust?

There are general policy principles that health systems can implement to earn, and maintain, the trust of members of under-represented populations. It is important to emphasize that every individual has unique experiences that may influence their relationship with the health system, and it would be inappropriate to assume homogeneity for any given group. However, given published evidence of potential contributors to mistrust among different groups, there are overall policy actions (*Figure 2*) that – if implemented in the context in which they operate – will help build greater health equity and, in turn, help health systems earn the trust of traditionally under-represented groups.[35–40]

Strong leadership at every level is required to develop and implement policies that adhere to these principles. Governments, healthcare professionals, and industry stakeholders should all lead by example, with collaborative and concerted efforts to build trustworthy health systems.

Figure 2. How can health systems earn trust?

Understanding	Inclusion	Communication	Data generation
Accountability: addressing the historical barriers to care	**Democratizing processes:** mutually developing system change	**Health literacy:** supporting an empowered population	**Standardized data collection:** building a common foundation
Person-centered care: ensuring an integrated approach	**Participatory research:** tackling the most relevant problems	**Addressing misinformation:** government communication initiatives	**Transparent governance:** responsible use, storage, and sharing of data
Complementary models of health: bridging the gap with biomedical care	**Workforce representation:** an impactful commitment to diversity	**Consistency and transparency:** building trust over time	

Understanding

Professionals in a health system must be attentive and listen to the people and communities they serve. To deliver person-centered care, health systems must build cultural sensitivity and understanding among the workforce.[41][42] It is also important to build sensitivity at the wider system level, creating health organizations that engage communities through participatory research and co-development of health interventions.[43] Building understanding of a community requires paying attention to the voices in that community. This is especially important to serve members of traditionally under-represented groups, who may be more likely to experience misunderstanding and discrimination because their experiences have not historically been accounted for in the health system.[44]

Accountability: addressing the historical barriers to care

Historical discrimination in healthcare settings has had lasting consequences, which continue to affect care today. There are many examples of how historical precedents and injustices have shaped modern health landscapes. They include: experimentation on marginalized communities; the medicalization of race, sexual orientation, gender identity, sex characteristics, and disability; and the norm of white male bodies in anatomy and clinical trial designs.[45] Acknowledging historical injustices in healthcare and understanding how they affect care today will help foster safer care, better health outcomes, and improved trust for all involved.

Public healthcare institutions must rethink how they interact with and serve people from under-represented groups. There is a growing demand for institutions to be rebuilt without the cultural and social impacts of historical violence, racism, ableism, Eurocentrism, and misogyny that have shaped so many social views and attitudes.[45] Tackling historical precedents and entrenched attitudes requires institutional change and an examination of how current health inequities are linked to historical failures.[45]

Some institutions are making pragmatic efforts to undo long-held practices that have affected healthcare education. The medical school of University College London took pioneering steps in 2021 to overhaul the undergraduate medical curriculum, including producing a new curriculum that offers more space to research methods from traditionally under-represented groups.[46] Meanwhile, Imperial College London has established The Women's Health Network of Excellence, which aims to help faculty and students overcome the historic gaps in research into women's health through interdisciplinary research and innovation.[47] These are important steps in preparing the healthcare professionals of tomorrow as more culturally sensitive and actively anti-discriminatory members of the workforce.

National policies are beginning to address the need for healthcare professionals to receive dedicated and regular training on inclusive practices. For example, national health strategies from Scotland, Northern Ireland, England, and Brazil require staff to participate in training on equality, diversity, human rights, intercultural competency, and anti-racism.[35 36 48–50] Similarly in France, the National Plan for Equal Rights, Against anti-LGBT+ Hate and Discrimination aims to introduce training and education in medical schools to raise awareness of the lived experience of people from the LGBTI+ community.[40] One local authority in the UK has defined what "good" training should include to help create a culturally sensitive workforce (*Case study 1*). It is equally important to provide healthcare professionals with the resources they need to adapt their practices to embody a more inclusive approach to care.

