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POLICY BRIEF 58

# Trust

## The foundation of health systems

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This policy brief is one of a new series to meet the needs of policy-makers and health system managers. The aim is to develop key messages to support evidence-informed policy-making and the editors will continue to strengthen the series by working with authors to improve the consideration given to policy options and implementation.

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A policy brief is a short publication specifically designed to provide policy makers with evidence on a policy question or priority. Policy briefs

- Bring together existing evidence and present it in an accessible format
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- Are underpinned by a formal and rigorous open peer review process to ensure the independence of the evidence presented.

Each brief has a one page key messages section; a two page executive summary giving a succinct overview of the findings; and a 20 page review setting out the evidence. The idea is to provide instant access to key information and additional detail for those involved in drafting, informing or advising on the policy issue.

Policy briefs provide evidence for policy-makers not policy advice. They do not seek to explain or advocate a policy position but to set out clearly what is known about it. They may outline the evidence on different prospective policy options and on implementation issues, but they do not promote a particular option or act as a manual for implementation.

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## Key messages

- **The concept of trust is complex and multifaceted.** Philosophy, sociology, economics, psychology and medicine understand it differently, and each offers insights into the importance of trust for health, health policy and health care provision and for social cohesion.
- **Trust in health systems is essential if they are to function effectively.** Trust underpins the solidarity that enables quality health care. It is central to the complex interplay of relationships that shape health outcomes.
  - Patients need to trust clinicians and care providers if they are to seek help promptly, share information and follow treatment plans.
  - The health and care workforce needs to trust that they will be valued if they are to stay in the sector, stay motivated and perform well.
  - Policy-makers need to trust that the health system will deliver quality care and do so efficiently if they are to invest resources. They also need to trust the public (and vice versa) in times of crisis.
- **New technologies in health have significant implications for trust. There is a need to:**
  - Regulate online resources and safeguard data privacy.
  - Manage the use of artificial intelligence (AI), which poses particular challenges for trust because the way it operates and the algorithms it uses are not transparent.
  - Ensure workforce monitoring and productivity tracking do not demoralize health and care workers.
  - Make sure technologies are reliable, accurate and used ethically and equitably.
- **Trust needs to be actively supported.**
  - Disinformation and misinformation erode trust if not addressed. They may be politically or commercially motivated, with misleading AI-generated content being particularly problematic.
  - Transparency reinforces trust and encourages accountability, whereas a lack of transparency on health care costs, medical errors and conflicts of interest all undermine trust.
  - The complexity of trust dynamics; the context; the experience, expectations and tolerance of different actors and social groups; and changes over time: all need to be taken into account in building trust.
- **Measuring trust is an important step in addressing trust deficits, but it is difficult.** Much research relies on surveys or interviews and focuses on patients' trust in doctors. There is little work on differences in trust in doctors rather than nurses or on trust in health care teams or organizations. It would be helpful if:
  - lessons from a range of disciplines could inform the way trust is understood (and translated);
  - trust could be studied as an outcome through experimental studies, qualitative and mixed methods measures and longitudinal research;
  - response formats and trust measurement tools could be improved and comprehensive data collected and updated regularly to assess differences within populations and changes over time;
  - centralized data sources were set up with international coordination underwriting comparability; and
  - minority or marginalized groups and their trust in health care could be given particular attention.
- **Engaging a wide range of stakeholders is essential in building trust. This requires:**
  - fostering collaboration across sectors;
  - including civil society, the media and the public;
  - engaging stakeholders in decision-making, for example through citizens' assemblies;
  - recognizing the value of lived-experience; and
  - encouraging co-production of care and tackling the power and information imbalances that undermine it.
- **Trust in health bodies can be encouraged by consistent delivery of quality care and by:**
  - a clear, shared vision and values – underpinned by ethical standards
  - an explicit commitment to stakeholder well-being that includes staff
  - embedding reliability, integrity and transparency into policy making, strategies and practices
  - leaders who exemplify integrity, ethical behaviour and accountability
  - openness on the use (and impact) of resources and in addressing waste or corruption
  - excellent communication of all the above.

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This document serves as an introduction to trust and health to inform the 12–13 December 2023 Tallinn Health Systems conference, Trust and Transformation: Resilient and Sustainable Health Systems for the Future and is presented as a draft for consultation. The authors will take onboard feedback received from conference participants and develop a final policy brief version more focused on health systems in the European Region for publication in early 2024.

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## Executive summary

### *The importance of trust*

Trust in health systems and health care is essential for their effective functioning. While the concept of trust is complex and multifaceted, what is clear is that it underpins relationships in the health care ecosystem, including between clinicians and patients, within clinical teams and with the public. Trust is crucial for social cohesion and equitable generation and sharing of resources for health care. Trust in health policies is vital for their effectiveness, and when individuals trust their health care systems it leads to better health outcomes. The successful responses to the COVID-19 pandemic (vaccine uptake and adherence to other public health measures) were underpinned by trust, although the inverse was true as well. Trust supports the principle of solidarity in health care systems, especially during crises.

Social trust and institutional trust are different but related. Social trust fosters optimism and encourages positive interactions between individuals, including strangers, while institutional trust relies on the expectation that institutions act in both the individual's and the community's best interests.

We can identify four important relationships in health that require trust.

- Patients need to trust clinicians and other health care providers to seek medical care promptly, to be open with their providers and to adhere to evidence-based guidance, leading to better outcomes and patient satisfaction.
- Health care workers' trust in the system is vital for motivation, staff retention and innovation, and erosion of this trust contributes to workforce shortages and reluctance to implement necessary transformations.
- Politicians' trust in the health system (including the health workforce itself) is necessary for adequate resource allocation and transformation.
- Experience in the COVID-19 pandemic has shown that politicians should trust in the public to make appropriate decisions providing they are given adequate support to do so.

There are, however, threats to trust in health systems including misinformation and disinformation, marginalization and discrimination, and a lack of transparency. Misinformation can undermine trust in public health agencies leading (for example) to decreased vaccination rates. Marginalized communities experiencing unequal access to health care may lose trust in the system. A lack of transparency regarding health care costs, medical errors, or conflicts of interest can erode trust in the health care system more widely.

### *Research on trust and health systems*

The literature on trust and health (systems) is extensive but complex. In the main it examines five primary areas of research: patients' trust in clinicians, clinicians' trust in patients, clinicians' trust in fellow clinicians, trust in particular health care organizations (such as hospitals or insurers) and general trust in health care systems.

Research on patients' trust in clinicians is extensive and often relies on surveys or qualitative interviews. Some interventions aimed at increasing trust have shown small positive effects on health care outcomes. However, there is a need for improved trust measurement tools, particularly for assessing trust in non-physician clinicians and health care teams, to address the challenges of reciprocity in the clinician-patient relationship and to understand differences in trust between doctors and nurses.

Trust among clinicians is less studied but complex due to varying vulnerabilities. Trust is linked to clinical competence and integrity, with an emphasis on autonomy and quality contributing to trust among colleagues.

Research on trust in health care organizations is sparse and mostly from the United States, making generalization to Europe challenging. Institutional betrayal, where organizations fail to protect dependents, has been noted.

Trust in health care systems in general is well researched, mainly through the use of surveys on public opinion. Honesty, communication, confidence and competence are key elements of trust that are commonly measured.

In summary, trust in health care is crucial but often poorly defined or understood. Definitions of key terms like trust and trustworthiness vary, and trust involves multiple decisions. Researchers should draw on other disciplines and address these complexities.

### *Disciplinary perspectives on trust and health*

The concept of trust appears simple, involving the expectation of reliable behaviour. However, it is complex and contentious across various disciplines, and especially so when applied to health, health policy and the provision of health care.

From a *philosophical perspective* trust involves more than reliance; it includes goodwill, commitment, and the expectation of trustworthy behaviour, such as by the clinician to the patient. Evaluative assessments like success, competence and aptness play a role in determining trustworthiness. A *sociological viewpoint* notes that social capital and trust are interconnected, with trust being crucial in societies with weak institutions. Trust can break down when events erode confidence in individuals or institutions. The evidence on social capital and trust is debated, with mixed associations to health outcomes. From an *economic perspective* trust is essential in situations of uncertainty and information asymmetry, such as clinical interactions. Game theory can inform rational decision-making in risky situations, such as clinical encounters. As trust involves emotions, perceptions and subconscious cues, a *psychological approach* stresses integrity and consistency



in behaviour as essential for trust. Good communication, empathy and respecting patient autonomy enhance trust. Cognitive biases can shape trust, affecting medical decision-making.

Recommendations for strengthening research on trust include studying trust as an outcome, conducting experimental studies, longitudinal research, and exploring trust dynamics in both directions. Consideration of spillovers of trust among different levels (health worker, facility, system) and participants' lived experiences are essential. Reflexivity is important for researchers studying trust, acknowledging their influence. Trust is a multifaceted concept, with various disciplines offering distinct perspectives and challenges in understanding and studying it in health systems.

### **Trust and technology**

The health care landscape is changing rapidly due to technological advancements. The response to the COVID-19 pandemic, for instance, benefited greatly from the explosion of eHealth and telehealth innovations. These technological developments have significant implications for trust in health care.

Patients need to trust that the health care equipment they use is accurate and reliable, and quality standards must be developed, implemented, and enforced by consumer protection authorities. Concerns arise regarding the regulation of online resources that offer health advice, especially when they are based in different jurisdictions, making oversight challenging.

Artificial intelligence (AI), powered by complex algorithms, plays a growing role in health care. Trust becomes paramount, both for clinicians using AI tools and for patients receiving AI-generated recommendations. Trust in AI is challenging because AI often operates as so-called black boxes that are difficult to interpret. Efforts to make AI more transparent through explainable AI (XAI) are ongoing but have mixed results. More widely, trust in health information dissemination is crucial, particularly during public health crises. However, disinformation and AI-generated misleading content, including deep fakes which may utilize trusted figures to spread falsehood, pose significant challenges. Disinformation has been shown to spread more quickly than accurate information, and can be generated for various motives, including political and commercial objectives. Microtargeting amplifies disinformation by selectively targeting vulnerable groups. Finally, modern health care relies on access to comprehensive clinical information, but concerns about data privacy and misuse can erode trust. AI's ability to deanonymize data raises privacy concerns, exacerbated by technologies like facial recognition. Employee monitoring and productivity tracking risk eroding trust among health care workers. Cyberattacks and hacking can damage trust in information systems and compromise data security.

