



International Experience Exchange
with Patient Organisations



IEEPO 2026 Position Paper

Humanising Healthcare: a call for transformational change

IEEPO Position Paper: Foreword

We are on the brink of a new era.

Leaders from around the world are meeting to discuss action on climate change. Increasingly, scientific evidence demonstrates that climate change is impacting both people and the planet – from the air we breathe to the water we drink; everything is inexorably linked.

The leaders and negotiators at COP26 in Glasgow, UK, have a monumental task ahead of them. The future of our planet depends on them working together; to put their differences aside and address some of the biggest challenges our world has seen.

Change of this magnitude is also called for across our global healthcare systems, which has been confirmed by the choice of topics at the 2021 World Health Summit. A paradigm shift is needed so we can reconfigure how to distribute healthcare fairly and without prejudice around the world; and underpinning that paradigm shift is the need for partnerships. The IEEPO Position Paper is called “Humanising healthcare: a call for transformational change”. It is unashamedly ambitious in its call for action and it is all achievable, but one thing is for sure – we will not succeed without multi-stakeholder and cross-border partnerships both within and outside of the healthcare ecosystem, working in step with each other and other leaders around the world.

We need to cultivate an inclusive approach, engage effectively across different cultures, and put the needs of different people at the heart of what we do – this is humanised medicine, a critical component to bringing about transformative change to our healthcare system. We call upon the IEEPO community to lead this transformation.



Mary Baker,
Former President,
European Brain Council,
IEEPO External Advisory Committee member



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IEEPO 2021 contributor and keynote speaker



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Lay language summary

The International Experience Exchange with Patient Organizations (IEEPO) is a patient-led initiative that aims to improve healthcare systems around the world. The IEEPO community has written a Position Paper to help support this goal in two ways:



1.

To unify their views on how healthcare services need to change to deliver better care for patients



2.

To make specific recommendations on how this change can happen

At the heart of the Position Paper is a call to “humanise healthcare”. This means re-building healthcare systems around the needs of patients and their communities. The Position Paper also argues for governments and the pharmaceutical industry to spend equal amounts of money on prevention and treatment; schools to focus more on health education; and tech companies to continue to invest in new ways to help people monitor their health and navigate health systems quickly and efficiently.

Finally, the Position Paper calls upon everyone to help make these changes so we can have a better, fairer, and more sustainable healthcare system, for all.



Executive summary

For the first time in living history a pandemic closed down the global economy and brought healthcare systems to their knees. Even before COVID-19, cracks were beginning to show. Originally designed for acute care, our healthcare systems were being crippled by the needs of an aging and growing population, and pressure for a transformative change in how we deliver healthcare had begun. Systemic challenges identified in the healthcare systems include:

- ▶ **Siloed health systems where different specialities, disciplines and stakeholder groups work in isolation from each other**
- ▶ **The evolving role of the patient community in shared decision making in healthcare**
- ▶ **The need for improved communication, specifically between patients and healthcare professionals as well as other stakeholders**
- ▶ **The dominance of a 'one size fits all' versus a personalised care approach**
- ▶ **The lack of digital access, literacy and tools, together with the absence of a systematic and trusted digital infrastructure for sharing information**
- ▶ **Need for patient-led evidence and patient-relevant data**
- ▶ **Legal/privacy concerns over patient data**

Rebuilding healthcare systems around the needs of patients¹ and citizens alike need no longer be a dream. The explosion in technology and the use of social media present new opportunities to help us reimagine and rebuild. We need a compassionate and sustainable system, one that brings patients, healthcare professionals, and other ecosystem stakeholders closer together in more trusting and equal partnerships to deliver holistic care for better outcomes.

Humanising healthcare is key to re-building sustainable healthcare systems and improving personalised healthcare

The core concept of the Position Paper and the work of IEEPO is the importance of “humanising healthcare”. Busch, Moretti, Travaini et al. (2019) acknowledge that the concept of ‘humanising’ is not yet well-defined or clear. They define ‘humanised care’ in opposition to the automated, impersonal, mechanical procedures in healthcare that tend to result from the growing deployment of and reliance on technology.

Humanised healthcare is about working hand in hand with patients and all stakeholders to create a more personalised approach. However, digital illiteracy and the inaccessibility of digital solutions can undermine this process. An extensive report by The Lancet describes many of the challenges faced in the course of the digital transformation in healthcare with digital becoming a new determinant of health (Kickbusch, Piselli, Agrawal et al. 2021).

1. For the definition of the term ‘patient’, refer to EUPATI: <https://toolbox.eupati.eu/resources/guidance-for-patient-involvement-in-industry-led-medicines-rd/>



The IEEPO Position Paper defines and examines these challenges and opportunities across five categories (listed below) and provides a roadmap for change that is validated by the international patient community.

- 1 Putting people at the heart of healthcare**
- 2 Humanising health literacy**
- 3 Humanising digital healthcare to build capacity by harnessing the power of patient data**
- 4 Humanising healthcare to focus on prevention and cure with a new 50:50 model**
- 5 Prioritising inclusion to humanise approaches to healthcare**

This Position Paper is unashamedly ambitious, whilst also suggesting and providing practical, evidence-based ways to make personalised healthcare achievable, working with innovators, tech, healthcare professionals, the biopharma/pharma industry, regulators, schools, academia, and governments to transform healthcare ecosystems.

Supporting evidence, published here for the first time, has been drawn from the IEEPO survey which was carried out in August and September 2021. The survey received 304 responses from patient representatives across the following regions: Europe, US/Canada, Asia Pacific, Latin America and Middle East & Africa. Results were also complemented by extensive desk research and expert interviews, building on the outstanding work that has already been done in this field.

Our goal is action!



**Change won't happen overnight but if we unite for change,
we will be able to transform our healthcare systems, together**
IEEPO External Advisory Committee (EAC)



It's imperative to work with all stakeholders across healthcare to advocate for a fundamental shift in the way we deliver healthcare that is built around the needs of people and their communities. Our calls to action are broad and all encompassing; we call upon governments to reconfigure and synchronise the delivery of primary and secondary care with a greater investment in prevention; schools and academia to partner with their local patient organisations to help build health literacy, the tech industry to continue to invest in information technology (IT) to bring patients and healthcare professionals together in more trusting and equal partnerships. Finally, we all need to take a more proactive role in understanding our individual health needs whilst we simultaneously call for change.

All chapters and topics in this Position Paper contain specific calls to action for different stakeholders in the healthcare system. These can be found at the end of each chapter. The IEEPO patient community will, together with its constituencies, work all over the world to translate these general calls to action into concrete and specific activities that respect the circumstances and cultural backgrounds of different settings.

We acknowledge, not all of the recommendations and calls to action in this Position Paper or in healthcare governance are easily applicable or feasible in resource-constrained settings.

To share best practices, each chapter includes at least one case study highlighting successful initiatives in that area.

Special thanks to IEEPO's External Advisory Committee for their support and contribution in developing this work and to the IEEPO patient community for their participation in the survey that underpins our findings.



Chapter 1:

Putting people at the heart of healthcare

Authors: Kin Ping Tsang, President, Rare Diseases Hong Kong; Mary Baker, Former President, European Brain Council; Mayra Galindo Leal, Director General, Mexican Association of the Fight Against Cancer

Imagine a healthcare system where compassion and care are valued equally



Problem Statement

Healthcare professionals (HCPs) need to “see” and treat the patient - not just the illness. Effective treatment and care combined with compassion and empathy lead to better health outcomes (Sinclair, Norris, McConnell et al. 2016). **A more holistic approach is therefore needed in healthcare; one that considers the patient, the caregiver and the HCP all as human beings with complex needs and circumstances.** This should be inherent in the daily work of HCPs, as it is often missing as described, for example, by Haslam (2015): “Compassion is not an optional extra, but far too frequently it is seen as being much less important than other aspects of care”.



Discussion Summary

The human rights perspective

A human rights approach to health is strongly believed in and endorsed. This Position Paper has been developed with the main objective of promoting inclusive access to healthcare, with a strong call to all stakeholders to respect human rights, specifically the right to health.

The Universal Declaration of Human Rights (UN, 2015) states that “everyone has the right to a standard of living adequate for the health and well-being of him/her and of his/her family, including food, clothing, housing and medical care and necessary social services”. The right to health is an inclusive one composed of different aspects that include freedom from discrimination and the right to health-related education among others.

The right for people to receive the healthcare services they need, when and where they need them, without experiencing financial hardship, referred to as universal health coverage below, also depends on patients taking a proactive role in their individual health. By assuming more responsibility for self-care, and engaging actively in preventative measures, patients can significantly reduce the burden on healthcare systems.

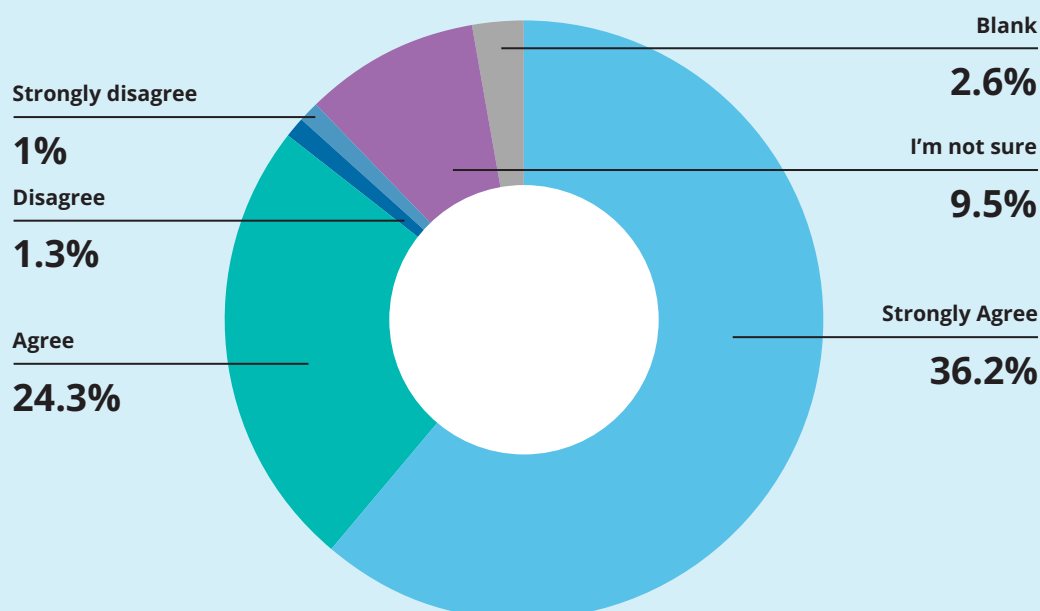
Findings from the IEEPO global patient survey demonstrated a clear ask for universal health coverage.