Person-centered care: ensuring an integrated approach

Every person has unique needs shaped by who they are and what they have experienced. When considering diversity, although one often thinks about the needs or experiences of under-represented groups, it is important to recognize that these groups, and people's identification with them, often intersect. Intersectionality refers to the overlapping identities that an individual may have (e.g., someone who is disabled and also Black), and how multiple forms of inequality or disadvantage can sometimes compound one another and create unique combinations of discrimination or barriers to accessing care.[52] Healthcare organizations must recognize this and regard each person as an individual, being mindful of the barriers that individual may face and avoiding generalizations or assumptions about what they may need.

> ### Case study 1. Birmingham City Council and the Cultural Intelligence Framework
>
> Birmingham City Council in England has developed an evidence-based cultural sensitivity model and training program for its employees that aims to support organizations and individuals working to understand, advocate for, and become trusted partners of members of under-represented groups in their community.[51] The framework recognizes the need to understand granular differences between communities, acknowledging that the over-simplification and homogenization of identities undermines understanding. The framework includes training on:
>
> - establishing a baseline of curiosity about and understanding of different specific communities,
> - becoming trusted partners of members of the specific community through learning from lived experience, testimonies, and active engagement,
> - becoming conscious decision-makers and advocates with patients and communities, and
> - becoming skilled in active allyship and antidiscrimination to make meaningful changes to inequalities and experiences.
>
> Learning across these practices is captured and evaluated through a reflective practice audit loop using peer reviewers to ensure that participants are consciously reflecting on learning and its application.
>
> The framework was the result of two years of collaboration between members of the African and Caribbean communities and academics in Birmingham and Lewisham. Together, these groups explored solutions to health inequalities, and highlighted that training must be detailed and specific to individual communities, and that people from these communities should be included in training practices.
>
> As of May 2024, the project is still in an evaluation pilot stage; therefore, there is limited information available on outcomes in changing practice.

Providing person-centered care means ensuring that the health system responds to the holistic needs of each individual. This means developing and supporting a workforce with enough time to fully understand patients' circumstances and preferences, enabling tailored care to respond to the needs of the individual. Suitable care might include adaptations to care settings and services, the type and way of communicating information (including providing information in different accessibility formats), and making people feel comfortable when they visit a healthcare setting.[53] All of these adaptations can help people fully benefit from their interactions with the health system. They can also enhance the therapeutic alliance between an individual and their treating healthcare professional, strengthening the person's connection and commitment to work with the healthcare professional, and giving the healthcare professional the right tools and resources to do this (*Case study 2*).[54]

> ### Case study 2. France's "consultations blanches": building trust between healthcare professionals and people with disabilities
>
> Mock consultations, or "consultations blanches," are preliminary medical appointments for people with disabilities who access primary and dental care services in France. They allow the person to familiarize themselves with the medical environment and meet their healthcare professional before a clinical examination or procedure.[55] Advance engagement can help people with disabilities focus on the medical appointment when it happens. This may be particularly important, for example, for people with intellectual disabilities or autism, who may require familiarity with the healthcare setting to engage with their care. But equally, these appointments allow anyone with significant disabilities to take time to get comfortable with their healthcare professional and clinical setting.
>
> Since April 2022, these primary care consultations have been reimbursed by social security and subsidized by the government.[56] This incentivizes healthcare professionals to improve their understanding of and exposure to people with disabilities while also allowing people to feel more comfortable accessing primary care services, increasing the likelihood that the consultation will meet their needs.

Improving the continuity and integration of care is important to support the delivery of person-centered care. Health systems are often fragmented, with gaps in communication and service provision between acute or hospital-based care and community-based care. This disconnect can cause delays and reduce continuity, becoming a source of mistrust if people feel unsupported in their continuing healthcare journey or rehabilitation.[57] The creation of cohesive care pathways and integrated care systems is essential to enable healthcare providers to treat patients holistically and be fully responsive to the context of their lives and needs. Moreover, integrated systems have been shown to improve population health and outcomes for patients.[58]

Complementary models of health: bridging the gap with biomedical care

Health systems that take a purely biomedical approach risk alienating people who value traditional or complementary healthcare practices. Biomedical approaches, which rely solely on biology to explain diseases and health, do not tackle the social and economic determinants of health that we know significantly influence health outcomes.[59] A health system is unlikely to foster and build trust if it is not understanding of people's wider social context, including traditional health knowledge (which is used by a large portion of the population in many countries).[60]