The evolving health care landscape with accompanying technological advancements introduces new dimensions of trust challenges. Ensuring accurate and ethical use of

technology, regulating online health resources, promoting trust in AI where appropriate, combatting disinformation (and misinformation), safeguarding data privacy, and addressing workforce monitoring are essential aspects of maintaining trust in health care systems.

### **Measuring trust**

Measuring trust in health systems and related structures presents challenges due to the absence of centralized data sources. Instead, and as seen in Europe, multiple sources track interpersonal trust and trust in specific institutions, utilizing household surveys. There are, however, several methodological challenges relating to the wording of questions and how easily concepts are translatable or understood by others (especially different ethnic minorities or social groups), as well as response formats such as scales or qualitative answers.

There is a variety of surveys that could provide data on trust in health systems. However, several, such as the Eurobarometer, European Social Survey and EU-SILC, seldom include questions about trust in health systems. The Organisation for Economic Co-operation and Development (OECD) has initiated surveys to measure public trust in certain institutions, but the inclusion of European countries remains limited, and there is a lack of historical time series data. The OECD also surveys trust in the appropriate use of personal data. These surveys offer insights into this aspect of trust but are limited in coverage and time. There are additional surveys that capture specific characteristics of health systems in smaller groups of countries.

In summary, there is no single comprehensive data source for assessing trust in health systems in Europe. Multiple sources, with varying methodologies and definitions, track trust levels and related issues. Given the critical importance of trust in health systems, particularly in adapting to future challenges, there is a clear need for comprehensive and regularly updated data to assess differences within populations and track changes over time.

### **Future directions**

This introduction to trust and health concludes with suggestions for future areas of work. These are, of necessity, expressed in broad terms as trust is highly influenced by context and can vary significantly among countries and even within countries. Factors such as previous experiences of social groups and their expectations play a crucial role. Trust can also change rapidly, as seen during the COVID-19 pandemic. Trust in one set of state institutions does not necessarily translate into trust in others, highlighting the complexity of trust dynamics. The evidence on what works to strengthen trust, either in general or in specific circumstances, is limited.

Yet despite its complexity, trust is essential for binding communities, ensuring cooperation, sharing resources equitably, promoting social cohesion and maintaining order and stability. Trust in health care and health systems contributes to this. Regular surveys should be conducted to measure various aspects of trust. International coordination

ensures comparability of results, supplemented by qualitative and mixed methods measures. Health policymakers should advocate for actions that reduce factors eroding trust, such as corruption. Collaboration across sectors is essential. Policies should incorporate principles that promote institutional trust, including demonstrating reliability, integrity, transparency, and a commitment to stakeholder well-being. Health bodies should establish and communicate a clear mission and values aligned with ethical standards. Leadership should exemplify integrity, ethical behaviour, and accountability and consistent delivery of high-quality care is essential. All are important for trust-building in health.

More specifically, engaging stakeholders through deliberative decision-making processes, such as citizens' assemblies, can be valuable for making contentious decisions, as can co-production, where addressing power and informational imbalances can foster increased trust.

Increasing staff retention in health workforces is a high priority, requiring a commitment to building trust among staff. Restoring trust of politicians in health systems involves shared visions, excellent communication and a realistic expectation of impact, especially when additional resources are allocated. Finally, there are some specialized issues, such as AI, that require particular attention.

In summary, building and sustaining trust in health systems is a complex but vital endeavour. It requires a combination of values, strategies and practices that demonstrate reliability, integrity, transparency, and commitment to stakeholders' well-being. Addressing threats to trust or restoring it where it has been eroded is essential for maintaining the integrity of the health care system. Engaging a wide range of stakeholders, including civil society, the media and the public, is essential in these efforts, for trust is a cornerstone of strong and effective health care systems.

## Policy brief

### 1. Introduction

#### 1.1 Trust at the heart of the health system

Health systems are, at their heart, a means of organizing many sets of human relationships and interactions to achieve a goal, the health of the population that they serve. All human relationships are, at one level, transactional. One person exchanges something with another and gets something else back in return. A patient gives a health worker information about their condition (and money sometimes directly or through their taxes) and (hopefully) receives, in return, a diagnosis and a plan of treatment. A health manager exchanges a salary with that health worker in return for their expertise and the provision of care to the patients attending the facility for which they are responsible. And a decision-maker may invest money into a particular policy direction, expecting patients and health workers to play their part in implementing that policy in ways that bring about positive outcomes.

In many cases, transactions between people are straightforward and easily verifiable. A customer visiting a shop exchanges money for a product. Customers often know what they want to buy, and can judge whether they have received it and whether it is at a fair price. However, in all but the simplest cases, a transaction requires a degree of trust (Box 1). When buying food, can the customer trust that it has been prepared in conditions that prevent bacterial or toxin contamination? When buying a part for their car, can they trust that it has been manufactured in a way that will prevent it from failing and causing an accident (Reynolds & McKee, 2010)? If they feel unable to trust the provider of these goods they will be reluctant to purchase from them.

#### Box 1: What is trust?

There is no universally agreed definition of trust. However, a widely used conceptualization sees trust as the belief that an object of trust (which can be a person or institution) will act in ways that produce positive outcomes, even if one cannot ensure it (Easton, 1975). It relates to vulnerability. A person demonstrates trust when they are willing to make themselves vulnerable, expecting that something good will be done by the object of trust, a person or institution that could do them harm. Thus, trust is seen as acceptance of some risk when faced with uncertain outcomes (Citrin & Stoker, 2018). Trust is usually relational in that “A trusts B to do X” (Hardin, 2002), although it is also possible to have general trust that is not linked to a specific action but rather the belief that the object of trust will do the right thing whatever it is (Nannestad, 2008). Trust is related to but different from reliance. Faulkner cites the example that one may rely on one’s car to start but not trusting it to do so as that would imply that the car had one’s interests at heart (Faulkner & Simpson, 2017). This is not limited to inanimate objects. Hardin cites the example of the philosopher Immanuel Kant, whose neighbours could rely upon him to walk past their windows at eight each morning (Hardin, 2002). However, as he did not do so for the benefit of those neighbours, they had no reason to trust him.

The concerns that may arise in any transaction can be addressed through trust. A consumer can trust the provider, believing that people are fundamentally honest or, at least, bound by the wish to create and maintain a reputation for acting honestly. Alternatively, regulation can seek to impose quality control systems along the supply chain and to ensure that standards are upheld, with sanctions for failures albeit that customers know that unscrupulous providers can often get around these measures. With or without regulation, providers often take measures to develop and maintain public trust, not least as a means to achieve a competitive advantage because they recognize that trust has a value.

The challenges are especially great in health care. There is a major asymmetry in the knowledge held by the two parties to the transaction (Arrow, 1978). The health worker will often be much better informed about the nature and severity of the range of conditions that the patient presents with and the treatments that can be provided. This means that the patient must trust the health worker and the treatment they provide. As with all products, they can also look to the many safeguards that health systems have put in place, such as those that specify which qualifications the health worker should possess and whether they have taken measures to keep up to date with emerging knowledge. They will wish to be reassured that the services they are given are evidence-based and that the medicines they are prescribed are safe and not counterfeit or otherwise unsafe (Attaran et al., 2012). Their trust has a value to care providers because when patients trust the health system they are more likely to follow the guidance given.

This trust must be earned and maintained over time. But it is easily lost, and, in some cases, individuals or organizations may be motivated to undermine it.

#### 1.2 Trust and transformation in the light of the pandemic

This publication has been written for a WHO Ministerial Conference held in December 2023 on the themes of trust and transformation (Kluge et al., 2023). Its starting point is the experience of the COVID-19 pandemic and, in particular, the insights gained from the evidence reviewed for the report of the Pan-European Commission on Health and Sustainable Development (the Monti Report) (McKee, 2021). Health systems in the European Region responded in different ways and achieved different outcomes. Some have adopted new ways of working, often taking advantage of technological advances that accelerated during the pandemic, such as rapid diagnostics and innovative means of online engagement (Green et al., 2022). Health workers have developed new roles and individuals more responsibility for their own health, facilitated by digital communication such as remote sensing using wearables or near-patient testing, as exemplified in the development of the lateral flow tests that transformed management of the pandemic. But some countries have also struggled, unable to rebuild workforces already depleted by underinvestment, and with the additional burden of burnout and illness, including Long COVID (Rajan et al., 2021). This situation, in part, reflects

and is exacerbating a crisis of trust; indeed, none of the positive examples will succeed if those involved lack trust in them and in each other.

This is apparent in a series of critical sets of relationships between patients, health care workers and politicians set out below (Fig. 1). The brief does not seek to capture all the trust relationships that underpin health services but rather to illustrate the important of trust and its role in enabling transformation. Of course, there are others, such as the trust of the public and health workers in politicians, with health worker strikes an example of where the latter breaks down (Weil et al., 2013). It does not ignore the importance of these other sets of relationships, or the role of issues like pay and conditions, but the specifics of these largely fall outside the scope of this publication.