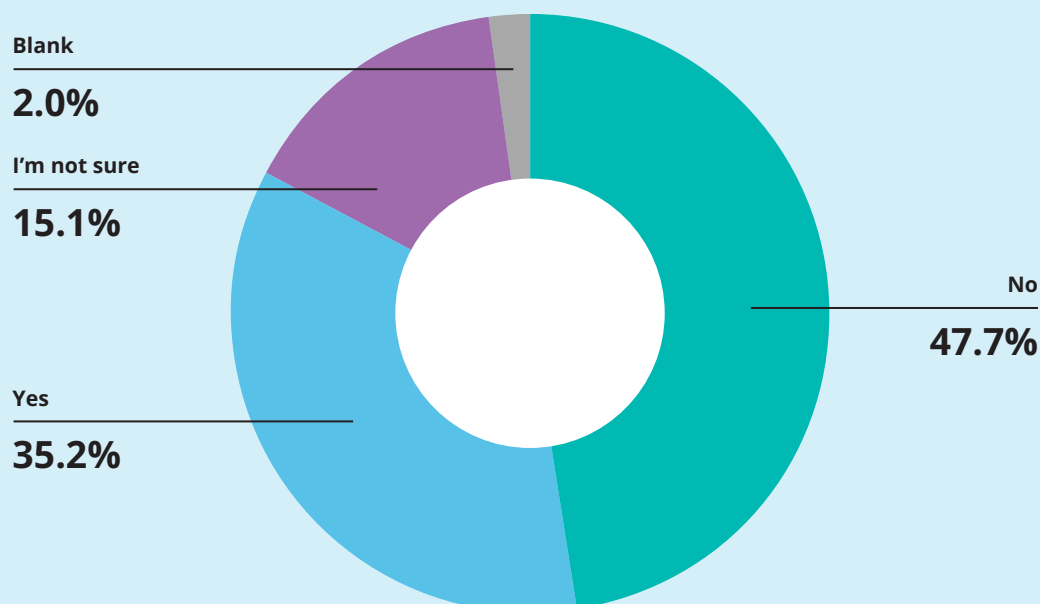
85.5% of the respondents agreed or strongly agreed that universal health coverage should be the goal when governments are investing in health. At the same time, the survey results also demonstrate that this is not happening to a satisfactory level everywhere.



To what extent do you agree with this statement: 'Universal health coverage should be the goal when governments are investing in health, to provide health services people need without financial hardship?'



In your opinion, does your country's healthcare system provide universal health coverage? *Universal health coverage is defined as: all people receiving the health services they need, when and where they need them, without suffering financial hardship, across the life course.*



When asked about the availability of universal health coverage in their countries, 47.7% of the respondents said it did not exist, while 15.1% were not sure. Not being sure if there is universal health coverage for the people who need it is more indicative of it not being available.



There is acknowledgement that healthcare systems across many different countries may have more pressing priorities, especially after the COVID-19 pandemic. However, the principles of fairness, inclusivity and humanisation should underpin all stages of the evolution of healthcare systems. The term compassion is defined as sensitivity shown in order to understand another person's suffering, combined with a willingness to help and to promote the wellbeing of that person in order to find a solution to their situation.²

Human beings are emotional creatures, and our emotions interact with and directly impact our physical health. Compassionate care that is sensitive and respectful of a person's pain as well as their emotional state can therefore transform health service delivery and lead to improved patient health outcomes.

Compassion also needs to be extended to healthcare professionals. Overburdened even before COVID-19, the situation worsened considerably during the COVID-19 pandemic with 50% of HCPs reporting burnout, according to a global study (Morgantini, Naha, Wang et al. 2020). Overburdening makes it even more difficult for healthcare professionals to find the time needed to provide the compassionate care that their patients need. This in turn can lead to a lack of trust and rapport between patients and HCPs that undermines entire healthcare systems. Compassion should not be an optional extra, however, far too frequently it is seen as being much less important than other aspects of care.

The IEEPO global community survey demonstrated that there are considerable shortcomings when it comes to the provision of compassionate healthcare.

37.5% of the respondents said that individual patients' needs are not recognised or treated with compassion in their country. Another 22.7% said they were not sure if this was the case, suggesting that even if there is compassionate care, it is not sufficiently visible.



To what extent do you agree with this statement: "Individual patients' needs are recognised and are treated with compassion by the healthcare providers in my country."

Blank

5.6%

I'm not sure

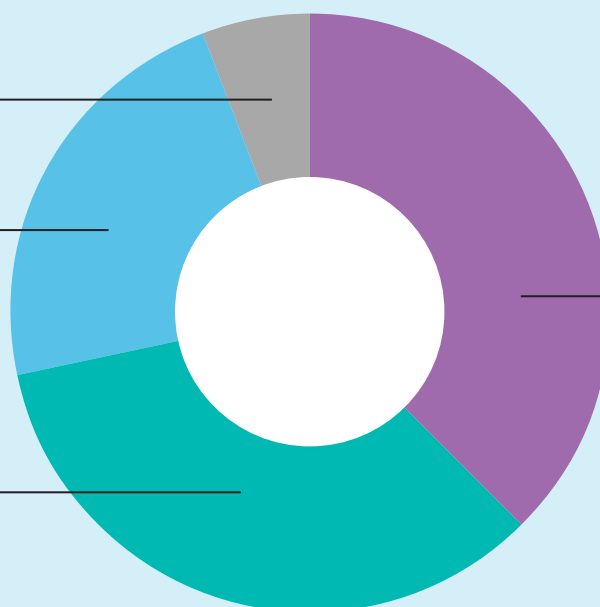
22.7%

Yes, I agree

34.2%

No, I don't agree

37.5%



2.<https://dictionary.cambridge.org/dictionary/english/compassion>



When asked specifically about compassionate care, respondents indicated three main challenges:

- ▶ **Insufficient resources**
- ▶ **Largely dependent upon the personal attitudes and mindsets of healthcare professionals**
- ▶ **Lack of digital tools that could streamline healthcare and improve efficiency, thus freeing up time and resources for compassionate care**

Paradigm change

Transforming healthcare into a more compassionate and humanised system requires a paradigm change. Instead of focusing on symptoms and illnesses, focus needs to be shifted to the people affected by them, acknowledging that the lives of patients, their caregivers and families are often profoundly changed or affected by an illness.

A more humanised and compassionate healthcare system also relies on listening to each other more. Improved listening skills will help further understanding, inform better joint decision-making and support co-creation of solutions and/or initiatives leading to better outcomes that matter to patients.

Improving health literacy to support self-care and empowering patients to take a more proactive role in managing their own health, also underpins this paradigm shift. The specific challenges in health literacy, and some suggested solutions are discussed in the chapter “Humanising health literacy.”

The evolution in data technology needs to be managed to help ensure healthcare becomes more humanised (as opposed to automated) and respectful of the different needs and circumstances of people. The chapter “Humanising digital healthcare to build capacity by harnessing the power of patient data” offers further insight and concrete proposals on how this could be achieved.

The International Alliance of Patient Organisations (IAPO)³ has also identified the five key elements of patient-centred healthcare:

- ▶ **Respect for everybody**
- ▶ **Empowerment and choice of preferences in healthcare services**
- ▶ **Participation and engagement in the healthcare system for patients on all levels and points as they know best what they need**
- ▶ **Information: the healthcare system should provide relevant and accessible information for all patients**
- ▶ **Support and service: a more holistic approach is needed**

Respect for all is prioritised as it is the fundamental requirement for humanised and compassionate healthcare. It is also one of the most important recommendations of this Position Paper.

Doing it together

The views and perspectives of patients still need greater legitimacy; and the institutional framework for authoritative patient involvement and co-creation is still missing.

Patient organisations should participate in and be better integrated into the medical education of healthcare providers in order to provide the patient perspective early on in their careers. Over time, a more empathetic and humanised approach to healthcare can emerge if all professions involved in healthcare service delivery learn how to work with patients, i.e. co-create with patients. Conversely, the conscious integration of patients (and their organisations) into medical education will further educate patient communities about the particular problems and challenges faced in healthcare.

3. <https://www.iapo.org.uk/>

Building upon IAPO's five key elements of patient-centred care, it is essential that patients are able to work efficiently within the health policy arena. More direct contacts and structured exchange between policymakers and patient communities should be built.

The chapter "Humanising health literacy" discusses the importance of self-care and the acknowledgment of traditional knowledge in health. These objectives also call for increased and enhanced cooperation with stakeholders in healthcare beyond the pharmaceutical industry and healthcare professionals. At the same time, it is imperative that patients and healthcare professionals build a stronger two-way rapport with each other. It is encouraged that doctors and nurses listen and really hear and understand their patients' needs; and likewise for patients to understand the pressures that the medical professions are also under as they try to help them. The need to strengthen partnerships between people with illnesses and healthcare professionals is critical. This process is not about demanding patient rights, it is about the exchange of solid and helpful information in order to support informed decision-making and better holistic care including self-care.

Last but not least, the continuation of meaningful and sensitive conversations across the broader industry including biopharmaceuticals, medical device manufacturers and pharmaceuticals is crucial. Despite this being a highly politicised and often conflict-ridden field, strong working relationships between the pharmaceutical industry and patient communities are essential and productive. Some describe this relationship as parasitical on both sides. In fact, it is a symbiotic relationship that creates mutual value for patients and society throughout healthcare systems: all stakeholders (and the state as well) need each other to thrive (Bereczky 2019).



Case Study: Australia's National Oncology Alliance

Project background and objective

National Oncology Alliance (NOA) is a coalition of cancer stakeholders founded by Rare Cancers Australia, bringing together patient organisations, patients, clinicians, and industry. Roche was one of several founding supporters of the alliance. NOA is co chaired by Rare Cancers Australia Chief Executive Richard Vines and Director of Cancer Medicine at Melbourne's Peter MacCallum Cancer Centre, Prof John Zalcberg.

The cancer community in Australia is fragmented, with different stakeholders often working in isolation to develop strategies to improve cancer care. This piecemeal approach risks not being able to realise the full promise of new science and emerging health technologies.

NOA set out to work collaboratively across the cancer community to co create a proposed 10 year national plan for cancer care in Australia. The aim was to bypass the entrenched positions and status quo and capitalise on the opportunities presented by emerging health technologies.

Activity detail and stakeholders involved

NOA began by issuing a discussion paper making the case for a new 10-year national plan for cancer care, followed by a series of 12 virtual workshops with a range of experts to discuss emerging therapies, patient centred care, AI and big data, genomics, clinical trials etc. Over 1,000 people attended, with an average of 85 per session, which formed the basis of the final Vision 2030 report.



The report articulates the future of cancer and identifies elements of the health system that will require change if patients are to achieve the best possible outcomes as treatments evolve and emerge over the next decade. The report was presented to the Minister for Health days before its public launch at Rare Cancers Australia's annual policy conference CanForum, which was attended by more than 1,000 stakeholders and opened by the Minister, who endorsed the report.

Activity outputs and outcomes

The Minister has referred the report to Australia's peak government cancer control agency Cancer Australia and asked them to implement it.

Cancer Australia's CEO is due to provide a progress update at Rare Cancers Australia's annual cancer congress in November 2021.

Further information: <https://www.rarecancers.org.au/>



Call to action

- 1** Patient organisations should facilitate conversations with all stakeholders about the need and value of compassionate care.
- 2** Create a Global Compassionate Care Charter in partnership with healthcare professionals, the patient community, and policymakers to educate on the integral, evidence-based value of compassion in healthcare, and gain support from policymakers and other stakeholders. Resources and tools need to be developed to support the creation of the Charter.
- 3** Bringing patients, caregivers, healthcare professionals, and other ecosystem stakeholders closer together so that they can listen to each other and understand different perspectives is key. One way of achieving this is to allow patients to participate in the medical and scientific conferences. This idea is explored further in the chapter: "Humanising health literacy".
- 4** Established patient communities should help develop patient organisations in resource-constrained countries to help ensure the global reach and education of all stakeholders.



Chapter 2:

Humanising health literacy

Authors: Alastair Kent, Former Executive Director, Genetic Alliance; Susan Thornton, Chair, Lymphoma Coalition

Imagine a healthcare system that complements evidence-based medicine with self-care and traditional knowledge about health. A healthcare system that acknowledges and respects traditional knowledge and elevates it to the level of evidence-based medicine.



Problem Statement

Lack of self-care and poor health literacy can result in people taking less responsibility for their own health and not engaging effectively with their healthcare systems.

Health literacy refers to a person's ability to understand and use information to make decisions about their health

Self-care is the process of taking care of oneself with behaviours that promote good health and encompasses good choices, exercise, sleep and proactive management of illness

Paakkari and Okan (2020) give the following guidance in their article: "Health literacy should be seen in relation to social responsibility and solidarity and is needed from both people in need of information and services and the individuals who provide them and assure their accessibility for the general population."