There is growing recognition of the importance of holistic well-being, accounting for social and complementary medicine. The social model of health has gained traction. It examines the social, cultural, political, and environmental factors that contribute to health – for example, it acknowledges that poor housing with damp can cause illness, kick-starting a series of negative events and stressors that

that contribute to ongoing ill health.[61] Traditional or complementary health knowledge – defined as the generational knowledge, practices, and beliefs indigenous to specific populations – can also be used to support health and well-being. The contribution of traditional or complementary health knowledge to healthcare is substantial and varied, from acupuncture to indigenous traditional medicine, osteopathy, and chiropractic practice.[62 63]

Inclusive health systems will validate and incorporate appropriate complementary approaches to care into their processes. Where recognition of complementary systems of medicine is lacking, national policymakers should support its implementation alongside established biomedical approaches to serve their populations. Health systems could implement reimbursement for complementary approaches – for example, by supporting social prescribing, which enables community-based practitioners to refer people to non-clinical services, such as sports or cooking services;[64] or by funding lymphatic drainage techniques that can be beneficial for people with lymphedema and fibromyalgia.[65] Canada is one country that incorporates complementary approaches into its health system; the Office of Natural Health Products recognizes the contribution of traditional health knowledge and federally regulates herbal medicines.[63]

Inclusion

Equitable healthcare should embody the principle "nothing about us without us" to enable efficient and effective care delivery. This slogan is used to communicate the idea that no policy should be established without the consultation or participation of members of the group(s) affected by that policy.[66] The inclusion of relevant voices in every facet of health policy planning, design, and implementation ensures that topics and issues of importance to the broadest possible population are identified and addressed.[67] Inclusive practices mean that groups or individuals from different backgrounds are welcomed, culturally and socially accepted, and treated equitably.[68] Such inclusion is essential to building an understanding of the priorities and experiences of different groups.

Democratizing processes: mutually developing system change

Democratizing healthcare involves empowering the patient in the development of health policies and processes. Active involvement in decision-making, such as through community representation on hospital boards,[69] can help build trust by ensuring that people feel their voices are being valued. The US Food and Drug Administration's (FDA's) Patient-Focused Drug Development Guidance supports this approach, addressing how stakeholders can incorporate patients' voices and views in medical product development and regulatory decision-making.[70] Another example comes from the electronic platform Patient Innovation, which allows people with different conditions, and their carers, to share health solutions with others.[71] Such initiatives may be especially important for traditionally under-represented groups who have historically been excluded from the decision-making processes that affect them.

Countries are beginning to embed citizen participation in the development of national health policies. This ensures that the policies reflect community priorities, empowering citizens to make changes to the health system. For example, France's National Health Strategy 2023–2033 commits to directly involving members of the public in the development of the health policies and systems designed to support them.[72] In Brazil, the 2023 National Plan for the Rights of Persons with Disabilities was meaningfully co-developed with Brazilian people with disabilities (*Case study 3*).

> ### Case study 3. Co-development of Brazil's national plan for people with disabilities[37]
>
> In 2023, Brazil's federal government published a new National Plan for the Rights of Persons with Disabilities, also known as Living without Limits. The plan includes "promotion of the right to education, social assistance and health," built around the principle of inclusion, featuring commitments to:
>
> - review the National Policy for Comprehensive Health Care for People with Disabilities, to better and more broadly meet current health needs,
> - expand the capacity for sexual and reproductive healthcare for women with disabilities, and
> - expand specialized rehabilitation centers for diagnosis, treatment, adaptation, and maintenance of assistive technology for the health of all people with disabilities.
>
> The plan was developed with input from people with disabilities and managed by the National Secretariat for People with Disabilities. Input included two rounds of public consultation and extensive dialogues with civil society, representatives of disability groups, and other grassroots movements involved in improving the lives of people with disabilities.