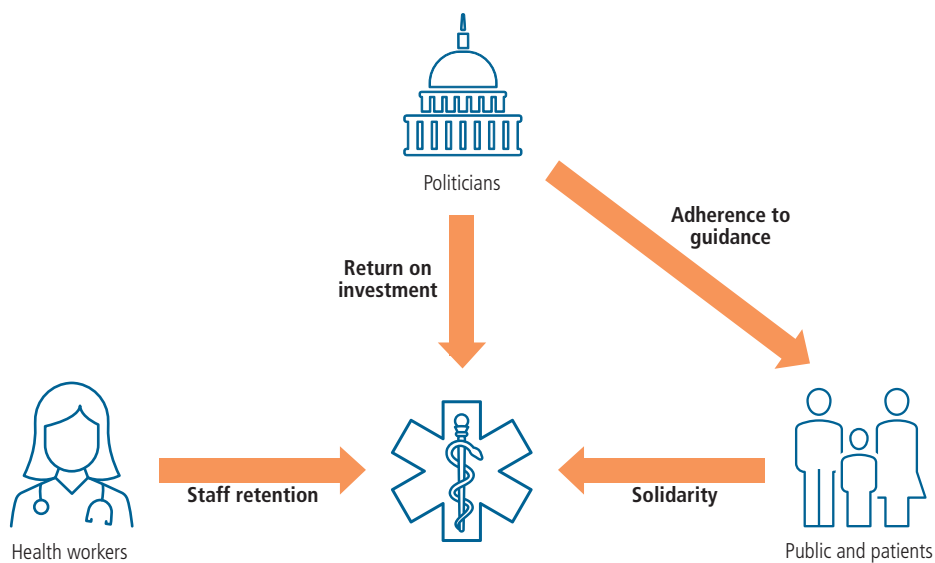
First, there is a loss of trust among the public that the health system will be there when they need it. In some countries, people are struggling to access care due to overcrowded health facilities, long waiting lists, and substantial out-of-pocket payments, with evidence that this may be leading to avoidable deaths (Jones et al., 2022). Their experiences leave them vulnerable to the arguments by some that universal health coverage, to which governments have committed to in the Sustainable Development Goals, is somehow unaffordable or unsustainable, which exacerbates the sense that people cannot rely on their health system.

Loss of trust has been further fuelled during and since the pandemic, by a discourse that attacks health workers and health systems, typically from those opposed to the measures that were necessary to interrupt transmission of SARS-CoV-2 (van Stekelenburg et al., 2022). This has been facilitated by the use of social media to spread disinformation seeking to undermine trust in science and

the health workers who use this science to inform the delivery of evidence-based care (Wang et al., 2022). Moreover, an increasing distrust of the so-called establishment or elite has emerged in recent times, exacerbated by the pandemic, but often fuelled by politicians seeking to create a divide between “them” and “us”. A growing populist agenda in many countries, in Europe as globally, has seen the medical establishment cast as part of “them” with health now part of partisan politicking. If the public is to retain and regain trust in science, in the health community and in the health system, they must be confident that the system can meet their needs now and in the future. This underscores just how important trust is to pursuing the necessary transformations required to address these challenges.

Second, there is a loss of trust among health workers, working in difficult conditions and feeling uncared for by their employers and those making policy for the health system. Many are exhausted and demoralised and have seen too many colleagues become severely ill or die. They feel neglected, leading some to look to other countries that offer improved conditions, while others reassess their work–life balance, a process that can lead them to leave the health workforce prematurely. The rise in partisan politics and othering of health and care professionals in many settings also contributes to an increasingly fragile health workforce. These factors soon create a vicious cycle as the work still has to be done by a now depleted workforce which in turn leads to the loss of more staff. If they are to stay, health and care professionals will need confidence that their working conditions can transform in ways that reflect their changing needs and allow them to deliver the care they wish to see for those they are responsible for. They need to feel valued and trusted.

**Fig. 1: Relations involving trust and health and the health system**



Source: Authors' compilation.

Third, there is a loss of trust among politicians in the ability of health systems to transform in ways that respond to the changing health needs of the population, to adapt to new opportunities to intervene, in particular digital innovations, and to meet increasing public expectations. Without this trust, politicians will understandably be reluctant to make the case for the investments that are needed to address and overcome the challenges ahead. The rise of populist politics and political leaders represents a threat from within, as many are directly undermining trust in health and health systems, and actively looking to cut public funds rather than invest in the transformation agenda required to strengthen health systems.

Fourth, the pandemic has highlighted another relationship of trust, that of politicians in the public. In a crisis, people may be asked to surrender some liberties. But can they be trusted to do so without punitive sanctions? Many governments doubted that the public could be trusted in this way but, as will be discussed, the evidence is somewhat more encouraging and suggests that there is scope for more co-production of health and of health system transformation.

The first three sets of issues are not new (and neither is the last, even if it has only started to be discussed recently). The problems associated with them have been building up for many years, but a combination of developments means that they can no longer be ignored. Ageing of populations is reducing potential recruits to the health workforce and increasing the numbers of older people with health needs that require their care. Geopolitical developments are fuelling inflation and disrupting supply chains, adding to the pressures on health systems. And a lack of leadership in and politicisation of key areas of public life in many countries, such as in health, represent a real concern.

The question then is, what type of transformation is needed and how can it be achieved? Trust is a core problem, so the solution must engage with those whose

trust must be earned. This calls for new approaches that are person-centred, engaging with the public, health workers and politicians. They must take account of how the work of health systems is becoming ever more complex, with the changing nature of disease, such as increasing multimorbidity, and of health care, with multidisciplinary teams bridging home and hospital, and bed and laboratory bench in the context of unprecedented environmental challenges. In this situation, the task of those in charge of the health system must be to support those delivering and receiving care to ensure that the right mix of health workers, with the right skills and technology (including medicines), are in the right facilities, in the right place, at the right time to meet the needs of the (potential) patient or population (Fig. 2). A central component of health policy and service design must, therefore, be the strengthening of public and health professional trust (Gille, 2023).

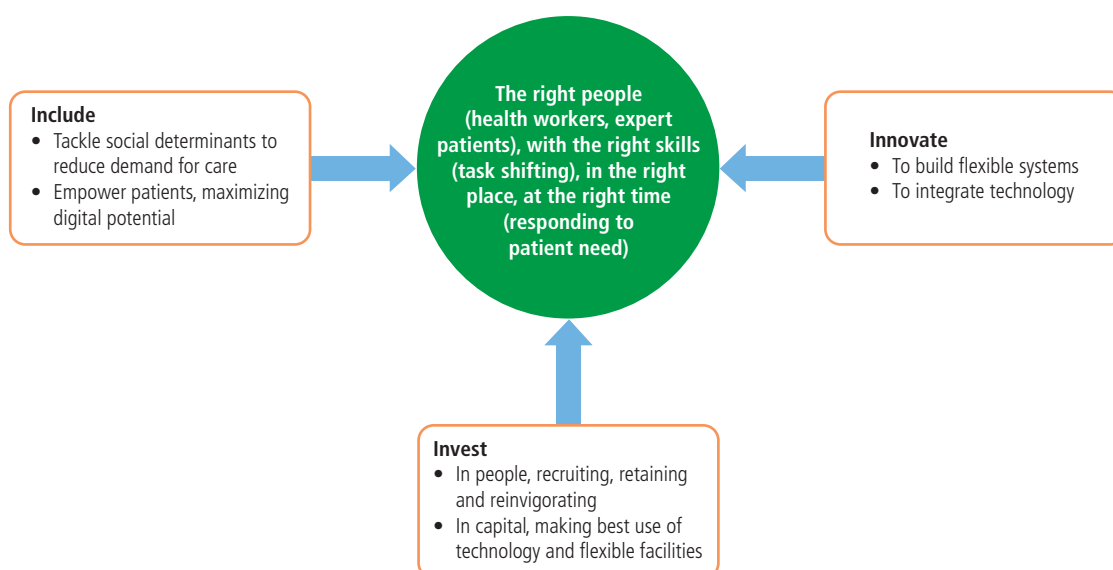
If this is to happen, health workers and managers must be incentivized, encouraged, and supported to work with patients, carers, families and communities to co-create solutions, while those at higher levels of the system must facilitate this process.

This requires a new approach to health systems, based on a commitment to include all stakeholders, invest the resources needed for change, and innovate with new models of care. So how do we make this happen? A first step is to challenge the sense of pessimism that has afflicted many health systems.

### 1.3 Outline of the remaining sections

This publication asks a series of questions. Why is trust important for health systems? What do we mean by trust, how have different disciplines approached it and how can we measure it? What has been happening to trust in health systems in Europe? What are the threats to trust in health systems? And where trust is being eroded, how can we restore it? It concludes with reflections on future directions.

**Fig. 2: The necessary transformation**



## 2 Trust and health systems

Trust in the health system is an indispensable cornerstone that upholds the foundations of effective health care functioning (Beller et al., 2022). Trust creates the intricate web of relationships within the health care ecosystem, from the bond between clinicians and patients through the cohesion within clinical teams to the transparent communication between the health system and the public. As in the evidence we assemble and discuss below, its importance resonates profoundly in myriad ways, amplifying the quality of care and health outcomes.

### 2.1 The importance of trust in health systems

Trust plays a pivotal role in the functioning, effectiveness, and sustainability of health care delivery. Serving as a catalyst for social cohesion, trust underpins cooperation and the equitable sharing of resources within societies. Trust instils confidence among individuals, promoting a sense of unity and a collective commitment to the well-being of all members. Moreover, trust is necessary if economies are to succeed in generating the necessary resources to support health care systems and if the public are willing to provide these resources, through their taxes and other contributions (Dann, 2022).

Collaboration and teamwork thrive in environments characterized by high levels of trust, laying the foundation for robust health care infrastructures. Innovative solutions to emerging challenges often involve task-shifting, with health workers developing new roles, facilitated by technological advances, such as digital communication and remote sensing using wearables or near-patient testing. However, none of these will succeed if those involved lack trust in them and each other. This aspect becomes even more critical in today's increasingly digital and interconnected world, where strong and trusted institutions are essential safeguards against exploitation.

High level health policies govern the allocation of resources, regulation of health care providers, and the overall structure of health care delivery. For these policies to be effective and accepted by society, they must command the trust of many stakeholders, including governments, health care providers, and the general public. When individuals and communities trust their health system, they are more likely to engage with health care services and adhere to public health recommendations, ultimately leading to better health outcomes.

Perhaps the most widely studied example of the importance of trust in health systems is in vaccination programmes (Badur et al., 2020). In countries where there is a high level of trust in the health care system, vaccine uptake rates tend to be higher. For instance, countries like Denmark (Nielsen & Lindvall, 2021) and Finland (OECD, 2021) consistently report high levels of trust in their health care systems, resulting in robust vaccination rates and successful control of vaccine-preventable diseases. In contrast, countries with low levels of trust experience vaccine hesitancy and lower vaccination rates, that are not explained by barriers to access as seen

in some eastern European regions during the COVID-19 pandemic (Beller et al., 2022).