Discussion Summary

Self-care has been an integral part of health and social services around the world for millennia. In its Guideline on Self-Care Interventions for Health and Well-being (2021), the WHO acknowledges the growing importance and urgency of self-care interventions in healthcare systems under duress.

Around the world, there has been a significant change in the general public's behaviour as a result of the COVID-19 pandemic. Many people have become more empowered in their self-care but the pandemic has also highlighted how poor health literacy can act as a barrier to self-care and as well as being an underestimated public health problem. For example, Leese, Backman, Ma et al. (2021) describes the importance of physical and mental self-care in rheumatoid arthritis patients with special focus on the impact of telemedicine. Another study conducted in several South-American countries confirmed that the prevalence of self-care practices increased after the first pandemic lockdown (Bermejo-Martins, Luis, Sarrionandia et al. 2021).



A consequence of the COVID-19 pandemic is the 'COVID Infodemic.' In a joint statement, WHO, UN, UNICEF et al. (2020) describe the infodemic as "an overabundance of information, both online and offline. The consequences of the infodemic are clearly visible: confusion, misinformation leading to decreased trust in science and the spread of wrong or misleading information about vaccines and ignoring health information because it is too overwhelming to understand (Hotez 2021). Conflicting attitudes have surfaced that ironically and simultaneously reject the authority of the state in health-related matters while relying on the state for healthcare services more than ever.

Self-care will not improve unless people have a better understanding of biology and medical language. Improvement in health literacy needs to be driven by people who are using health services instead of people who deliver them, a recommendation that is referenced in this chapter's calls to action.

Health literacy is still too weak

In their analysis of knowledge maps of health literacy research, Qi, Hua, Xu et al. (2021) found that health literacy needed improvement, even in academic circles, and that cooperation and the exchange of information between stakeholders is far from ideal. In a German study comparing the health literacy of the population before and after the COVID-19 pandemic, Schaeffer, Berens, Gille et al. (2021) found that 58.8% of the population still have very low health literacy levels, despite a 3-percentage point improvement observed as an effect of the pandemic.

The democratisation of science

There is often a wide and harmful gap between the scientific community and the general public. The effects of this are increasingly visible in the growing anti-science sentiments and movements during the COVID-19 pandemic, undermining the related vaccine research and rollout efforts (Hotez, 2021). There are several explanations for the erosion of respect for science, which stem mainly from psychology and political science (e.g. Burrage 2015; Saltelli 2018; Hotez 2021).

It is not sufficient to blame biases and lack of education when trying to understand why science is losing its reputation. When sharing medical information, further thought and care needs to be considered to ensure it's clear, succinct and simplified. Even if science is not always straightforward or cannot posit ultimate truths, some key messages can and should be conveyed in a manner that makes them justified and unambiguous.

Patient organisations can play an essential role here. Already, many patient organisations are involved in the development of lay language summaries in a wide variety of situations including the development of research protocols and the writing of patient information and package leaflets, as well as a host of other educational materials. However, information should continue to be delivered to people in creative formats that engage them, such as audiobooks, podcasts, visuals (videos and drawings), theatre, etc. In order to communicate information effectively there needs to be a thorough understanding of different patient populations. In October 2021, the European Commission published a Good Lay Summary (LS) Practice that outlines the most important principles for why and how summaries should be developed. The guidance states: "The contributions from patients should be regarded as valuable input into LS planning, review and dissemination, ensuring the suitability of the LS for patients, trial participants and the general public. Patients can contribute by providing perspectives and terminology that may be different to those of researchers and healthcare providers.

Social media plays an important role in communicating understandable science and today, a considerable amount of patient data with transformative power comes out of social media. For example, if one person tweets about a weird side effect or symptom, someone else from the other side of the world might respond with a similar experience – then another, then another and so on. After two weeks, they set up a group for themselves to continue the discussion, and that's how a community can be born on social media. It has allowed the creation of large, international, even global disease communities that have developed through sharing information.

The real-life patient experiences that are built via these online communities can pull together what was previously sporadic information into a large body of meaningful evidence.



The role of education and its intersection with health

Transformational change is not just the responsibility of healthcare systems, it also includes:

- ▶ **Investment in health literacy**
- ▶ **Understanding the role of education – including academia**
- ▶ **Recognising the contribution of the biopharmaceutical industry in creating open and transparent dialogue**
- ▶ **Caring for a sustainable approach including our environment to minimise air pollution and support broader environmental goals**

Traditionally, patient organisations have played a key role in promoting health literacy. Many of them, especially umbrella organisations like the European Patients' Forum, Rare Cancers Australia, EURORDIS, RARE-X, IAPO, EUPATI, and community-led programmes and platforms like IEEPO have an excellent track record in providing educational resources, training programmes and comprehensive libraries for health-related education - both general and disease specific.

Designing and developing health literacy materials can also be achieved together with other communities. Community-based groups, including faith-based institutions, schools and universities and grassroots organisations, can all play a valuable part. Kramish Campbell, Alicock Hudson, Resnicow et al. (2021) describe the significant role of local institutions in advancing health education and participatory research. A study from India acknowledges the role of public schools specialising in health education and urges for the development of their network (Jain, Joshi, Bhardwai and Suthar 2019).

These efforts and projects deserve support and should not be seen as competitive but rather complementary to the offerings of educational systems. In order to ensure that patient groups can continue this important work the following resources need to be secured: unlimited and safe access to state of the art scientific information, broad and reliable disease information, educational resources, advocacy, including tools for advocacy capability development, and advocacy resources. This is why there is a call for the admission of patient experts and representatives into medical scientific conferences and symposia, and various open access initiatives in scientific publishing.

Aligning patients (especially expert patients and organisations) with the circulation of scientific information will not only make sure that they can disseminate credible and reliable information, it will also contribute to the democratisation of science and in turn, increase inclusion. It will facilitate a better bidirectional flow of information: not only will patients better understand what is happening in health-related research, they can also contribute more by collecting, organising and analysing real-world patient data and making it relevant for the wider scientific community.

The anti-vaccination movements that emerged in the wake of the COVID-19 pandemic provide an excellent example in which one can observe the impact of health illiteracy. It is strongly believed that a general lack of understanding of what a vaccine is, and what effect it has on the body's immune system, has fuelled the anti-vaccination movement.

If health literacy was taught in schools from an early age, all citizens could grow up with a better understanding of how their bodies work and the role of science (medicine and otherwise) in maintaining and restoring their health. Consequently, improving health literacy is an overarching need encompassing health and educational policy, ethics, and active policy making on the part of governments.

Attitudinal change is needed in governments and healthcare systems, and other stakeholders as well. New approaches should be centred around the cooperation of equals for common objectives, such as access to health and realising that money spent on prevention and healthcare is an investment in the future rather than a sunk cost.

The pharma and biopharma industry also plays a role. A culture of openness to build active trust in research and development, with all key stakeholders working together in partnership based on shared values in order to achieve this.





Case Study: Song and dance in disease prevention in Sub Saharan Africa

Project background and objective

With almost two-thirds of all people living with human immunodeficiency virus (HIV) there, the region of Sub Saharan Africa has seen a ravaging impact of the pandemic. In addition to the very high number of people, especially women living with HIV, the number of annual new infections is also the highest globally.

The usual prevention, disease awareness and health messaging developed for the Global North does not always work well in settings in Sub Saharan Africa where the population affected by HIV is different from the Global North, literacy levels are not always on par, and cultural traditions are different from those in countries where scientific research and political advocacy around HIV/AIDS are devised.

There are some important health related messages that people living with HIV can benefit from regardless of the setting they live in, and which can make it easier for them to pursue self-care and prevention.

Due to the similarities between the HIV and the COVID-19 pandemic, several approaches developed for HIV prevention and health literacy in Sub Saharan Africa can also be implemented in COVID-19.

Activity outputs and outcomes

HIV related songs and dance have become an important vehicle to distribute key health messages to populations that are hard to reach by printed materials or social media (Browning)

Based on the numerous projects in the dissemination of prevention, treatment and health related information through the use of arts (including but not limited to song and dance), a substantial body of evidence has emerged, which can be adapted also to settings different from Sub Saharan Africa.

Non-traditional, arts-based methods used in HIV/AIDS are increasingly used in COVID-19 related education and information work (Thompson, Nutor, Johnson 2021).

Further information: https://www.nashvillescene.com/arts_culture/dancing-their-disease/article_ed2d0e31-feaa-5e88-909a-92ff5c9f7632.html





Call to action

- 1 Stakeholders should develop joint strategies that address the current challenges in achieving health literacy by incorporating the specific needs of patient populations so that they are involved in the design, and delivery of solutions. Example challenges include, elderly patients may be socially isolated as a result of the pandemic, digital illiteracy and the 'digital divide' affects how people access health information and therefore manage their own health.
- 2 Governments should invest strategically in health literacy education and to mandate health literacy as a fundamental life skill to be taught in schools.
- 3 Patient organisations need to be resourced and supported by all stakeholders to enable them to play their own part in advancing high quality research and healthcare that is relevant, user friendly and able to make best use of scarce resources in order to maximise health gain.
- 4 Develop a lay-person's guide or global glossary of the concepts and phenomena in the healthcare system that affect everyone. Such a glossary can then be adapted to the local needs and circumstances. The participation of patient experts and patient organisation representatives in scientific and high-level policy and health technology conferences needs to become standard practice. This requires the clarification of underlying legal constraints and regulations in some regions of the world.



Chapter 3:

Humanising digital healthcare to build capacity by harnessing the power of patient data

Authors: Durhane Wong-Rieger, President & CEO, Canadian Organization for Rare Disorders; Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations; Nicola Bedlington, Former Secretary General, European Patients' Forum; Nicole Boice, Co-Founder, RARE-X Founder, Global Gene

Imagine a healthcare system where digital is a determinant of health, and which respects the data acquired from and generated by patients and acknowledges their contribution to science.



Problem Statement

Data ties the individual and the system together as, without data, there is no such thing as personalised health. Eliassen (2021) suggests a new social contract that is respectful of not only the existing human rights perspective but also considers the rights associated with personal (and health) data. A proposed new social contract could encourage individuals to be active participants in, and take more ownership over, their health. This necessitates empowering patients and the general public to generate and share data responsibly and be empowered to use digital healthcare. While digitalisation plays an increasing role in the evolution of healthcare, there are substantial gaps in its implementation that need to be discussed and tackled.



Discussion Summary

Digital healthcare has become an important trend and future direction in healthcare, especially in resource-rich countries. This acceleration of digital health services and research has been documented by e.g., Beaverson in 2020, and then also in a Briefing to the European Parliament in 2021 (Negreiro 2021). A proposal of 2021 from the US White House's Office of Science and Technology Policy suggests the exploration and implementation of an "AI Bill of Right,"⁴ i.e. a comprehensive framework that provides a "good way to regulate artificial intelligence's role in shaping a fair[er] society without deciding what that society should look like, including how power should be balanced among individuals, corporations and the government" (Walsh, 2021).

The role of digitalisation in healthcare

Eric Topol suggests that digital health tools and applications will change healthcare in the near future and will also lead to more control by patients in terms of what happens to their health and data (2015), with this trend confirmed in a study by the Copenhagen Institute for Future Studies (2021). They find



that “health literacy in the future comes from turning personal health data into knowledge that helps individuals understand how their behaviour affects their health in the long term and how to act on this knowledge.” However, the accessibility of digital health tools is not uniform across communities around the world: these technologies tend to be expensive, a large portion of them are not available under open access, and they are otherwise resource-intensive. A report published in The Lancet points out that “the effect of digital transformations has been so pervasive that it might soon become a dominant prism through which we can understand and address health and wellbeing dynamics” (Kickbusch, Piselli, Agrawal et al. 2021).