Participatory research: tackling the most relevant problems

Certain groups are traditionally under-represented in research. Populations recruited into clinical trials and health research are often not representative of the target population for whom the given medicine or health intervention is intended, making it difficult to extrapolate findings to the entire population.[73][74] For example, women and members of the LGBTQ+ community have been historically excluded from medical studies and pharmaceutical research.[75][76] This is also the case for racial and ethnic minority groups, despite many people from these populations facing a disproportionate burden of diseases such as diabetes, asthma, and hypertension.[77][78]

Regulatory bodies in different countries are trying to reverse this trend. The FDA has issued guidance to the pharmaceutical industry to enroll more participants from under-represented racial and ethnic populations in clinical trials.[73] In the European Union (EU), the 2014 EU Clinical Trial Regulation requires that participants in clinical trials represent the age and gender groups that are likely to use the product being investigated.[79] Making research more diverse is also a priority for the National Health Service (NHS) Health Research Authority in the UK.[80] These initiatives will be even more important with the emergence of novel technologies such as artificial intelligence (AI), which, among other applications, can learn from existing data to propose diagnostics and treatments or support engagement and adherence.[81][82] Such tools will only fulfill their potential of increasing accuracy and reducing healthcare costs if they are developed with appropriate data.[82]
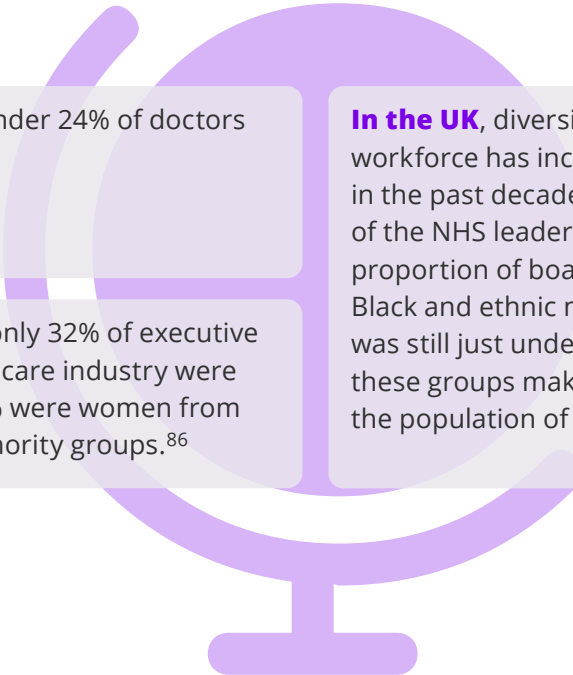
> "Clinical trials provide a crucial evidence base for evaluating the safety and effectiveness of medical products; therefore, enrollment in clinical trials should reflect the diversity of the population that is ultimately going to use the treatment."

Food and Drug Administration, US Department of Health and Human Services[77]

Engaging members of the community in the development and implementation of health interventions is essential to ensure that those interventions are relevant to people's needs. The use of methods that are developed in direct collaboration with those affected by the issue being tackled is known as participatory research. In the context of healthcare, it engages people who are the target population of a given intervention (such as a new technology, therapy, or screening tool) in research planning and implementation.[83] This increases the likelihood that the health intervention will meet the needs of the target population – and that they will be willing to use it.[83] For example, in Australia, the lung cancer screening program was designed with close involvement of the Aboriginal community to ensure that all materials, information, and services were appropriate to the needs and preferences of this community.[84]

Workforce representation: an impactful commitment to diversity

In many countries, healthcare workforces are not representative of the populations they serve:

In Japan, in 2022, under 24% of doctors are women.[85]

In the US, in 2022, only 32% of executive officers in the healthcare industry were women, and only 4% were women from racial and ethnic minority groups.[86]

In the UK, diversity in the healthcare workforce has increased dramatically in the past decade, but a 2022 review of the NHS leadership found that the proportion of board members from Black and ethnic minority backgrounds was still just under 14%,[69] despite these groups making up at least 18% of the population of England and Wales.[87]

Data from other traditionally under-represented groups are not readily available, but are likely to mirror these trends. Workplaces must support diversity and tackle discrimination at each level of the health system.