The COVID-19 pandemic brought trust to the forefront in several ways beyond vaccination. A meta-analysis of 67 studies found that trust was associated with most COVID-related outcomes but it mattered who was being trusted (Devine et al., 2023). In general, trust in health authorities was associated with greater vaccine uptake while trust in government was associated with greater adherence to measures such as mobility restrictions. Looking at some of the individual studies, the PsyCorona study, using data from 23 countries, found that higher trust in government regarding COVID-19 control was significantly associated with greater adoption of a range of positive health behaviours, including handwashing, avoiding crowded spaces, and self-quarantine (Han et al., 2023). A study from the United States found trust in government sources of information was associated with greater knowledge about COVID-19 and greater adherence to social distancing, while trust in social media was negatively associated with both (Fridman et al., 2020). Trust in government sources was higher among older white respondents. A European study found a positive association between political trust and reductions in mobility during the first COVID-19 lockdowns (Bargain & Aminjonov, 2020). Other studies, such as one using data on incidence and mortality from the European Centre for Disease Prevention and Control, found higher trust to be associated with lower COVID-19 incidence and mortality (Farzanegan & Hofmann, 2022). A study comparing Canada, Denmark and the United States concluded that trust in government was more important than resources in vaccine uptake and adherence to protective measures (Falkenbach & Willison, 2022).

Taking this evidence together, one group of authors has argued that high trust in government played a major role in determining COVID-19 infection rates. Whether this position is confirmed or not, their conclusion resonates: "perhaps this pandemic can be a catalyst for the societal reforms needed to earn and nurture public confidence and social solidarity. COVID-19 has shown that the democracies that can mobilise public trust are best placed to survive and thrive even in the face of great adversity" (Bollyky et al., 2022).

Beyond the pandemic, trust also plays a critical role in health policy implementation. Policies aimed at improving public health, such as smoking cessation (Lindström et al., 2000), programmes to tackle the harm caused by gambling (van Schalkwyk et al., 2021), or campaigns to combat infectious diseases, rely heavily on public cooperation. When individuals trust that these policies (or their authors) are guided by their best interests and are implemented transparently and fairly, they are more likely to support and adhere to them. Conversely, in settings where trust in the health care system is low, adherence may be undermined, hindering the achievement of the intended goals.

Trust in health systems also reflects resource allocation and equitable access to health care services. In countries where there is a high level of trust in the government's ability to distribute resources fairly, health care resources are more likely to be allocated in an equitable manner. For example,

in the Nordic countries, there is both more equal access to health care services regardless of socioeconomic status (Baroudi et al., 2022) and trust in public institutions is high. In contrast, regions with low trust experience disparities in health care access and outcomes.

Beyond individual well-being the erosion of trust can damage public willingness to uphold the principle of solidarity, which is foundational to many health care systems, particularly in Europe. Trust in the health care system is essential to maintain the social contract that underpins these systems. Bor reports findings from a series of surveys that tracked public opinion throughout 2020 in four countries: the United States, Denmark, Hungary and Italy. (Bor et al., 2023). The findings were complex. The headline result is that social solidarity remained remarkably similar in their sample compared to values in surveys conducted prior to the pandemic. However, there were some differences in the detailed findings. There were decreases in tolerance towards immigrants among Danes and Americans, but these negative changes were counterbalanced by smaller movements in the opposite direction in some other variables and in support for redistribution among Americans. By April, social solidarity slightly increased in Hungary and Italy but decreased in Denmark and the United States but there was no evidence that social solidarity had been eroding throughout 2020. This study makes two other important contributions. First, due to its panel design, following the same people over time, it suggested that some previously described associations from cross-sectional studies were artefacts. Second, it found an association between individual levels of anomie, or a sense of meaninglessness, and extreme discontent, a finding that could have longer term political consequences, with other work by some of the same researchers in a larger group of countries linking the discontent that is associated with what they describe as pandemic fatigue to support for protests and conspiratorial thinking (Jørgensen et al., 2022).

## 2.2 Social trust versus institutional trust

It is important to differentiate social and institutional trust. Social trust reflects an optimistic perspective on the world and encourages interactions among strangers, predicated on the belief that they are sincere and do not set out to harm you. Institutional trust is characterized by the expectation that governmental authorities, law enforcement and public institutions, in general, act in the best interests of the community.

Trust in institutions is not unconditional. Researchers have used their experiences to test a series of hypotheses about how institutional trust develops (Mishler & Rose, 1997). Institutional theories see trust as driven by the characteristics of those institutions as they are viewed by individuals while cultural theories see trust in institutions as an extension of each individual's general trust in society, often learned when young and subsequently projected onto the institutions they interact with. These can be divided into macro- and micro-level theories. Macro-cultural theories emphasise the role of national culture in shaping trust, while micro-cultural theories consider how each person's trust has been shaped

by their previous experiences. Macro-institutional theories base trust on the overall ability of institutions to perform, while micro-institutional theories are based on the sum of personal experiences with them. Research using multilevel models following the political transitions in countries of eastern Europe and central Asia in recent decades provide a rich source of data. These support the micro- theories, finding marked variations in institutional trust according to individual characteristics, but also some support for macro-institutional theories, specifically in an inverse association between trust and perceived levels of corruption (McKee et al., 2013).

Trust in institutions is readily damaged. Surveys by Transparency International find that the health sector is viewed as among the most corrupt in many countries (Hutchinson et al., 2019) with corrupt practices taking a variety of forms including informal payments, unauthorised absences and procurement, with widespread abuses in several countries during the COVID-19 pandemic (García-Altés et al., 2023) undermining confidence. Trust also plays a crucial role in ensuring adherence to societal norms, regulations and rules within health care systems. Individuals are more likely to comply with prescribed medical procedures and protocols when they have confidence in the institutions overseeing their care. However, it is easily lost. A well publicized breach of COVID-19 regulations by a senior figure in England was associated with a marked fall in confidence in the government's ability to handle the pandemic (Fancourt et al., 2020).

Trust also fosters an atmosphere of innovation, where individuals feel secure in taking calculated risks to drive improvements in health care practices and outcomes. Additionally, communities with high levels of trust are better equipped to respond effectively to crises, resulting in faster recovery and resilience. In essence, trust in health systems is not merely a desirable attribute but a fundamental pillar upon which the success and resilience of health systems rest.

In many countries, institutional trust has been experiencing a noticeable decline despite objective improvements in public services over recent decades, although there have been some exceptions, with increases in the early 2000s in some former Soviet countries (McKee et al., 2013). Also called the delivery paradox, this phenomenon of decline in trust while services are improving challenges the conventional belief that improving the quality and efficiency of public services inevitably leads to increased trust in the institutions delivering them. Several factors contribute to this paradox. Rising expectations result from improved services, making citizens more critical of institutions that fail to meet higher standards, potentially eroding trust. Complex and opaque bureaucracies can hinder accountability, leading to perceptions of inefficiency and corruption. Historical failures, external influences on public opinion, diverse societal priorities and a gap between expectations and outcomes further complicate trust-building efforts. Addressing this paradox necessitates a multifaceted approach, including measures to increase transparency, accountability, and public engagement, alongside management of evolving expectations, something that will be discussed in a later

section on building, restoring and maintaining trust in health systems.

At its most basic, the delivery paradox underscores the need for institutions to not only enhance services but also cultivate a model of trust inspired by social collaboration. This model recognizes citizens as active partners in the relationship, respecting their competence and agency, particularly in matters such as health management, where individuals are increasingly informed and discerning.

### **2.3 Trust of patients in the health system**

The relationship between clinicians and patients lies at the heart of the health system, and trust is its bedrock (Goold, 2001). Patients entrust their well-being to the hands of health care professionals. In return, clinicians rely on patients to provide accurate information about their health and circumstances. This mutual trust is pivotal; without it, the efficacy of medical treatments and the quality of care diminish significantly. Trust has been linked to treatment adherence and predicts continuity of care (Thom et al., 2004). Trust enables patients to confide in their health care providers, sharing their symptoms, concerns and fears openly, which is crucial for accurate diagnoses and effective treatment plans (Mechanic & Meyer, 2000).

Trust is a reciprocal process and fosters mutual understanding and empathy (Hojat et al., 2013), two indispensable components for building deeper and more meaningful relationships within the health care system. Clinicians who trust their patients are better equipped to understand their unique needs, preferences and values (Street et al., 2009). This empathy facilitates patient-centred care (Eklund et al., 2019; Kwame & Petrucka, 2021), where health care decisions are made with consideration for the individual patient's circumstances, promoting a higher quality of care and patient satisfaction (Walsh et al., 2019).

Trust also encourages individuals to seek medical care promptly, preventing conditions from deteriorating. When patients trust the health care system and their health care providers, they are more likely to act proactively to address their health concerns, leading to earlier intervention and better outcomes. Trust also profoundly impacts the patient experience. Positive encounters built on trust enhance patients' experiences, making them feel heard, respected, and cared for. This, in turn, contributes to one of the primary objectives of health systems—responsiveness to patient needs and expectations (World Health Organization, 2000).

Trust in the health care system is not a mere luxury but an absolute necessity and underpins all of the building blocks of health systems. Trust elevates the quality of care, enhances patient outcomes and ultimately underpins the very essence of health care itself: the well-being of patients (Berger-Schmitt, 2002).

### **2.4 Trust of health workers in the health system**

Workforce shortages, driven substantially by failures of retention of skilled staff, are already among the greatest threats to the sustainability of health systems in Europe (Zapata et al., 2023). If these health workers are to stay, they need fair incomes, reflecting what they can earn should they seek employment in other sectors; supportive working environments, such as well-designed facilities and access to technology; equitable and safe working conditions, free from discrimination, bullying, and other forms of mistreatment; and opportunities to progress in their careers. More than that, they must have trust that the health system cares about them and will provide these conditions in the long term. Regrettably, some or all of these conditions are lacking in many health systems as is the trust that the system will address the gaps in provision. The consequence is that health workers are leaving health systems, taking early retirement, seeking other ways to use their skills, such as in information technology, or emigrating to countries offering better conditions. Thus, one in three medical students in the United Kingdom does not intend to remain in its National Health Service (Ferreira et al., 2023).