Digital health technologies need to be aligned with country infrastructures and support services as also acknowledged by the WHO’s Global Strategy on Digital Health 2020-2025: “countries will adopt digital health in a way that is sustainable, respects their sovereignty, and best suits their culture and values, national health policy, vision, goals, health and well-being needs, and available resources” (WHO 2021). Gaps exist regarding local research and implementation of digital technologies which are currently mostly focused at global and aspirational levels. Groth, Nitzberg and Zehr (2019) state several challenges in the development and increased use of AI: vague or non-existent definitions of what AI is; very general strategies and vague objectives; scepticism; fragmentation; and the lack of computing capacities.

Member States of the World Health Organization (WHO) have adopted the Global Patient Safety Action Plan 2021–2030 (GPSAP 21-30) at the 2021 74th World Health Assembly, through its Decision WHA74(13) Agenda item 13.1. The GPSAP 21-30 has made room for patients to be owners and generators of patient safety data through the Framework for Action - The 7x5 Matrix and ensured a constant flow of patient and family generated data, information and knowledge to drive mitigation of risk, a reduction in levels of avoidable harm and improvements in the safety of care.

Further, each WHO Member States, when deciding in adopting the GPSAP 21-30 at the 74th World Health Assembly, resolved to work in collaboration with and include data from other stakeholders in addition to patient organisations in their society like their national civil society organisations, professional bodies, academic and research institutions, industry, and other relevant stakeholders to promote, prioritise and embed patient safety in all health policies and strategies.

Data and the person

With the explosive increase in the collection and processing of health-related personal data, the individual becomes their own biobank (Hafen 2019), storing large amounts of relevant data that make sense on their own and also as part of a big data environment. However, integration requires a bidirectional flow of data: from the patients to the data processors, and from the data processors back to the patients. It’s important to ensure that there is a feedback loop to patients on how their data is used to improve prevention, diagnosis, treatments, and services. This feedback loop will, in turn, empower them to advocate for wider data sharing.

Despite some progress with the implementation of the UN’s Sustainable Development Goals5, not everybody is accessing or is even aware of their basic human rights. However, the smart use of health data should direct both people and data towards more inclusive access to healthcare, and evidence-based patient advocacy also requires reliable data. The WHO suggests in its Global Strategy on Digital Health 2020-2025 that “digital health will be valued and adopted if it: is accessible and supports inclusive and universal access to quality health services.”

Closer cooperation across stakeholders including public institutions, companies and patients is essential. From the history of patient involvement in policy and research it’s clear that patient organisations are in an ideal position to facilitate cooperation. For example, involving patients in the innovation cycles is essential as they are the end users, and increasingly manage data. Some patient organisations have already begun to act as “honest data brokers” Hafen (2019).

Patient data should thus be seen as the expression of the experience of the patients. Data can be cold, objectified and quantified, but it can also be filled with life if the focus is shifted back on the experience of the person represented by the data. Even in the case of simple metrics like blood pressure and weight – the question should also be asked: is the person living well and happy? Are they healthy?



Harnessing the power of patient data

The emergence and development of big data has affected life profoundly. Research topics are prioritised and healthcare systems are organised around different priorities now, and these priorities are increasingly linked to data. When assessing the impact of data, Hunter (2020) speaks about the “industrial revolution in biomedical research.” Patient constituencies are rightly concerned about how the misuse of data can be limited. At the same time, many patients are casual about the use of their data, and they need to understand what their data is used for and by whom. Referencing the Consultation Paper on Citizen-controlled health data sharing governance (Dantas, Mackiewicz, Tagueo 2020), the European Patients’ Forum points out: “technology will always find its way if a culture of trust is settled first. Indeed, trust is seen as the cornerstone of this equation.”⁶ A reasonable framework is needed to protect the integrity of patient data and minimise abuse, and to build trust. As argued below, there can be no personalised and humanised healthcare without the responsible use of data.

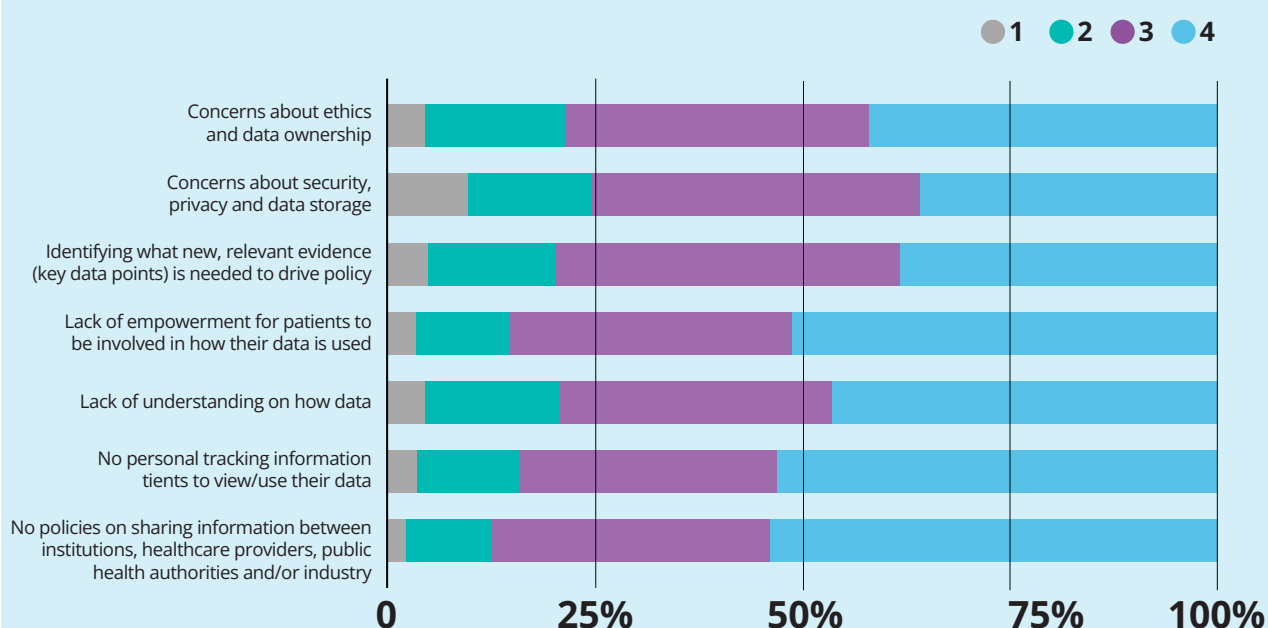
An important piece in the puzzle is the area of confidence and trust around responsible data sharing. The concept of ‘responsible data sharing’ is relatively new, and it is work in progress. One meta-analysis suggests that while there are some convergent basic principles around what responsible data sharing means, a consensus or generally accepted, universal guidelines have not yet emerged (Kalkman, Mostert, Gerlinger et al., 2019). The same authors suggest the following areas to consider when working towards responsible data sharing:

- ▶ **Societal benefits and value**
- ▶ **Distribution of risks, benefits and burdens**
- ▶ **Respect for individuals and groups; and**
- ▶ **Public trust and engagement**

The IEEPO global community survey states a clear need by patient communities to have more influence in and control over how data are shared and used.



What are the biggest barriers for the patient community / your organisation when it comes to generating and/or using patient data? Please rank using a scale of 1 to 5 (1 = lowest barrier, 5 = biggest barrier)



6. <https://datasaveslives.eu/blog/building-citizen-trust-in-the-digital-society122020>

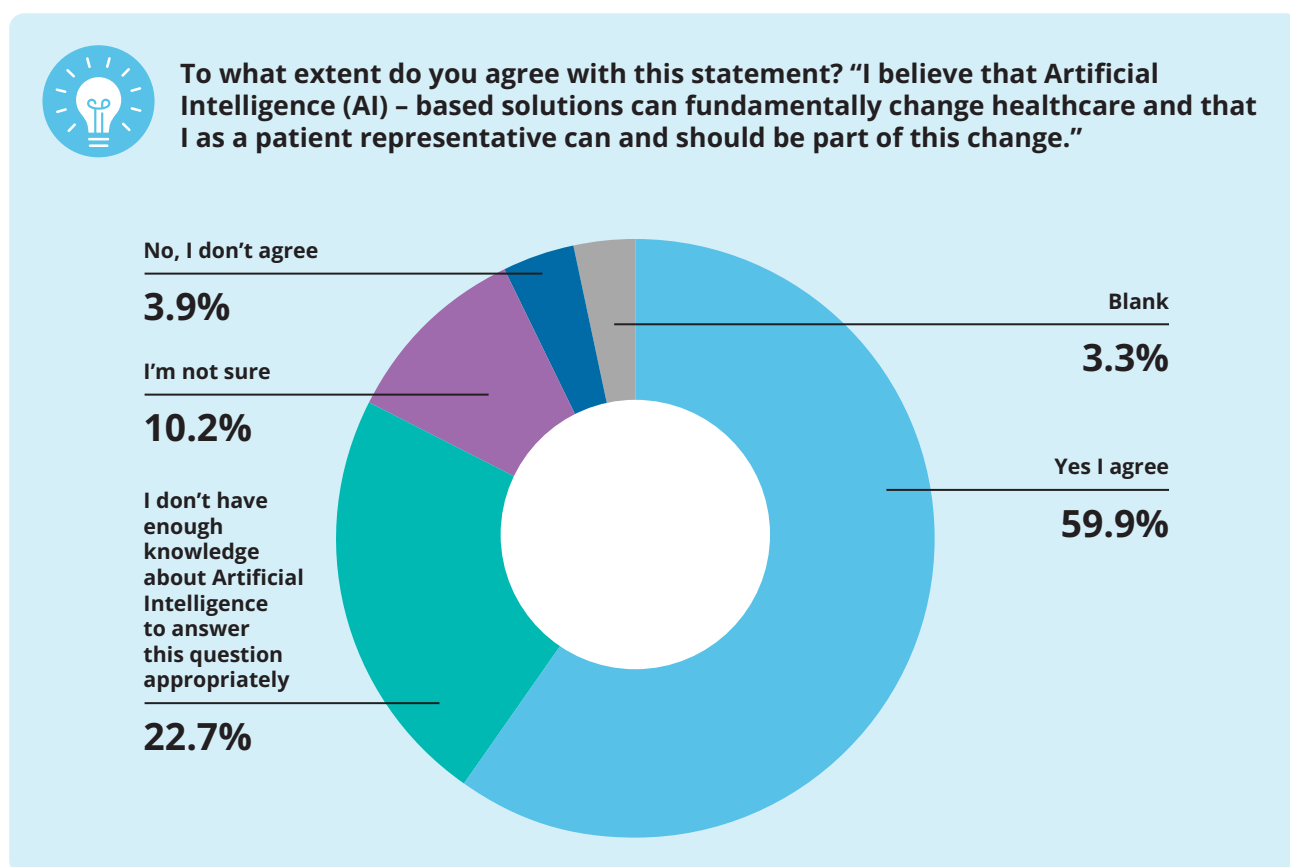


When asked about the biggest barriers for the patient community when it comes to generating and/or using patient data, the respondents saw the lack of clear policies on sharing data across different stakeholders as the most important factor that prevents them from participating.

Initiatives like Data Saves Lives⁷ try to deepen and enlarge the scope of responsible data sharing by discussing quality mutual information. This aspect is discussed in more detail in the chapter on “Humanising health literacy.”

One major concern remains: how does one collect, analyse and utilise real-world evidence? It's believed that the key to the ultimate transformation lies there. Patients should be able to collect and mine information in a way that can help them make important healthcare decisions. Artificial intelligence (AI) can be a major asset in this field as AI can come up with meaningful explanations and evidence. Real-world patient data is key to incorporating real-world evidence in the body of scientific research consistently and meaningfully.