Greater representation and inclusion of different communities in the workforce can facilitate more effective communication and better health outcomes. People seeking care tend to prefer healthcare professionals who have a shared identity with them.[88–90] "Racial concordance theory" shows that people who share racial and ethnic identities with their healthcare professionals experience improved communication, quality of care, and better health outcomes.[89 91] In Australia, increasing the number of Aboriginal health workers in community health centers has been demonstrated to improve outcomes (*Case study 4*). And, of course, shared identities and the "proximity" between a healthcare professional and person receiving care go beyond race and ethnicity, to include language, age, gender, values, geographical location, and socioeconomic position.[90]

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Case study 4. Improving health outcomes with more Aboriginal workers in Australian community health centers

Efforts to improve health outcomes for Aboriginal people in Australia have a long history. For example, in 2002, Australia's first Indigenous-run kidney health facility was established in Broome, after Aboriginal medical leaders advocated for Aboriginal people to receive treatment where they lived.[92] Historically, Aboriginal people with renal failure had to travel great distances to major cities for care[92] and there is evidence they were under-represented across the healthcare workforce – making up only 1.3% of healthcare professionals in 2001.[93]

As the clinic expanded, Aboriginal health workers were recruited to support patients. The Aboriginal-led service is culturally sensitive to Aboriginal people,[92] and attendance at renal treatment appointments has significantly improved since the clinic was established.[94]

Initiatives such as this culminated in a formalized Partnership Agreement in 2019 between the Commonwealth Government, state and territory governments, and the Coalition of Peaks (a representative body of Aboriginal and Torres Strait Islander community-controlled peak and member organizations) to close the gap in outcomes for Aboriginal and Torres Strait Islander people.[95] This is the first time that Australian governments have shared decision-making with Aboriginal and Torres Strait Islander representatives.

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Community health workers can play a valuable role in bridging the gap between healthcare workforces and traditionally under-represented communities.
They are often trusted members of their communities who receive specific training that enables them to provide essential services such as making home visits and distributing educational materials.[96] Their existing relationships with the community allows them to act as "cultural brokers," helping with language barriers, navigating the health system, and building trust.[96] In many countries, the value of community health workers was demonstrated during the COVID-19 pandemic, when they built on established trust and communicated health messages in an effective and engaging way.[97] In the US, there have been concerted efforts to gather standardized data on the type of support that community health workers provide,[98] so any gaps in training and health services can be addressed.

Communication

Information and communication are a central tenet of establishing and maintaining trust. Clearly communicating medical information, including how it is used to guide decisions about a person's care, is vital to securing and maintaining trust.[99][100] Transparency and consistency in public health messaging and individuals' care plans can support people's health-related decisions, including their willingness to engage with healthcare providers.[100][101]

Health literacy: supporting an empowered population

Health literacy refers to people's ability to find, understand, and use information to guide health-related decisions.[102] As people build their understanding of health information, they can feel empowered in discussing their concerns with their healthcare professional. Research has found that having lower health literacy was associated with a lower likelihood of using medical websites for health information and a greater likelihood of using social media, blogs, and friends.[103] A 2018 survey from Taiwan found that people with higher health literacy had, overall, higher levels of trust in physicians and in the health system, even after the results were adjusted for other sociodemographic characteristics like age, gender, and education.[104]

Building health literacy is a continuous process that must reach all members of the population. Efforts to improve health literacy should be embedded within the entirety of public health approaches. Among other actions, this includes developing educational materials that resonate with specific communities, providing the materials in accessible formats, and building diverse networks to disseminate health information more effectively.[105]

Addressing misinformation: government communication initiatives

Mistrust or misunderstanding of official health information may lead people to rely on inaccurate sources. The level of trust that communities have in their healthcare institutions can affect how health information is received.[106] Evidence suggests that some people from communities that feel isolated because of racial prejudice, neglect, or historical marginalization may be more reluctant to follow public health advice or use official information sources.[106][107] Instead, they may turn to alternative and potentially inaccurate sources of data, engendering misinformation and obscuring health information.[108] The power of social media in distorting information and creating misinformation is well recognized.[109] The COVID-19 pandemic was an example of this phenomenon, with confusion and false information undermining scientific evidence;[106] limited perceived government transparency on vaccine research in some countries gave space for such misinformation to flourish.[110]

Governments and healthcare professionals can mitigate the negative effects of misinformation by providing clear, accessible, and accurate information.
Healthcare professionals and the pharmaceutical industry have a responsibility to ensure patients have clear information on health-related topics.[111] Governments should also transparently provide appropriate information in public health messaging. Health messaging needs to be sensitive to varying levels of health literacy, and it should also account for language differences and accessibility needs.[103] The format and method of communication is crucial: trusted messengers, including community health workers or community leaders, can be deployed to build on their relationships with the community and share health information.[112] In addition, with growing reliance on digital health information platforms, governments should support initiatives to improve digital literacy and should also work closely with healthcare professionals and community groups to develop appropriate and consistent messaging through these channels (*Case study 5*).