The situation has been exacerbated by the experience of the pandemic. Burnout and moral injury, the phenomenon more often used in military parlance where an individual experiences psychological trauma because of their inability to help others, were widespread (Williamson et al., 2023). This situation was not helped by shortages of essential personal protective equipment, coupled with widespread accounts of procurement scandals and profiteering that prevented their being delivered (McKee, 2020).

This loss of trust has consequences that go beyond retention of health workers. It is seen in the breakdown of relations between health workers and governments that has contributed to strikes in some countries (Deakin, 2023). Strikes by health workers are extremely rare and should be seen as a signal that there is a major problem in the health system necessitating decisive action to fix it (Weil et al., 2013). This loss of trust also creates a reluctance by health workers to innovate and thus take forward the transformations that are needed.

Health care providers, such as physicians and nurses must trust the policies and regulations governing their practice. Trust in these regulations fosters a conducive environment for health care professionals to deliver care effectively, knowing that their actions align with established standards and guidelines.

### **2.5 Trust of politicians in the health system**

Health systems will only be able to transform to meet changing needs and expectations and to foster trust if they receive adequate investment. This is often dependent on politicians making the necessary resources available. Yet they will only do so if they trust the health system to use those resources wisely. Without this trust, politicians will understandably be reluctant to make the case for the investments that are needed to address and overcome the challenges ahead.



Addressing this lack of trust has two aspects. The first involves providing reassurance that the resources are indeed being used appropriately, for example by having robust health technology assessment systems. The second is to challenge the frequent characterization of all forms of variation in use of resources as waste. Some may be legitimate, as when facilities serving disadvantaged populations must do more to address the health consequences of failings in other sectors (although more often these populations are actually underserved in relation to need, illustrating what is termed the inverse care law (Tudor Hart, 1971), and some may reflect a failure to recognize the need for a degree of redundancy in a system in case of emergencies. Thus, some European health systems that had long been accused of profligacy prior to the pandemic (for example by virtue of high levels of provision of intensive care facilities) were better able to respond to the pandemic, with one analysis suggesting that, even at low occupancy rates in normal times, this may be a cost-effective element of pandemic preparedness (Gandjour, 2021).

This aspect of trust is, however, the least understood of those examined in this brief. Insights are more likely to be found in political biographies and other historical studies than, at least at present, in empirical research (although these need to be understood in context). These sources can offer inspiration and suggest topics for future research. It is also possible to draw on the literature on agenda setting, such as Kingdon's model of policy streams (Kingdon & Stano, 1984) or Jenkins' (2013) practical guide to getting politicians to prioritize mental health, for ideas and suggestions of wider relevance.

## 2.6 Trust of politicians in the public

The trust that politicians have in the public has only recently been recognized as important in the context of health policy. This is a consequence of experience during the pandemic. For example, in the United Kingdom some politicians and their advisers hesitated to impose major restrictions in its early stages, based on the erroneous view that the public would not comply or would become fatigued (Reicher, 2021). This perspective has been linked to delays in introducing restrictions on mobility, even though, even at the time, it was clear that any delay would have severe consequences with a virus that was spreading rapidly and exponentially (Arnold et al., 2022).

Reicher and Bauld have described how governments tend to view the public as psychologically flawed, subject to biases, and unable to deal with complex, uncertain or probabilistic information (Arnold et al., 2022). From this perspective, the individual is seen as what they describe as a "fragile rationalist". Reicher has linked this to the concept of nudge, which he characterises as the idea that individuals must be helped to make the right decision by changing the choice architecture. If this is indeed the case, then it is even more important that people are guided to particular decisions in a crisis. However, he questions this assumption, noting that the main explanations why people do not make the right choices people often lie in areas outside their control.

Moreover, as Drury has noted, panic is very rare and people tend to support one another in emergencies, even if they are strangers, and where disasters do happen it is rarely due to psychological dysfunctionality (Drury, 2018). Rather, it is more likely to be due to failures by those in charge, such as blocking exits and having too little information rather than too much (Drury et al., 2020).

The pandemic offered a wealth of empirical evidence on this issue. Tracking data from mobile phones showed how people changed their behaviour rapidly in the early stages, including in Sweden where legal restrictions were much less stringent than in other European countries (Vannoni et al., 2020). There has been no evidence of significant fatigue, with adherence remaining high as long as a threat remains (Reicher & Drury, 2021). Overall, the experience of the pandemic reinforces the view that people should be trusted, that most breaches of rules are a consequence of necessity, and punitive measures, such as fines, are often counterproductive. Instead, measures that strengthen communities and mutual support are more likely to be effective.

## 2.7 The role of social participation

Social participation plays a crucial role in building trust within health systems, underpinning optimal relationships between governments, health care institutions, civil society and the community. Civil society organizations can play an important role (Box 2).

### Box 2: Aspects of social participation

**Civil society:** Civil society organizations (CSOs), often characterized by their independence from both the public and private sectors, can play a variety of roles depending on the context and the government's disposition toward them, with the level of trust or mistrust in this relationship influencing the nature of interactions and their impact.

**Community:** The term community encompasses groups of individuals who share common attributes or interests, often carrying connotations of bonds, trust, social cohesion and relationships, whether membership is by choice or based on shared characteristics.

Social participation mechanisms seek to enable civil society and the public to be informed and engaged in health care decision-making processes. When people have access to information and can actively participate in discussions about health care policies, they are more likely to trust that decisions are being made transparently and accountably. For instance, in Sweden, citizens participate in the planning and allocation of health care resources through local health councils, fostering trust in the health care system's fairness and openness. Additionally, social participation ensures that a diverse range of voices and perspectives are considered through a process of shared decision-making, a sense of ownership, power diffusion and responsibility for health outcomes is fostered. However, it is necessary to avoid engagement that is merely tokenistic, marginalizing individuals with experiential knowledge. This not only fails to influence policy but also carries significant risks, including erosion of trust between stakeholders and in the participatory process itself.

It is axiomatic that democratic principles and values are the foundation of a participatory space. A participatory space for health, especially one where visible efforts are being made to equalize the balance of power, requires inclusion of voices heard through demonstrations, protests, strikes, petitions and other campaigns. Taking unsolicited public engagement seriously can help to overcome social and political power barriers (Matos & Serapioni, 2017; Nelson et al., 2018). At the very least, acknowledging the messages that the population, communities and civil society put across to decision-makers via such means increases the level of trust between population and government.

### **2.8 What are the threats to trust in health systems?**

If trust is a cornerstone of effective health systems, its erosion can have far-reaching consequences. Several threats pose significant challenges to trust in health systems, with each threat carrying its own unique implications. They include misinformation and disinformation, marginalisation and discrimination, and lack of transparency.

One of the greatest contemporary threats to trust in health systems is the proliferation of misinformation and disinformation, particularly in the context of health care. It is important to differentiate these concepts. Misinformation is a passive or inadvertent spread of misleading and false information, whereas disinformation reflects the deliberate and concerted spread of misleading and false information (Wang et al., 2022). Misinformation proliferates partly because people accept advice and information from friends, family and people they feel their community trusts above official sources (Rodgers & Massac, 2020). Misleading or false information about vaccines has been associated with decreased vaccination rates and heightened risks of preventable disease outbreaks. During the COVID-19 pandemic, the rapid spread of misinformation about the virus, treatments and vaccines on social media platforms contributed to vaccine hesitancy and undermined trust in public health agencies (Roozenbeek et al., 2020). However, vaccine hesitancy long predates the most recent pandemic, with disinformation relating to the alleged, and false association between the MMR (measles, mumps, rubella) vaccine and autism being perhaps the most widely studied example (Sadiq MT and Saji KM, 2022).

Internet and social media platforms like Twitter (renamed X in July 2023) and TikTok have become breeding grounds for misleading health content (Buchanan, 2020), as shown in a review of access to social media influences and population health decisions (Swire-Thompson & Lazer, 2020). The prevalence of health misinformation was the highest on Twitter (now X) and on issues related to smoking products and drugs. However, misinformation on other major public health issues, such as vaccines and diseases, was also found to be high, leading individuals to question the credibility of health authorities and institutions (Suarez-Lledo & Alvarez-Galvez, 2021). Another study found some US physicians (more typically male and specializing in alternative medicine) spreading a variety of misinformation related to COVID-19 using Facebook, Twitter and YouTube (Sule et al., 2023).

Marginalisation and discrimination present a formidable threat to trust in health systems (Wesson et al., 2019). There is extensive empirical evidence that members of a group, defined according to characteristics such as race, ethnicity or socioeconomic status, tend to favour other members of that group (Balliet et al., 2014), and that this is mediated, to a considerable extent, by different degrees of trust (McKeown & Psaltis, 2017; Montoya & Pittinsky, 2011). When marginalized communities experience unequal access to health care, lower quality of care and worse health outcomes, their trust in the health care system can erode, leading to delayed presentation and consequently poorer outcomes, for example. There is, however, evidence that intergroup trust can be increased using methods that address unconscious bias (Duncan et al., 2023).

The absence, in many countries, of health and social data disaggregated by ethnicity is a major barrier to understanding these associations (Routen et al., 2022). This can, to a very limited extent, be addressed by one-off surveys, such as research showing markedly lower vaccine uptake among Roma in central Europe, a population that has often well-founded distrust in state institutions (Duval et al., 2016). The importance of having such data is apparent from the experience of those few countries that do collect it, especially the United Kingdom, where certain ethnic minority populations fared far worse during the pandemic (Katikireddi et al., 2021).

A lack of transparency within health care institutions and policies can also erode trust. When the basis of health care costs is opaque, where medical errors are not openly acknowledged, or where conflicts of interest are not disclosed, patients and the public perceive a lack of accountability and ethical behaviour within the health care system. The United States offers many examples. One is distrust of the pharmaceutical industry, seen as profiteering from the pricing of essential medications, such as insulin (Knox, 2020). This lack of transparency regarding essential drug pricing has resulted in calls for greater accountability and disclosure (Mossialos & McKee, 2003), as patients and the public seek to understand the reasons behind such cost increases and their impact on health care access. Trust in the industry has also been eroded by evidence of the role of the Sackler family in driving the opioid epidemic (Keefe, 2021).