The IEEPO global community survey asked the patient communities specifically if they wanted to be part of this transformative process in terms of the deployment of artificial intelligence in healthcare.



Almost 60% of the respondents agreed with the statement that patient community representatives should be part of the change brought about by the use of artificial intelligence.

This approach should lead to more recognition of and respect for traditional knowledge in health. This refers to anecdotal knowledge and experience that has not until now, been captured and described in the scientific paradigms (such as randomised clinical trials or studies). Traditional knowledge can also be turned into evidence with the help of big data and artificial intelligence (e.g., Mainenti 2019). Inclusion of traditional knowledge will also help reflect different cultures and societies as it allows consistent focus on certain aspects or parameters that are universal, such as biological features (Mukerji, Sagner 2019). It also allows the comparison of universal features of humans with variables that allow for diversity - genetic diseases and their treatment being a case in point. Real-world data will look different in different

7. <https://datasaveslives.eu/>

societies and cultures; therefore, contextualisation is key as it will change the utility of the data. In summary, traditional knowledge that now exists mostly as anecdotal evidence can and should be elevated to the level of reliable scientific evidence, thus creating a gateway to respectful and personalised healthcare.

Who controls the data?

Can it be argued that patients should control their own data? The jury is out on whether it is patient ownership or control that is needed. Patients need to be able to access their own data at any time and contribute with their experience. This is because patients are keen to see principles in place for the easy exchange of data across systems, so that the same information is given over and over as they move through the healthcare system. An environment needs to be created where data can flow freely across the systems without the need for costly and cumbersome interfaces and transformations. The proposed new European Health Data Space sets out to facilitate this objective: “A common European Health Data Space will promote better exchange and access to different types of health data (electronic health records, genomics data, data from patient registries etc.), not only to support healthcare delivery (so-called primary use of data) but also for health research and health policy making purposes (so-called secondary use of data).”⁸

It is continuously stated that health data is the new oil: a natural resource that can be mined and used for many different profitable and beneficial purposes (Jacob, 2019). But is it really true? And are there perhaps opportunities to fast track some of the challenges? New ways need to be found to collect, analyse, and use data provided by patients voluntarily and involuntarily, whilst ensuring the data is unbiased. The risk of bias arises from the socio-cultural and economic backgrounds of the patient communities: the availability of digital means to collect data is not secured in many regions of the world. Wearables and smartphones are not available for patients in resource-constrained settings and collecting health data from chats and text messages is problematic.

However, it's advised to start small and scale up. Social and community level projects can be designed to embed personalised healthcare through data. For companies, it may be a new strand in their corporate social responsibility efforts to dig deeper into health data to increase inclusive access to healthcare.

In summary, patient data and input has a key role to play in:

- ▶ **Shaping health policy**
- ▶ **Participating in and shaping research and development**
- ▶ **Patient reported outcomes**
- ▶ **Patient quality of life reports; and**
- ▶ **Quantitative and qualitative data from the patient community that can be used to advocate for improved policies around prevention, early diagnosis and holistic care (which goes beyond treatment), around disease management and treatment**

New data models can give individuals a better overview of their own health and can motivate them to take responsibility for their health. The system must, in return, provide the individual with tools to be able to collect and make sense of their own data. Big data and artificial intelligence should be used as a gateway to the integration and better understanding of traditional knowledge in health (Janska 2008) for it to become a gateway to personalised healthcare. This process needs consistent and easily accessible approaches in health literacy as discussed in the chapter “Humanising health literacy.”

8. https://ec.europa.eu/health/ehealth/dataspace_en





Case Study: Enabling the Future of Cell & Gene Therapies through Non Proprietary Patient Owned Data Collection

Project background and objective

Though developing any therapy for a rare disease can be challenging, cell and gene therapies face additional hurdles both in the development phase and long after they are approved. During the discovery and development phase of rare disease therapies, the small patient populations that define these conditions can limit the understanding of a disease. The gold standard registration trial is often not possible in cell and gene therapy because of the lack of data and patients.

Real-world evidence is one of the tools that can help address the challenges in both shaping the development path of an experimental therapy and also in providing insights into the safety and durability of these emerging therapies once they are approved. Understanding how a disease manifests itself, the way it progresses, and how measures of biomarkers of a given disease fluctuate and change over time is critical if a developer of a therapy hopes to provide proof that an experimental therapy is delivering meaningful benefit to a patient.

Activity outputs and outcomes

By enabling rare patient communities to more easily gather, structure, and share critical data securely through a common platform in collaboration with researchers, drug developers, and clinicians anywhere in the world, RARE X will accelerate diagnosis, disease understanding, and development of future treatments and cures across more than 9,500 rare diseases.

One way to address the shared need for data is to eliminate the data silos that currently exist throughout the rare disease ecosystem. A federated data system is a meta database made up of connected databases. The databases remain independent and self contained, but they are transparently connected and can be queried together. Such a framework allows for the sharing of large datasets from around the world.

For patient communities, RARE-X supports their efforts to collect data, structure it, adhere to rigorous standards, and share it responsibly. Equally important, the organisation ensures data that is developed with proper quality checks is validated and adheres to good clinical practice standards. For researchers and therapeutic developers, RARE X's federated data platform gives access to the data they need to identify, develop, and track the impact of breakthrough treatments and cures.

RARE-X federated data platform is being developed with direct input from industry partners and regulators to ensure collaborators gather the data required and that the data adhere to regulatory standards.

The organisation is initiating a series of demonstration projects in partnership with rare disease communities, biopharmaceutical companies, academic medical centres and other partners. The pilot programs will apply technology proven in other large scale public health and genomic data sharing initiatives to support the global needs of those developing treatments and caring for rare disease patients.

Further information: <https://rare-x.org/2021/03/29/white-paper-enabling-the-future-of-cell-gene-therapies-through-non-proprietary-patient-owned-data-collection/therapies-through-non-proprietary-patient-owned-data-collection/>





Call to action

- 1 Patient communities should be empowered to generate data and share insights with both public health authorities and industry, in order to 'have a seat at the table.' They can provide valuable data and patient insights to inform regulatory decisions, such as HTA processes, treatment reimbursement and work with industry to strengthen disease advocacy and medicines research and development (see case study above).
- 2 Build bridges and trust across disease areas and countries and work together with companies and with public institutions and civil society to share knowledge about responsible health data sharing.
- 3 Healthcare stakeholders, including industry, policymakers, healthcare professionals and technology companies must champion 'responsible and inclusive innovation' and enable access in addition to privacy and transparency.
- 4 Create a guidance framework in partnership with the patient community, data experts, and policymakers that sets out best practice and ethical standards for how to generate, use and store patient data. The guidance framework should include transparency and greater understanding amongst patients, healthcare professionals/providers and policymakers around the value of patient data and how to use it safely and ethically.
- 5 Stakeholders should consider a code of conduct to support the goal of inclusive access to artificial intelligence solutions, new and existing technology.
- 6 Advocate for patient involvement in co-creating solutions to humanise digital healthcare so they become innovators and instigators of change and transformation.



Chapter 4:

Humanising healthcare to focus on prevention and cure with a new 50:50 model

Authors: Ivica Belina, President, Koalicija udruga u zdravstvu; Maira Caleffi, Founder and President, FEMAMA and IMAMA

Imagine a healthcare system that is constructed around people and views health expenditure as an investment in our future rather than a sunk and unrecoverable cost.

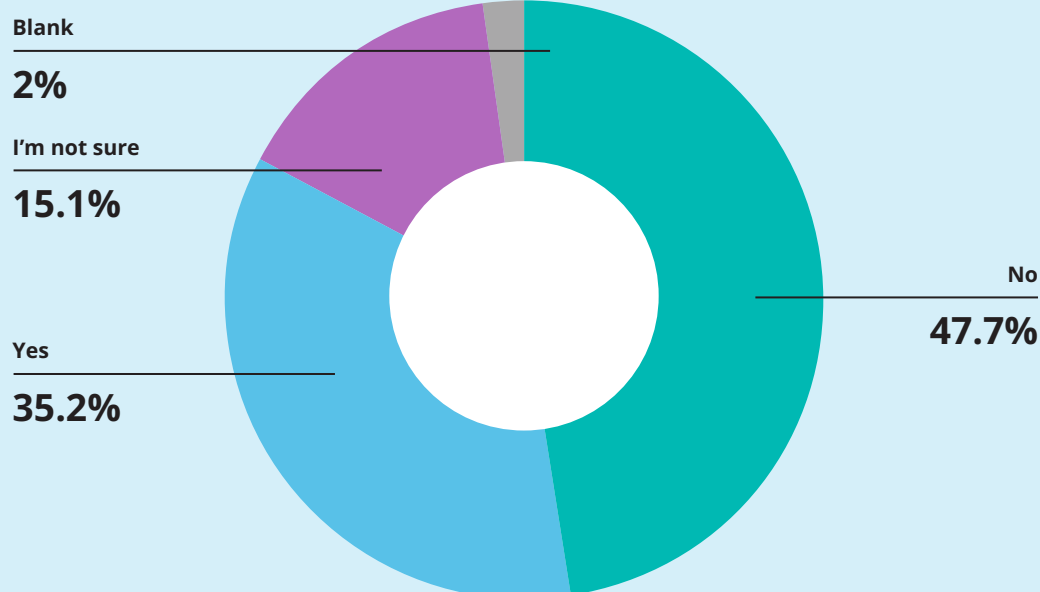


Problem Statement

Universal health coverage is a fundamental right for all, and people should have access to the health systems they need, where and when they need them. Healthcare and social systems need to shift to providing preventive services while still providing treatment to individuals and equipping them with the tools required to enable them to take responsibility for their health. One of the main issues identified by IEEPO during and in the aftermath of the COVID-19 pandemic is that nearly half of the countries surveyed perform insufficiently in the provision of universal health coverage.



In your opinion, does your country's healthcare system provide universal health coverage?





Discussion Summary

In the IEEPO international patient survey, 47.4% stated that their country's healthcare system did not provide universal health coverage, and 15.1% were not sure that it did. One of the main reasons for this shortcoming is the separation of primary and secondary healthcare and incomplete communication between them. In a networked and increasingly digital world, it makes little sense to talk separately about primary, secondary and tertiary care – all should be synchronised. They are all part of one system. However, far too many healthcare systems are fragmented and work in silos according to primary and secondary healthcare, or according to disciplines and therapeutic areas (Sperling 2020).

Collaboration between primary and secondary care is not only about the distribution of costs and funding, but also respecting the role of all participants across the healthcare systems. Humanising primary care means that family doctors (they go by many names: general practitioners, house doctors, primary consultants) should be more involved in healthcare and not just work as administrators and gateways to secondary services.

Governments should be responsible for the synchronisation of care as this is part of the healthcare infrastructure in their countries. Governments are also well positioned to facilitate the necessary cooperation across different stakeholder groups, supported by effective policies. There is a clear need for "human-centred" designs across all healthcare spectrums (including new technologies). This is vital as it can help optimise the patient experience.

The new social contract

The concept of a new social contract based on the acknowledgement, respect and active implementation mainly in the area of personal (health) data has been discussed in the literature for the last decade. IEEPO 2021 contributor and keynote speaker and health science researcher Bogi Eliassen suggests that the clarification and transparency of rights attached to data and their handling requires a new social contract that transcends the current one and spans over national borders (Mitchell, 2021).