Case study 5. The role of governments in supporting responsible health messaging to overcome low vaccine confidence

Low vaccine confidence has been a growing concern over the past decade. When an outbreak of yellow fever was ongoing in Brazil in 2018, misinformation about vaccines spread via social media.[113] Such misinformation reportedly stopped people from getting vaccinated,[113] and there is wider evidence that anti-vaccination rhetoric on social media is correlated with lower vaccination uptake.[114-116]

While misinformation spread, the Ministry of Health launched the "Health Without Fake News" campaign.[117] [118] As part of the campaign, people could send health news and information to a WhatsApp number to check its accuracy.[118] In the first three months, almost 4,000 messages were received, 25% of which contained false health information.[118] A substantial number of the messages related to vaccinations.[117]

Consistency and transparency: building trust over time

People come into contact with the health system in various ways and settings; consistent communication across sources is paramount to maintain trust. Trust is not built in one interaction, but rather over time and through multiple interactions.[119] Messaging from different healthcare providers and services should be aligned with the most recent evidence so that people seeking care do not get confused by different data. For example, ensuring consistency in recommendations and practices as people transition from one health setting to another will be key to maintain their trust in the system.[120] [121] This may be particularly relevant for people with chronic conditions or disabilities, to whom changes in the evidence base and best practice over time should be transparently explained.

Information and communication must also adapt to changes in the way healthcare is delivered. The growing use of virtual consultations and telemedicine has helped break down geographical barriers, especially for those living in remote and underserved areas;[122] however, if virtual care is not carefully designed and implemented it also risks reinforcing inequities by excluding people who may be less comfortable with or able to use virtual platforms.[123] [124]

Data generation

As health systems become increasingly data-driven and digitalized, ensuring transparency in the way people's data are collected, used, and interpreted is fundamental to building trust. Data is the bedrock of evidence-based decision-making. But effective data collection requires that healthcare organizations are trustworthy: people need to trust that health systems are using their personal data appropriately, that it is not being shared without their consent, and that their right to privacy is always protected.[125] The governance of health data must also be made explicit – particularly as private-sector digital health companies become increasingly involved in healthcare, for example through mobile health apps and digital health platforms.

Mistrust of data collection systems may lead to reluctance to share data, and this may be particularly pertinent for members of traditionally under-represented groups. Healthcare organizations hold and examine patient data to identify ways to improve the quality, timeliness, and safety of care that they deliver.[125] A history of intentional and accidental misuse of personal data, which has often affected people from traditionally under-represented groups, has understandably contributed to reduced willingness to share data.[126] [127] In some instances, concerns about data privacy and mistrust of digital platforms may reduce people's willingness to share their data, these existing concerns may be exacerbated by AI-produced information.[128]

Standardized data collection: building a common foundation

Understanding diverse experiences and generating evidence-based solutions depends on the right data being collected and reported. In some countries, data cannot be collected, disaggregated, analyzed, or used due to inadequate data collection methods and tools.[39] [49] [51] [129] For example, Indonesia is experiencing challenges in collecting data on disability in children, as the data collection tools available are designed for adults and do not account for the typical variation in development during early childhood.[130] Internationally, many data sets on disability are collected on a one-off basis and disaggregated data is rarely included in electronic health records.[129] Such limitations in data collection create significant barriers to understanding the health needs of specific populations and developing targeted actions to address those needs. Several governments have taken steps to expand data collection and analysis to include key demographic characteristics such as ethnicity, race, gender, and sexual orientation (*Case study 6*).[38] [131] [132]

Case study 6. The push for equitable data in the US

Following the 2021 Executive Order 13985 on advancing racial equity and support for underserved communities, the US government established the Equitable Data Working Group.[39] In 2022, the group published a report called *A Vision for Equitable Data*, which featured a list of recommendations, including the following:[132]

- Make disaggregated data the norm, while protecting privacy.
- Catalyze existing federal infrastructure to leverage underused data.
- Build capacity for robust equity assessments for policymaking and program implementation.
- Galvanize diverse partnerships across levels of government and the research community.
- Be accountable to the American public.