Transparency is especially important in relation to medical errors, whether they actually occur or are perceived as being common. They can lead to patient harm or even loss of life, and have the capacity to shatter trust in health care providers, institutions and the overall health care system. One example from the United Kingdom, a scandal at the Mid Staffordshire NHS Foundation Trust, exemplified how widespread neglect and poor standards of care can leave patients and their families feeling that their safety and well-being have been compromised and severely erode trust in the health care system (Holmes, 2013). Secondly, even the perception that medical errors are commonplace can be detrimental. In France, reports of medication errors in hospitals have been linked to concerns that individuals have become wary of seeking medical care due to fears of becoming the next victim of a mistake (Azar et al., 2021).

Transparency and accountability are thus fundamental to ensuring trust in health care. Health care providers and institutions must openly acknowledge errors or investigate their causes although medical errors, if given a high profile by the media, can significantly impact public perceptions and thus trust in the health care system. This was the case in Germany when incidents such as wrong-site surgeries or medication mix-ups involving well known hospitals gained extensive media attention and had negative consequences for trust (despite the transparency (Stauch, 2011). This highlights the importance of preventing such events from happening in the first place.

### 3 Research on trust in health systems

This section draws extensively on a recent review by Taylor and colleagues, which examined the literature on trust in health care spanning the last 50 years (Taylor et al., 2023). They begin by noting how the experience of the pandemic “has clarified the role that trust played in virtually every element of health care delivery”. Thus, lack of trust delayed care and reduced vaccine uptake, adversely affecting health. Health workers realised how much their safety and that of their families relied on trusting colleagues, employers, and patients. However, they also note that the literature on trust “can be as frustrating as it is voluminous”, with simple questions being met with complicated answers.

They identified five broad groupings within the literature: patients’ trust in clinicians; clinician trust in patients; clinician trust in clinicians; patients’ and clinicians’ trust in organizations (which they combined as this literature was sparse); and general trust in health care systems by patients, clinicians and the general public.

Research on the first of these, trust of patients and clinicians, is the most extensive. Referring to a seminal systematic review published in 2004, which said that the “evidence base to support the claims about the impact of trust on therapeutic outcomes is in short supply” (Calnan & Rowe, 2006), they noted limitations in much of the subsequent work, which was dominated by cross-sectional surveys or qualitative interviews, with a few intervention studies. However, they also cited a recent systematic review, which although only looking at general trust rather than trust by the patient in the specific clinician, did identify 13 randomized controlled trials. The interventions, all intended to increase trust, included measures designed to improve communication, motivational interviewing, shared decision-making, patient centred care, empathic care, and cultural competency training. Together, they found a small but significant effect on health care outcomes, including pain and anxiety, and markers of diabetes control (Kelley et al., 2014).

The authors note how most studies use validated scales to measure trust. These typically include concepts of honesty, communication, confidence and competence, although fidelity, system trust, confidentiality and fairness also featured, although less often (Ozawa & Sripad, 2013). Three are now the most widely used, the Group-Based Medical Mistrust Scale, Medical Mistrust Index, and Health Care System Distrust Scale. However, they note that research on the psychometric properties of these measures is limited (Müller et al., 2014).

They make three recommendations. First, they call for improved instruments for measuring trust, with additional validation of their psychometric features. They call for measures that assess trust in clinicians other than physicians, and in the teams that are increasingly involved in providing health care. Second, they note the challenges involved in taking account of reciprocity, whereby the quality of the clinical interaction is influenced by both the trust of the patient in the clinician and of the clinician in the patient. Here, they also highlight the challenges that arise,

whereby trust in the clinician is related to trust in the health facility that employs them and in the health system more generally. Third, and noting that their focus is on the United States health system, they call for research that seeks to understand differences in trust in doctors and nurses.

They find many fewer studies looking at trust in patients by clinicians. In contrast to the literature on trust in clinicians by patients, these studies do tend to consider the reciprocity involved in the relationship. However, this is a relationship based on two different types of vulnerability. The patient is vulnerable to harm caused by the clinician whereas the vulnerability of the clinician relates to their reputation and professional standing. Here, the authors call for innovative designs, such as those that examine how trust changes over the course of what, for chronic conditions, can be a long-term relationship.

Many of the papers about relations between clinicians and other clinicians that included the word trust in the title did not really focus on it. Where they did, trust was seen as an aspect of clinical competence, although one conceptualized trustworthiness as a function of both competence and integrity (Duijn et al., 2018). One study identified high autonomy and an emphasis on quality rather than productivity as predictors of trust by colleagues from a range of professional backgrounds in physicians (Linzer et al., 2019). Another saw trust as being justified where the individual or organization is perceived to have “the competence, willingness, integrity, and capacity ... to perform a specified task under particular conditions” (Lundh et al., 2019). The authors call for more research on trust among clinicians with different professional backgrounds and in hierarchies where there are formal power differentials (Umoren et al., 2022).

The sparse literature on trust in health organizations is also dominated by research from the United States, and thus might not easily be generalized to a European context. In particular, it has been noted that the growth of managed competition and with it the creation of a consumer mindset, has undermined trust, as patients “question the motives and decisions of these organizers and providers of care” (Mechanic, 1996). This is increasingly recognized as a problem, with evidence linking mistrust to underutilization of services (Taber et al., 2015). This literature also invokes the concept of institutional betrayal, where health organizations fail to act to protect those dependent on them. A recent example was the response by managers in a hospital in England to a series of unexplained deaths among babies where paediatricians had raised concerns about a nurse but were rebuffed and were even required to apologize to her. She was later convicted of multiple murders (Alexander, 2023). The authors note the scarcity of research on this particular relationship and, especially, the lack of research on trust of clinicians in their employing organizations.

The final type of trust is that in health systems in general. This literature is reasonably large, with many studies using data from surveys of public opinion. A 2013 systematic review identified 45 measures of trust within the health system (Ozawa & Sripad, 2013). They developed a concept map of the elements contained within them, finding that

honesty, communication, confidence and competence were most often captured by those measures, with less attention given to concepts such as fidelity, system trust, confidentiality and fairness.

A 2019 systematic review examined mistrust, defined as “a tendency to distrust medical systems and personnel believed to represent the dominant culture” (Benkert et al., 2019). The authors found that medical mistrust was often associated with earlier negative interpersonal experiences with health care personnel and while medical mistrust predicted a number of outcomes associated with service delivery, they found no clear link to health outcomes.

In summary, the review by Taylor and colleagues stresses the importance of trust and shows how the term is widely used but often inadequately defined or poorly understood (Taylor et al., 2023). It sets out an ambitious agenda for research. However, it also highlights two important issues that must be addressed. First, definitions of key terms, including trust and trustworthiness, are still contested. Second, trustworthiness cannot be fully observed by either those whose trust is sought, or by the researchers seeking to understand the phenomenon. Thus, although a patient may have a well-founded expectation that a clinician will treat them well, they cannot predict the future so their perception will also be influenced by their attitude to risk. Another problem is that trust is a complex phenomenon, involving many different decisions. Hence, it can be difficult to know whether two people, both recording scores of four on a five-point scale of trust, actually mean the same thing.

Finally, the authors suggest that researchers working in this field draw on insights from other disciplines, such as philosophy, sociology, economics and psychology. These are summarized in the next section.

## 4 Disciplinary perspectives on trust in health systems

Superficially, the concept of trust seems quite simple. I can be confident that, in any exchange, I will get what I expect. Mechanic has defined it as at its core, a belief “that individuals and institutions will act appropriately and perform competently, responsibly, and in a manner considerate of our interests” (Mechanic, 1998). Yet the concept of trust has generated much disagreement about its nature, its role in transactions, and its value in several disciplines, including philosophy (Carter & Simion, 2023), sociology, economics and psychology.

### 4.1 Philosophical perspectives on trust

We begin with a series of issues that concern the nature of trust. The first of these issues is the relationship between reliance and interpersonal trust. While a patient may rely on a doctor to get their diagnosis right, several writers have argued that this is not sufficient to count as trust. By analogy, one might rely on a shelf not to fall down and shatter a precious ornament but one would not usually say that one trusted it not to. Jones has argued that while one can rely on many things, such as the shelf not falling down, one can only trust someone that has a will and can thus decide whether or not to act in a way that is trustworthy (Jones, 1996). Thus, extending the shelf analogy, the trust is in the person who fixed it to the wall or who selected the material from which it was constructed.

Baier has argued that trust involves goodwill (Baier, 1986). There is an expectation that the person being trusted acts in a certain way because they have your interests at heart, not that they are doing it begrudgingly, accidentally or because they are being forced to do so. In contrast, Hawley rejects the view that it is goodwill that is necessary for reliance to become trust, instead arguing that it is commitment (Hawley, 2014). She uses an example where a work colleague who is a poor judge of quantities reliably brings extra food to work, so that one can depend on being able to eat their leftovers. This only becomes trust when they commit to doing so, perhaps because they enjoy eating with you.

Hawley distinguishes the consequences of failures by things that have will or have no will (Hawley, 2014). To return to the earlier example, should the shelf fall down one would be disappointed, whereas should an individual act contrary to what was expected, for example by saving money by not using the right fixings, it would be seen as betrayal. Faulkner invokes ideas of predictive and affective trust (Faulkner, 2011). The former simply involves relying on someone to do the right thing because they usually do. When they fail to do so, then the response is disappointment. However, in the latter case there is not just a sense of reliance but also a normative expectation that the person ought to be dependable so, if they are not, it is seen as betrayal. In summary, trust is more than being reliable. It involves a commitment to behave in ways that lead to one's actions being reliable.

A second issue relates to the question of trust to do what? Writers on trust distinguish three-place trust, where A trusts B to do X (for example to water your plant when on holiday) but not to do Y (such as look after your child), from two-place trust where A trusts B generally. While the practical difference is obvious, the philosophical discussion has centred on which derives from the other. Most writers argue that two-place trust derives from three-place trust. In other words, if A trusts B to do enough things, then the relationship becomes one of two-place trust. Critics of this view argue that it fails to take account of the nature of other aspects of relationships that influence trust, such as love and friendship, that are typically unconditional (Domenicucci & Holton, 2017). The importance, for the present purposes, is that trust in, for example, health workers, can derive either from the view that they can be trusted because, for example, they have certain skills (thus, one would trust a surgeon to remove an appendix but not necessarily to paint a portrait) or because they have shown the commitment and vocation to become health workers and so, should they take to portraiture, can be trusted to do it to the best of their ability.