While a new social contract may indeed emerge from the processes and developments we see in the collection, processing and usage of health data, this will be a longer process. It's time for action, to ascertain inclusivity, fairness and transparency. IEEPO contributors argue that the existing human rights framework and the regulations currently in place in several countries and regions of the world provide sufficient leverage to move towards these objectives. Patient communities should drive the discussion around awareness and understanding the importance of the existing social contract and its potential changes. All stakeholders are called upon to consistently respect and apply these frameworks for a humanised approach to healthcare.

Prevention

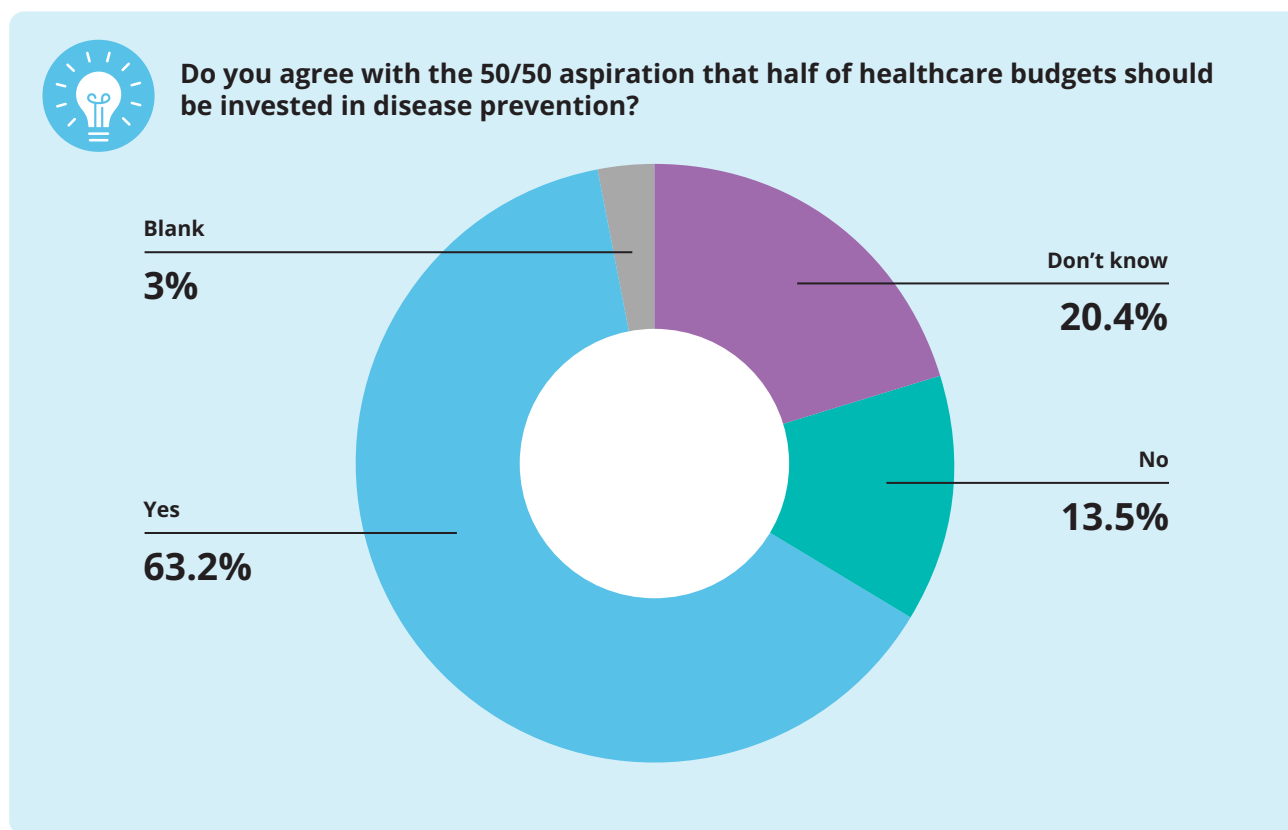
Healthcare transformation is not feasible without the conscious integration and upscaling of wide primary, secondary and tertiary prevention efforts. The following should be considered:

- ▶ **Preventable and avoidable illnesses and give people the opportunity to understand their situation and the risks that they face then provide the tools that help them to mitigate risks**
- ▶ **Some illnesses such as those of genetic origin cannot be prevented, however, their impact can be mitigated. There needs to be awareness in individuals and families about what they can control, and prevent which will, in turn, lead to reduced stress on the healthcare systems, less costs, and better outcomes. Education, awareness raising, dissemination of information, even the provision of nutritional additives can contribute to this objective**
- ▶ **The need to educate people so they can develop the necessary skills that will help them to avoid harmful behaviours and adopt lifestyle choices to help reduce the likelihood of illness**
- ▶ **Challenges in respect of people who are currently healthy, but who have a specific condition and are using healthcare systems**



Being healthy or unwell isn't black and white, it is not an either-or matter but rather a spectrum that is dynamic and variable across time and culture.

The respondents in the IEEPO global community survey were clear about their preferences regarding prevention and treatment:



63.2% of the respondents agreed that half of healthcare budgets should be invested into prevention, with the other half invested into treatment.

Investment in disease prevention is crucial in a world where patient comorbidities are rising, and populations are ageing. Half of healthcare budgets should be invested in disease prevention and strengthening primary and secondary healthcare systems, with the other half spent on treatment (50/50 model). Healthcare systems face economic resource challenges and pressures in all countries. However, the 50/50 model encourages a shift in mindset to see healthcare spending as a long-term investment in society, rather than a cost to it.

Investment into primary healthcare makes sense

A scoping review by the WHO⁹ suggests that while there is no clear data yet “primary care can produce a range of economic benefits through its potential to improve health outcomes, health system efficiency and health equity.” The scoping review goes on to suggest a conceptual framework that shows that admissions into secondary healthcare drop, and outcomes improve within stronger primary healthcare settings.

A case needs to be made, in economic terms, to convince policymakers that stronger primary healthcare services make sense economically. Weak primary healthcare results in lost capacity, waste, lack of information, lack of resources, high infant and maternal mortality and declining mental health outcomes.

9. https://www.who.int/docs/default-source/primary-health-care-conference/phc---economic-case.pdf?sfvrsn=8d0105b8_2

Consolidation of data

The systematic and careful consolidation of large datasets sitting with different providers under unified principles of data governance can yield better results in primary and secondary healthcare. Integration of primary and secondary healthcare can be facilitated by available data technologies. The increasing digitisation of healthcare, insights gained from big data, and the utilisation of patient-led data generation have already progressed significantly. The use of technology has soared by and this opportunity is explored in greater detail in the chapter “Humanising digital healthcare to build capacity by harnessing the power of patient data.”

The value of big data and the use of sophisticated technologies is to serve the common goals of humanising and democratising healthcare. Social return and value cannot be measured with the usual business metrics, and it is vital that tech technology is deployed as an enabler – not an objective within itself.



Case Study: MAMatch!: a journey-sharing experience – Bringing patients together through technology Project background

Project background and objective

People often feel alone and seek support through dating apps. In Brazil despite there being 66,000 new cases of breast cancer in Brazil in 2020, there was a lack of cancer centered apps in the app store.

In order to address this, Femama¹⁰ created an app similar to Tinder to match interest between people who had been diagnosed with breast cancer, to share doubts, challenges, learning, victories, find support and understand their rights. The app was called MAMatch! (Mama means ‘breast’ in Brazilian)

Activity detail and stakeholders involved

Once the app was created, the organisation launched the FEMAMA October Pink Campaign in 2018 to drive users to the app.

Activity outputs and outcomes

By 2020, the app had 1,700 active members registered from more than 70 non governmental organisations around Brazil.

Information from tracking behaviour on the app led to an improvement in the understanding of the needs of women living with breast cancer.

Further information: [https://www.femama.org.br/site/br/noticia/mamatch apoio no combate ao cancer de mama na palma da mao](https://www.femama.org.br/site/br/noticia/mamatch%20apoio%20no%20combate%20ao%20cancer%20de%20mama%20na%20palma%20da%20mao)

10. Breast cancer related patient organisation





Call to action

- 1** Governments should be held responsible for driving the synchronisation of care between primary and secondary services to humanise healthcare.
- 2** All stakeholders should partner under the leadership of the patient community to develop a strong economic argument to drive investments towards primary care with emphasis on prevention and early diagnosis (50/50 model).
- 3** Patients and citizens should receive much greater support and education on self-care and prevention against the most common chronic conditions. This should include support for campaigns and infrastructure that increase disease awareness, education around screening and early detection, and access to holistic care services.



Chapter 5:

Prioritising inclusion to humanise approaches to healthcare

Authors: Ranjit Kaur, President, Breast Cancer Welfare Association Malaysia; Raquel Peck, Chair, IEEPO 2021 programme, former CEO, World Hepatitis Alliance & Founder, CLARION I

Imagine a healthcare system that respects inclusivity and treats everybody as equal.



Problem Statement

Inclusivity must be central to humanising healthcare systems and ensuring patients are treated as individuals that share the same biology and essential humanity, despite their differences.¹¹

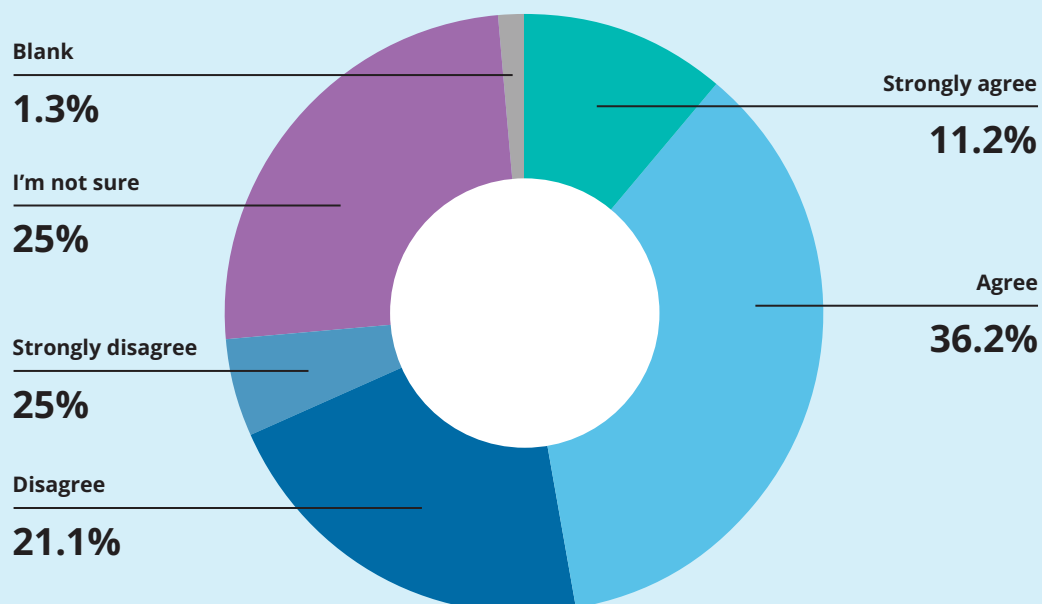


Discussion Summary

The international survey performed by IEEPO asked participants about their views on inclusive access in their healthcare systems.



To what extent do you agree with this statement? “The healthcare system in my country is working to decrease the unfair and avoidable health differences (access, resources and outcomes) people may face because of race, religion, gender, disability, age, sexual orientation and socio-economic background”



11. <https://www.qcc.cuny.edu/diversity/definition.html>



The answers show a mixed picture. Most of the respondents (47.4%) agree or agree strongly with the statement that their healthcare systems work to decrease differences based on discrimination. 26.4% disagree with this statement, however 25.0% are unsure.

A broad and sensitive use of the term inclusivity should be instilled, which encompasses certain domains that appear to be less obvious in the conversation around inclusive access. Greater attention should be paid to how healthcare systems can be strengthened to serve all patients, regardless of socio-economic background, country healthcare infrastructure, location, language or any other societal and personal circumstances. This should be factored into patient interactions and experience, and co-creation at every step in the holistic healthcare journey, from prevention to diagnosis, treatment, and survivorship.