The recommendations were developed based on consultations with advocates, experts, and affected communities.[132] The report was also based on robust interagency work to identify gaps in the evidence base and ways to address the lack of sufficient or disaggregated data.

Relevant federal and state agencies are in the process of adopting these recommendations.[133] If they succeed, authorities will have access to more accurate health profiles of different people and be able to develop effective and targeted health interventions accordingly.

Data collection methods and definitions should be standardized to ensure clarity and support transparent communication. Establishing standard definitions and methods for data capture allows comparison and consolidation of data between studies and data sources, and across time.[134] As more attention is paid to collecting data about traditionally under-represented groups, standardization in the way data are defined and collected will support greater understanding and monitoring of inequities as a basis of building evidence-based solutions. Standards should be co-developed with the populations being assessed, to ensure they are relevant and representative.

Transparent governance: responsible use, storage, and sharing of data

Ensuring security in the way people's data are handled is an essential shared responsibility between those involved in data collection, storage, and use. The emerging data ecosystem effectively requires data sharing across multiple platforms. Health systems must implement strong information-security measures to reduce the risk of accidental or deliberate disclosure, access, or damage – ultimately ensuring data are collected and shared in a way that maintains the trust of the people providing the data.[125] Health organizations must work collaboratively with policymakers and industry stakeholders to implement cohesive guidance and regulatory frameworks to protect data from misuse and make sure that people are always informed of how their health data will be used.

Data should be used responsibly, with benefits directly felt by the communities who provided the data. Health data should be directly used to improve clinical decision-making, refine care pathways, and increase efficiency of services – ultimately leading to better health outcomes.[135] Sharing the outputs and benefits of research with the people who provide the data will likely improve trust in health and research institutions.[135] Moreover, explaining how the data are analyzed can help overcome concerns about data privacy and management.[128] "Explainable AI" is one initiative that aims to do this, demonstrating to patients and healthcare professionals in simple language how AI has used data to come to its decisions and conclusions.[136]

3 We must act now to build trust

Trust is a fragile connection between members of the public, healthcare professionals, and the wider health system. Many people from traditionally under-represented communities have justifiably lost trust in the health system; ongoing discrimination, racism, implicit bias, and services that do not meet their needs have all contributed to this. Trust and health equity can exist in a mutually reinforcing loop: supporting health equity will help rebuild trust and, in turn, increased trust will enable greater engagement with the health system and improved health outcomes for traditionally under-represented groups.

Any intervention aimed at improving trust in the health system must be locally adapted and implemented. National governments must develop policies and provide funding to support change. It is then pivotal that health policies and interventions are co-designed and deployed in a way that meets the specific needs of the communities they are meant to impact. The recommended actions outlined in this report will have to be uniquely implemented in each local context.

Everyone has a responsibility to enact change. Inequitable health systems affect everyone, so each person must do their part in supporting members of traditionally under-represented groups. Governments, healthcare providers, non-governmental organizations, and industry must take accountability and leverage their position to advocate for and fund organizational change:

- Introduce mandatory, regular training for healthcare professionals on disability, cultural sensitivity, anti-racism, and active listening. Where this has already been introduced in legislation, ensure its regular implementation and monitoring.
- Update educational curricula to tackle historical biases in care.
- Ensure care is always person-centered and holistic, acknowledging the overlapping identities and unique circumstances of each person. Support workforce planning that gives healthcare professionals the time to listen and build relationships with people seeking care.

- Co-develop health policies with members of the group(s) affected by the policy. Advocate for inclusion of diverse perspectives in healthcare planning and shared decision-making.
- Implement requirements for health research to represent the diversity of the local and national population.
- Leverage the unique position of trusted messengers and community health workers to reach communities and communicate health information effectively, and offer training for people to fill these roles.
- Implement national standards to comprehensively collect disaggregated data on health outcomes for members of traditionally under-represented groups.

The time for action is now. We must act now to overcome increasing inequities, worsening health outcomes and growing healthcare costs. By acting now we can build more sustainable health systems, ready for the challenges of tomorrow. It is time to work together to earn back trust, to build equitable health systems, and to ensure no one is left behind.

Acknowledgments

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