A third issue introduces the question of whether one's beliefs are relevant to considerations of trust (often employing the philosophical term *doxastic*, which simply means relating to an individual's beliefs) (Adler, 1994; Hieronymi, 2008). *Doxastic* accounts of trust, at their most basic, see trust as where A believes that B will do something, while Hawley develops this to see trust as where A believes that B will not just do it but is committed to doing so. Meanwhile, non-*doxastic* accounts recognize that such a belief can be present but is not essential for trust, for example where there is respect that they will try to do it but no belief that they will always succeed (Baker, 1987). Others invoke optimism that they will do the right thing, even if one does not believe with certainty that they will (Jones, 1996).

These questions have relevance to how one approaches trust in health care. A *doxastic* approach has the advantage of simplicity. The patient trusts the health worker because they believe they are competent. Without such belief, they will require other evidence that this is the case. This could take the form, for example, of a public report of their clinical success rate, a measure fraught with problems, including methodological ones (McKee & Hunter, 1995). *Doxastic* accounts also distinguish trust that someone will do something well from the optimism that arises from desperation where a patient clutches at straws (causing themselves to believe in an outcome that is very unlikely) lest they lose hope.

This issue is also relevant to the other side of the health worker–patient relationship, where the health worker trusts the patient to adhere to the therapy they have been prescribed. Given the extensive literature on non-adherence to many long-term treatments, the health worker may trust the patient to take their tablets but not necessarily believe that they will (non-*doxastic*). However, this can develop into therapeutic trust, whereby trust is seen as a means to promote trustworthiness (Frost-Arnold, 2014). Thus, rather than castigate the patient, the health worker will emphasize the trust they have that the patient will do all they can.

A further issue to be considered is how trust relates to the risk that is inherent in trust. Thus, the patient recognizes that there is always a risk that something could go wrong with their treatment. The question then becomes how they respond to it. They could accept it, thereby preserving the therapeutic relationship with the health worker, or they could seek to minimize it, for example by getting second and third opinions or demanding to see the health worker's qualifications. However, that could undermine the trust on which the relationship is based (Faulkner, 2011). This, like so many of the issues discussed in this brief, is subject to changing norms. Thus, in the United Kingdom, a failure by a clinical team to seek specialist advice gave rise to a movement (Martha's Rule, named after the young girl who died) that has attracted widespread political support to give patients and their relatives the right to seek a second opinion (Mills, 2023).

A second set of issues relate to norms in trusted relationships. There are two types to be considered, the first related to the norm that one will be trusting of someone who invites you to trust them and the second, the norm that someone who is trusted should be trustworthy (Fricker, 2018).

Carter argues that when deciding to trust someone, one should consider three evaluative assessments: success, competence and aptness. Trust can be justified if the person trusted succeeds in what they should do or if they display competence that allows one to rely on them doing the right thing. However, while these two considerations will often coincide, someone can be competent but not succeed, for example due to a lack of judgement at some point. The third is therefore aptness, where their success is explicitly derived from their competence (Carter, 2020).

While these considerations relate to whether someone is entitled to trust another, Fricker has asked whether we have an obligation to do so, examining the situation that arises when someone who merits trust is dismissed because of prejudice on the part of the person being asked to trust them (Fricker, 2007). She illustrates this by reference to the book *To kill a mockingbird*, where a Black man on trial before a White jury for a crime of which he is innocent has his testimony dismissed. This is relevant in health care where, for example, a patient distrusts their health worker on the grounds of their ethnicity rather than their competence.

The literature on trustworthiness is complex but, to simplify it, debate arises around issues such as whether it relates to trust in general or in a particular matter (the two- and three-place issue discussed above) and whether it is sufficient to be reliable or requires something else, such as goodwill, also discussed above.

So far, this section has focussed on trust. However, there is also debate about the opposite of trust. Three terms, low trust, distrust, and mistrust, are commonly used, each with potentially different meanings.

Low trust is, arguably, the easiest to understand. It arises where someone is willing to make themselves vulnerable in an interaction with someone they might trust, albeit with limited enthusiasm. This differs from distrust, where they will be reluctant to do so because they expect that

the person being trusted will be incompetent or actually seek to harm them (Hillen et al., 2011). Thus, Mechanic has argued that distrust is not the opposite of trust but is an alternative to it (Mechanic, 1996). It is the difference between mistrust and distrust that is more problematic. Griffith and colleagues have suggested that distrust relates to the perception of a specific person or organization, while mistrust is a more general scepticism, arising for example from experience of historical injustice and systemic racism (Griffith et al., 2021). This is consistent with an earlier review that noted how, although the two terms are often used interchangeably, distrust refers to a lack of trust based on prior experience in a particular context while mistrust refers to a general sense of global unease (Brennan et al., 2013).

## 4.2 Sociological perspectives on trust

Consistent with other disciplines, sociological research differentiates trust in general with trust in specific individuals or organizations (Fukuyama, 1996). Much of the literature has focused on its antecedents and determinants (Schilke et al., 2021). In particular, it examines how characteristics such as social position, prior experiences and opinions can influence levels of trust. As with much of the literature on trust and health systems, there is a distinctly American focus. This tends to emphasise the growing distrust associated with the increasing commercialisation of American medicine (Imber, 2008), with evidence that both clinicians have lower trust in for-profit health plans (Schlesinger et al., 2005). However, there is other literature finding, for example, that poor self-rated health in a Swedish study was mediated in part by underuse of the system by those who lacked trust in it (Mohseni & Lindstrom, 2007).

Seligman's seminal book, *The problem of trust*, distinguishes trust in systems from confidence in them, arguing that trust is more important when institutions and systems are breaking down (Seligman, 2000).

An important body of sociological literature addresses the relationship between trust and social capital. Social capital comprises the networks and norms that facilitate coordination and cooperation for mutual benefit. It encompasses connections among individuals and the social networks and norms of reciprocity and trustworthiness that arise from them. Trust is often seen as a key element of social capital, acting as the glue that holds networks together. In this literature, trust has several important benefits. First, it reduces transaction costs. High levels of trust mean that people spend less time and resources verifying information or guarding against potential exploitation. Second, it facilitates cooperation. When trust is widespread, individuals are more likely to engage in collective action and community endeavours. Third, it promotes economic growth. Societies with high social capital, characterized by trust and reciprocity, often experience better economic performance due to smoother transactions and reduced need for rigorous regulations.

The relationship between social capital and trust is bi-directional. High levels of trust can lead to greater social capital, and in turn, a rich stock of social capital can further enhance and sustain trust within a society. This mutual

reinforcement creates a feedback loop where societies with high trust and social capital can continue to thrive and grow stronger over time. However, breakdowns in trust can erode social capital. Events like financial crises, political scandals or episodes of societal unrest can diminish trust among individuals or between the public and institutions. Once depleted, trust can be challenging to rebuild, leading to a weakening of social capital and its associated benefits.

The evidence on social capital and trust is, however, contested, as is the role that it plays in health. In a 2003 paper, Pearce and Davey Smith questioned what they described as a “vague, popular concept”, arguing that the evidence linking social capital and health was often conflicting (Wilkinson, 2002). One problem is that, as with trust, there are definitional and terminological problems. Thus, while a 1916 paper argued that interactions based on goodwill, fellowship, and mutual sympathy led to the accumulation of social capital, which satisfied both the needs of the individuals involved and the whole community (Hanifan, 1916), later writers have differed in which of these levels they see as most important. Is social capital primarily an attribute of the individual or of the community, or of both? Bourdieu takes the former position, arguing that an individual benefits as a consequence of their social networks, by virtue of the power they can exert within them (Wacquant & Bourdieu, 1992), power that is determined by context and social norms. Meanwhile, Putnam sees social capital as “features of social organizations, such as networks, norms and trust that facilitate action and cooperation for mutual benefit.” (Putnam, 1993). Others, however, have argued that both are important. Szreter and Woolcock argued, just after Pearce and Davey Smith published their paper, that there was already an extensive body of research showing positive associations between different aspects of health and social capital (Szreter & Woolcock, 2004). Shiell and colleagues, writing in 2020, identified 28 further systematic reviews, all but one finding positive associations with at least one aspect of health, even if the results can be inconsistent (Shiell et al., 2020).

This matters for health systems. There is a small but growing literature showing that high levels of social capital are associated with better health outcomes, although, primarily, where health systems are weak. Thus, one study using the same methodology in countries at all levels of development found that social capital was associated with improved hypertension control, but only in countries where investment in health systems was low (Palafox et al., 2017). Other evidence suggests that the inclusion of peer support into packages of care may improve outcomes (Schwalm et al., 2019).

### 4.3 Economic perspectives on trust

Economics offers several perspectives on trust relevant to health care. One is the importance of trust in situations where there is uncertainty and asymmetry of information, a situation that characterizes many clinical interactions, as described in a seminal work by Arrow (1978). He emphasized the importance of professional ethics, exemplified by the Hippocratic Oath, as a means of building trust.

Another is the use of game theory (Blake & Carroll, 2016), and in particular the Prisoner's Dilemma, which examines the rational approach to an interaction that is potentially risky, such as a clinical encounter (Nay & Vorobeychik, 2016). Where one party distrusts the other, they may act in ways that lead to a worse outcome than if each trusted one another. This has also been used in its iterative form to compare responses in circumstances where the encounter is one-off or one of many in a long-term relationship, such as arises with a chronic disease (Tarrant et al., 2010). Individuals engaged in the latter who are acting rationally are less likely to exploit one another. Game theory also offers insights, through the use of bargaining scenarios, into decisions made at the end of life, when trust is especially important (Slomka, 1992). It has also been employed to understand vaccine uptake and, in particular, the way that free-riders can prevent achievement of herd immunity (Chapman et al., 2012). Other applications relate to building trust between multiple providers contributing to the care of a patient with multimorbidity or providers colluding in a health care market in the face of the entry of a competitor (Bettinger, 2016).