Inclusivity covers the following areas:

- ▶ **Inequalities in access to health according to ethnic background**
- ▶ **Differences between urban and rural areas, and other geographical inequities (e.g., distance from medical centres)**
- ▶ **Differences affecting nomadic communities**
- ▶ **Differences on the basis of educational background**
- ▶ **Linguistic differences**
- ▶ **Differences on the basis of literacy**
- ▶ **Different health challenges resulting from migration**

The need for a broader definition of inclusivity is associated with the growth in migration trends across the globe. The resulting variety in cultures and socio-economic status calls for more sensitivity towards different needs and circumstances.

Inclusive access to healthcare is key to ensuring innovation (Hewlett, Marshall and Sherbin 2013). When differing perspectives are embraced and represented, there are more opportunities to co-create new and surprising solutions. When personalised healthcare or precision medicine are mentioned as an important emerging trend in healthcare and health related research (Obama 2015), this encourages increased respect for the needs, genomic setup and circumstances of individuals and their communities. Personalised healthcare cannot become a privilege contributing to more inequality. Poverty and extreme poverty are still often a reason for discrimination and stigma.

Promoting fairness and reducing exclusion in healthcare, research and development requires open conversation about underlying biases and systemic barriers. An article in *The Scientific American*¹² acknowledges that individuals from underserved communities are underrepresented in clinical trials. These affect not only patients and citizens but also healthcare professionals. Doctors, nurses and healthcare service personnel also represent different socio-cultural backgrounds. Efforts to improve communication and understanding must be mutual and inclusive across all levels. Wilbur, Snyder, Essary et al. (2020) assert that 'A diverse healthcare workforce is necessary as a means to help care for an increasingly diverse patient population.'

The role of language

Acknowledging differences in language means more than reflecting and respecting linguistic differences. As previously discussed in the chapter on "Humanising Health Literacy", there is also a language barrier between the medical profession, policymakers, and patients. This language barrier also creates power imbalances as described by Galjour, Schwarz, Rusike et al. (2021). While most people understand basic information about their bodies, health and illnesses, the language of health can be very different across different stakeholders. The use of language also extends to making sure that

12. <https://www.scientificamerican.com/article/clinical-trials-have-far-too-little-racial-and-ethnic-diversity/>



healthcare professionals avoid judgmental language, while their demeanour remains respectful of the patient.

Patient organisations are, however, in an excellent position to manage this difference. They can not only translate medical language into lay terms through brochures, websites, social media and lay language summaries, but they can also convey lay concepts about health in scientific and medical terms. In addition, the importance of arts (theatre, song, dance, visual arts, storytelling, etc.) in health promotion and health literacy is well documented (e.g., Bunn, Kalinga, Mtema et al. 2020). Patient-led research is thus a key tool for the acknowledgement of differences and the elimination of discrimination whilst also helping tackle stigma against low-educated people and those living in poverty. This fundamental challenge is discussed further in the chapter “Humanising health literacy”. McCorkell, Assaf, Davis et al. (2021) describes the importance of patient-led research in the field of Long COVID and find that “people experiencing the illness are best able to identify the questions to ask and issues to investigate that matter to them and also to design effective solutions based on their intimate familiarity of the illness”. Another key issue is trust: Heath (2019) points out that “delivering care in the language with which the patient feels most comfortable, creating a positive and non-judgmental environment, and being honest with patients will be key to creating trust.”

When talking about language, one should cast a wider net than to just focus on linguistic differences and the need for translations. The bulk of scientific and medical literature is in English, which poses a problem on two levels:

- 1 Patients who don't speak English, or don't speak it well, cannot access important and potentially life-saving information unless translations are produced (Woolston, Osório 2019)
- 2 Scientific and medical literature produced in languages other than English tend to fall off the map of science (Huttner-Koros 2015).

Knowledge is empowering

Keeping community members alive and healthy is an instinctive commandment that transcends history and cultures. There is, however, considerable conflict between what is acknowledged as evidence-based medicine, and what is seen as traditional, alternative or complementary medicine. There must be a clear line between real and fake medicine - and this distinction should be maintained in the interest of real health improvements globally. The growth of anti-science movements in the wake of the COVID-19 pandemic is a warning sign that there is an urgent need for better health literacy.

The importance and empowering aspects of learning and knowledge have been described in the literature of patient involvement several times (Epstein, 1995; Bereczky, 2020). Knowledge is also fundamental in tackling stigma and discrimination as it is common for humans to fear and loath what is not known well enough (Carleton, 2011). The case study of the U=U Campaign (Undetectable means Untransmittable) in the HIV field provides a good example on how the dissemination of a fundamental piece of scientific knowledge can contribute to the reduction of stigma and discrimination. The aspect of co-creation and joint delivery with patient communities play a major role in these efforts.

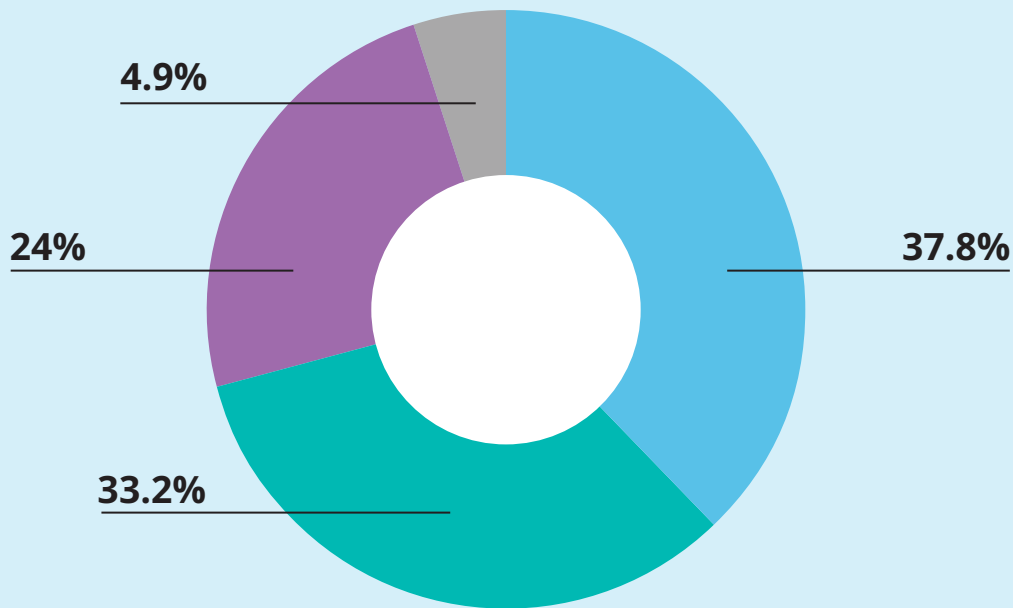
Taking the message to the people

Effective outreach work that includes targeted efforts to address specific groups is key. Sometimes, “hard-to-reach” populations are not hard to reach, a different approach needs to be tested. Taking the first step towards disempowered groups is the first step towards reducing inequality resulting from discrimination. Even if certain populations cannot find the way to access healthcare services or don't know how to navigate the system, all stakeholders can still move towards them and bring these services closer to them. Therefore, in the calls to action, all stakeholders should reach out to underserved populations and to examine their own biases that may act as barriers to access to health. The principle of “meeting patients where they are” (and not where you want them to be) was already described by Hughes in 2013 and has become imperative when talking about reaching vulnerable populations. The IEEPO global community survey also provides further insight into this issue.





In your country / region is there a strategy to adapt the way health service delivery and information is made available to different communities (incl. underserved, marginalized groups), depending on their situation and how they access information? For example, rural communities who are isolated may not receive timely information about updated treatment regimens or timely access to digital tools / technologies.



- I am not aware of any existing / emerging strategies to adapt how health information is delivered to different
- I do not have enough knowledge in order to answer this question
- I am aware of existing / emerging strategies to adapt how health information is delivered to different communities
- Blank

When asked about a specific country strategy to bring information closer to specific groups (such as underserved or marginalised groups), 37.8% said that they were not aware of such a strategy, while 33.2% stated that they don't have sufficient knowledge to answer the question, suggesting that even if such a strategy exists, they don't know about it. It seems that there are few conscious efforts to bring health related information closer to vulnerable and marginalised communities. Once again, it's argued that, given they have sufficient resources, patient organisations are in the right position to facilitate and to streamline this line of work.





Case Study: Undetectable means Untransmittable

Project background and objective

The U=U Campaign is a global example about how the dissemination of a fundamental piece of scientific knowledge can amplify a powerful public health message. It is also an example of how partnership working between healthcare professionals and patient communities can play a major role in changing peoples' behaviour, improve health outcomes and lead to a reduction in stigma and discrimination.

In recent years, an overwhelming body of clinical evidence has firmly established the human immunodeficiency virus (HIV) Undetectable = Untransmittable (U=U) concept as scientifically sound. U=U means that people living with HIV who achieve and maintain an undetectable viral load (the amount of HIV in the blood) by taking and adhering to antiretroviral therapy (ART) as prescribed cannot sexually transmit the virus to others. Evidence for U=U was developed over many years of research, collaboration and study including observational studies, expert opinion based on reviewing evidence, prospective observational studies, randomised clinical trials and further expert opinion in 2016 which led to the development of the U=U campaign.

Distilling the message into a single, powerful and meaningful statement "U=U" was intended to promote prevention at all levels, including primary (preventing transmission to uninfected persons) and secondary (ensuring regular viral load monitoring and health screenings).

By focusing on being 'undetectable', an objectively measured health indicator, U=U provides people living with HIV with an unambiguous health target that emphasises personal responsibility and the importance of reliable and affordable access to medicines and diagnostics.

Activity detail and stakeholders involved

Launched by the community of people living with HIV in 2017, U=U became an international campaign aimed at raising awareness of prevention. By January 2021, more than 1000 organisations from 102 countries had signed up, including international bodies and medical associations.

More specifically, the U=U message has also been incorporated into clinical guidance. Discussing U=U in clinical settings is vital because patients are more likely to believe information that they hear directly from their peers living with HIV in addition to healthcare providers or doctors.

In May 2019, these results were published in The Lancet, and became one of the most widely and rapidly reported international headline HIV news in mainstream media.

Further information: <https://www.preventionaccess.org/>





Call to action

- 1** All stakeholders should focus on the humanising of healthcare and how the person in need can become the point of gravity of their work.
- 2** All stakeholders should ensure that there is representativeness in their work, become a more inclusive team at every level, and look at their constituencies critically. Representativeness means the inclusion of all affected populations regardless of their socioeconomic, ethnic or other backgrounds. All stakeholders should strive to be aware of their own biases and identify them to be able to tackle them. Self-critical engagement with biases and prejudice will lead to more inclusion and sensitivity to the challenges of underserved populations.
- 3** Sensitivity to language as a tool for building trustful relationships should be developed consciously in all stakeholders including policymakers, healthcare professionals, researchers, and patient organisations.
- 4** Science and educational systems need to acknowledge the importance of inclusion. Early inclusion training will result in better anti-discriminatory practices throughout the entire healthcare continuum. Researchers and the clinical profession should include “real” instead of “ideal” patients in clinical trials to make sure that outcomes are more meaningful and those in need are served better.



General conclusions and recommendations

Imagine a healthcare system that is respectful of and builds on the broad cooperation of patient communities.

In a talk delivered at the IEEPO 2021 conference, Bogi Eliassen defined the following key factors for the transformation of healthcare:

- ▶ **Building a 'global co-operative of health' that includes perspectives from the 'bottom-up' across all levels, priorities and groups/stakeholders**
- ▶ **50/50 aspiration – investment in primary healthcare systems, disease prevention**
- ▶ **Personalised health is not just about precision medicine; it is also about screenings, early detection, and early intervention as well as related care including services, tools etc.**
- ▶ **Empowering patients to understand and take ownership of their own health and care and how they use their data, transparency, traceability**
- ▶ **Empowering patients to be the bridge builders across disease areas and countries and work together with companies and with public institutions**

The role of cooperation

As Bogi Eliassen and Mary Baker state in the Foreword to this Position Paper, we can only be successful if we work together.

In the past, there has been unnecessary and harmful competition between patient organisations and across disease areas, specifically competition for research attention and resources. However, humanised healthcare and universal health coverage are imperatives that call for multi-stakeholder cooperation and partnering to tackle competition. The work and nature of patient organisations do not fit traditional business logic, and they are based on sharing rather than accumulating resources (Bereczky 2019).

It's crucial to also raise the expertise and knowledge of patient organisations and patient leaders. The role of patients in the healthcare landscape is still largely ignored. Despite some good examples like the Innovative Medicines Initiative and Horizon Europe frameworks of the EU, there is a lot more to do if we want to include patients as the 4th P in public-private partnerships (PPP). However, this requires resources, people, money and technology.

Despite these challenges, if we put our hearts and minds together in true partnership, patient organisations around the world can become the force required to drive transformative change.

13. https://ec.europa.eu/info/research-and-innovation/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe_en





Prioritised calls to action

In conclusion, the IEEPO Position Paper defines the following calls to action as priorities:

- ▶ **Patient organisations should facilitate conversations with all stakeholders about the need and value of compassionate care**
- ▶ **Develop strategies that address the current challenges in achieving health literacy by incorporating the specific needs of patient populations so that they are involved in the design, and delivery of solutions. Example challenges include, elderly patients may be socially isolated as a result of the pandemic, digital illiteracy and the 'digital divide' affects how people access health information and therefore manage their own health**
- ▶ **Patient communities should be empowered to generate data and share insights with both public health authorities and industry, in order to 'have a seat at the table'. They can provide valuable data and patient insights to inform regulatory decisions, such as HTA processes, treatment reimbursement and work with industry to strengthen disease advocacy and medicines research and development**
- ▶ **Governments should be held responsible for driving the synchronisation of care between primary and secondary services to humanise healthcare**
- ▶ **All stakeholders should focus on the humanising of healthcare and how the person in need can become the point of gravity of their work**



Annex

About IEEPO

The International Experience Exchange with Patient Organisations (IEEPO)* provides a platform for the worldwide patient community to collaborate and collaborate on creating changes to achieve this vision together. If we focus on understanding healthcare systems from a patient perspective, we can transform this vision to the benefit of the worldwide patient community.

Our work to date has already yielded significant and transformational results with outcomes documented on IEEPO.com alongside numerous publications from different contributors and participant organisations of IEEPO. The work of IEEPO is structured around four distinct yet interrelated domains:

-  **THINK**
Thought leadership that future-gazes for emerging health trends and serves inspirational and practical content to patient organisations and all others engaged in health.
-  **LEARN**
An ongoing educational library of content, practical tools, materials and resources across a range of topics, to upskill patient organisations of all sizes and in all geographies.
-  **CHANGE**
A debating forum that engages policymakers, regulators & health care experts with advocates on health policy issues, at a global, international and national level to help set strategies and inspire action.
-  **MAKE**
Content outputs that are informed by an evidence-based advocacy approach, reflecting digital health and future approaches to healthcare co-created for and with the community for local implementation to strengthen patient voice in the healthcare ecosystem. IEEPO is sponsored by Roche and organised in partnership with an independent Chair and an External Advisory Committee of global leaders in patient advocacy. More information to find at **www.ieepo.com**.

14. <https://www.ieepo.com/en.html>



About the IEEPO Position Paper

This IEEPO Position Paper is based on a global community demand and call to action to empower change and transformation of healthcare systems. It explores the learnings and recommendations from various sources of information and is informed by the input of:

- ▶ **The work of all four domains of IEEPO under the leadership of the External Advisory Committee and the IEEPO programme chair**
- ▶ **A global patient community survey developed and conducted by IEEPO in August and September 2021**
- ▶ **Findings and outcomes of the IEEPO virtual conferences in 2020 and 2021**
- ▶ **Desk research covering the latest information and publications on the state of healthcare around the world and the need for transformation and humanisation**
- ▶ **Interviews conducted with contributors of the MAKE domain and other domains of engagement of IEEPO**

The Paper contains an analysis of certain areas that the IEEPO community and the contributors see as pressing and in need for change. Most importantly, the Position Paper contains specific calls to action that sit within each chapter:

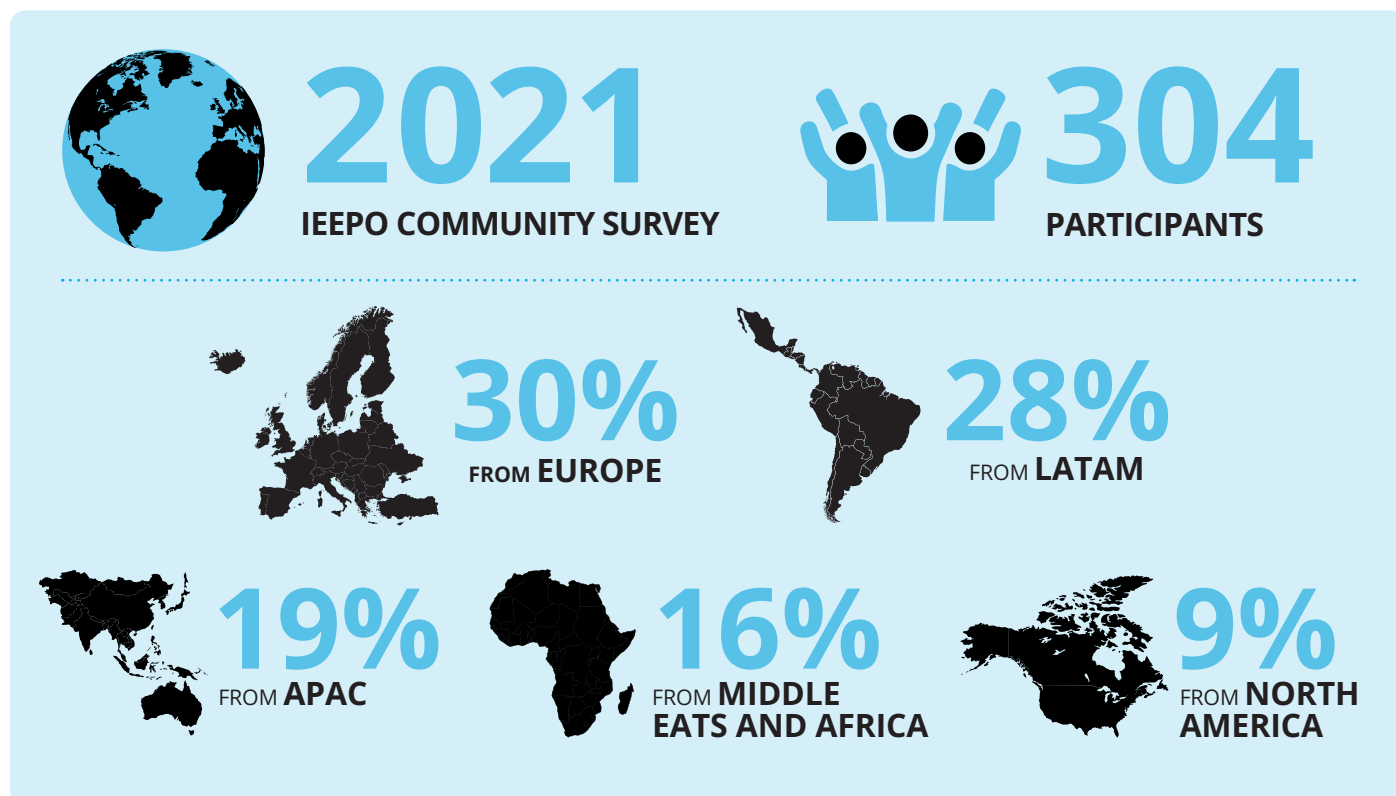
- 1 Putting people at the heart of healthcare**
- 2 Humanising health literacy**
- 3 Humanising digital healthcare to build capacity by harnessing the power of patient data**
- 4 Humanising healthcare to focus on prevention and cure with a new 50:50 model**
- 5 Prioritising inclusion to humanise approaches to healthcare**



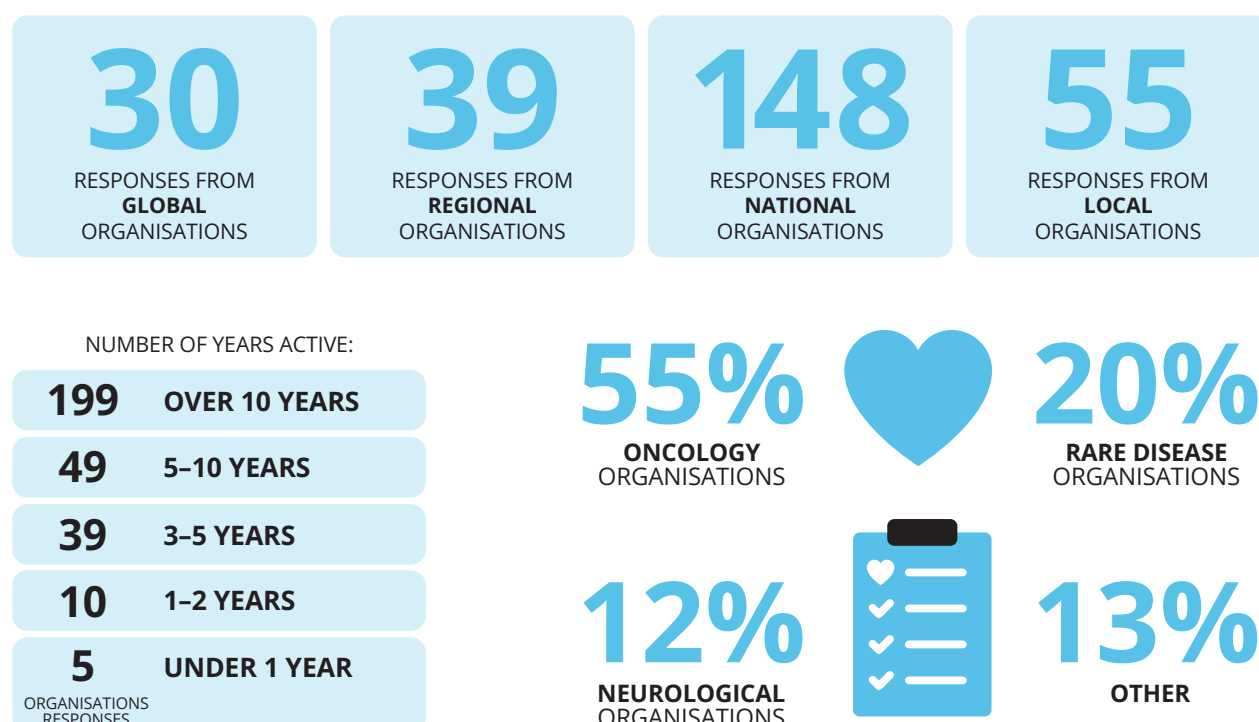
About the IEEPO Community Survey

This IEEPO Position Paper elaborates on the findings and outcomes of a global patient survey conducted by IEEPO in 2021. Results and a breakdown of participants from the community survey include:

Geographical breakdown:



Organisations Breakdowns:



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Thank you