A third addresses the problem that no one can know another person's value set. Thus, the patient cannot know whether the clinician will exploit them. In these circumstances, the patient will rely on signals that the clinician is trustworthy (Hampshire et al., 2017). This can take a number of forms. One is credential display, where physicians may display their qualifications and awards prominently in their offices, serving as a signal of their competence and expertise. Ratings on online comparison sites now play a similar role. Another is physical appearance and demeanour demonstrated, for example, by wearing a white coat or carrying a stethoscope. Diagnostic tests can also act as a signal, being used not only to gather essential information but also to reassure patients and signify thoroughness. Therapeutic regimen signalling occurs where a health care provider prescribes a certain treatment that indicates the severity or nature of the condition to the patient, for example, when they refer them to a specialist. However, signalling can also have adverse consequences, for example, when it leads to overtreatment.

Economics has also contributed some methodological innovations, in particular the trust game (Berg et al., 1995). This is used to study trust and reciprocity in economic and social interactions. Researchers analyse the decisions made by players to understand factors influencing trust, cooperation, and risk-taking behaviour. The game can reveal insights into how individuals perceive and respond to trustworthiness and how they balance self-interest with cooperation in various situations.



**Box 3: The trust game**

The trust game is an exercise commonly used in psychology and behavioural economics to study trust and reciprocity in human interactions.

The game typically involves two participants. They are usually anonymous to each other and cannot communicate directly. One player, often referred to as the “Sender” or “Trustor”, is given a certain amount of money (or points, or another form of currency). The Sender then decides how much of this money to send to the other player, known as the “Receiver” or “Trustee”. The amount sent is tripled (or multiplied by another factor) as it is transferred to the Receiver. The Receiver now knows how much they have received (which includes the multiplied amount the Sender sent). The Receiver then decides how much of this total to send back to the Sender. The game ends after this exchange, and both players keep the money they have at this point.

The trust game is insightful because it reveals how individuals perceive and respond to trust. The Sender’s decision to send money can be seen as an act of trust, betting that the Receiver will reciprocate. The Receiver’s decision to send money back can be interpreted as an act of reciprocity or trustworthiness. Researchers use variations of this game to understand how factors like communication, reputation, group identity, and past experiences influence trust and cooperation. The game provides a simplified model to observe and analyse human behaviour in a controlled setting, offering valuable insights into social, economic, and psychological dynamics.

**4.4 Psychological perspectives on trust**

Psychology provides a rich framework to understand the dynamics of trust in health care. Trust, linked inherently to emotions, perceptions and experiences, is influenced by a variety of psychological processes. This literature often focuses on how an individual who is party to an encounter decides whether it is safe to expose their vulnerability. Often, they make use of subconscious clues and heuristics to decide whether the person they are interacting with is trustworthy. The ability to do so is seen as an evolutionary adaptation as being able to decide who can be trusted makes it less likely that one will be exploited (DeSteno, 2014; DeSteno et al., 2012). There is a body of research, in laboratories and in real life settings, showing how people derive clues from body language and demeanour that help them make these decisions, even though there is no obvious reason why these should be linked to trustworthiness (Krumhuber et al., 2013). However, as Lorie and colleagues have shown, based on an extensive review of the literature, that while some non-verbal expressions have meanings that are universal, others are culturally specific (Lorie et al., 2017). A classic example from history was when Frances Younghusband, leading an armed British incursion in Tibet, believed that the Tibetans lining the streets clapping his progress through villages were welcoming him, unaware that it was what they did to drive out demons (French, 2016). Elbaum has argued that clinicians have a moral responsibility to ensure that they are aware of cultural differences, especial when interacting with groups that have previously suffered discrimination in their encounters with the health system (Elbaum, 2020). Trust deepens when there is consistency in behaviour. If patients experience consistently high-quality care and feel they are treated with respect and consideration, their trust in the health care system grows.

The psychological literature emphasises the role of integrity in deciding about trustworthiness and, in particular, how clinicians reconcile conflicts between selfishness and selflessness, with the latter an indication of being trustworthy. Other insights draw on evidence on the role of expectation. Trust develops when there is a belief that a person or an organization will act in our best interest. Previous positive past experiences with health care providers can establish and reinforce such expectations, leading to increased trust, while negative experiences, which may relate to other health systems as is the case with migrants, can undermine trust (O’Donnell et al., 2008).

Perceptions of trust are also important. Trust is more likely to develop if patients perceive their health care providers as competent. As discussed above, this perception can be influenced by the provider’s communication skills, credentials, demeanour and even the environment of the health care facility. Effective communication, where information is conveyed clearly and questions are addressed, can enhance trust. Conversely, perceived secrecy or withholding of information can erode trust. Similarly, demonstrating a commitment to patient autonomy, whereby they have a voice in decisions about their care, can foster trust, while feeling coerced or having a lack of agency can reduce trust. Good communication skills can support a therapeutic alliance (Elbaum, 2020), a term used to signify a partnership between the patient and clinician, and which has been shown to improve outcomes (Kinney et al., 2020; Sulaman et al., 2023). Empathy is an important aspect of communication, manifest as the ability to listen actively and build rapport, a crucial skill for health workers. Feeling understood and cared for on a personal level can significantly bolster a patient’s trust.

Cognitive biases are important because they can shape trust in health care. For example, confirmation bias might cause patients to seek out information that aligns with their existing beliefs about a treatment, which can either enhance or diminish trust in medical advice (Kappes et al., 2020). They also affect how people weigh the perceived risks and benefits of medical decisions. If the perceived risk is high (for example, in invasive procedures), trust becomes even more crucial.

**4.5 Taking a holistic view**

Taylor and colleagues argue that each of the disciplines discussed in this brief can be seen as pairs of glasses, each helping the wearer to see unique features of what they are observing. This means that a philosopher may see evidence on trust in a different way from, say, an economist. As a consequence they are likely to speak past one another as it is difficult for someone to wear more than one pair of glasses at once.

They make a series of recommendations to strengthen studies on trust by health services researchers. First, trust should be studied as an outcome and not just as an input to the delivery of health care, with a specific call for research that explores how trust can be rebuilt once it is lost, drawing on ideas of moral repair (Walker, 2006). Second, they call for more experimental or quasi-experimental studies to evaluate interventions. Third, they argue for more longitudinal studies

to complement the existing body of evidence dominated by cross-sectional ones, noting the particular importance of this approach for conditions that involve repeated interactions (Rotenberg & Petrocchi, 2018). Fourth, they note how trust arises from the relationship between two people, such as patients and clinicians, but very little research looks in both directions. As they note, “a patient’s trust in a clinician can be influenced not only by what that patient thinks about the clinician but also what the patient thinks the clinician thinks of them”. Fifth, they call for studies that consider spillovers of trust between clinicians, health facilities and plans, and health systems. Sixth, while recognizing that many studies have looked at trust and characteristics such as race or sexuality, they identify a need to make more use of participants’ lived experiences, with mixed methods offering considerable potential. Seventh, echoing an issue that will be discussed in the next section on explainable AI, they propose further discussion about the pursuit of maximal or optimal trust and, in particular, how the latter might be measured. Finally, they argue that researchers studying trust should adopt a reflexive stance, that is, how trust is built over time through analysis and testing of assumptions rather than granting impulsive or instinctive trust, noting how their presence and worldview is likely to influence the information they obtain.

## 5 Trust, technology, artificial intelligence and health (systems)

Much of this brief is concerned with trust between patients and health workers (or more broadly, the health system). However, the delivery of health care is changing, driven largely by the pace of technological advances. The response to the COVID-19 pandemic was transformed by the widespread availability of lateral flow tests, allowing individuals to conduct diagnostic tests that would previously have required transporting a sample to a laboratory. Many people with long term conditions now manage them using wearable equipment that can monitor, in real time, parameters such as blood glucose or heart rhythm. The potential of these devices is expanding rapidly with developments in machine learning or artificial intelligence (AI) more generally.

These developments have many consequences for trust. Thus, patients should have confidence that the equipment they are using is accurate and providers that their patients are using the equipment effectively. This requires the development and implementation of quality standards and their enforcement by consumer protection authorities. These are under-resourced in some countries and can be susceptible to corruption. Another area raising concern is the availability of online resources that offer advice to patients, which because they may be based in another jurisdiction can be difficult to regulate. Finally, AI has given rise to some complex issues related to trust, addressed in the next section.

### 5.1 Trust in algorithms

AI, powered by complex algorithms, is a rapidly developing field, with profound implications for trust in general, and for health care in particular. Areas of particular concern include the use of AI in the clinical encounter, its use to generate and propagate disinformation, and concerns about privacy.

AI systems can perform close to, or in some cases as well as, trained clinicians, especially in areas that depend on pattern recognition, such as detection of abnormalities in images (in areas such as radiology, histopathology or dermatology) (Rajpurkar et al., 2022; Schwalbe & Wahl, 2020). In a recent study, members of the public preferred responses to medical questions from a chatbot over those provided by a physician in almost 80% of cases (Ayers et al., 2023). However, some caution is needed (McKee & Wouters, 2023). For example, algorithms trained on data from one population may generate misleading results when applied to another (Wadden, 2021). Algorithms may also reproduce existing biases in treatment when, for example, they use subtle clues to determine a patient's race in a setting where there are already racial biases in treatment decisions (Gichoya et al., 2022; Obermeyer et al., 2019). Over time, dependence on AI may lead to deskilling and loss of experience among the current generation of trained clinicians, so that it may be more difficult to identify when algorithms do go wrong. Finally, there is inherent uncertainty in health care but when two clinicians disagree they can often resolve the issue by discussion. This is so far not yet possible with a machine (Grote & Berens, 2020).

Trust is important in this relationship between clinician and machine. If clinicians do not have sufficient trust they will not use them. Conversely, if they have too much trust they may allow the output of the algorithms to override what might be their correct clinical judgement (Asan et al., 2020).

This can be difficult to address because machine learning models often function as black boxes, with working that is difficult, or impossible, to interpret and understand. There are three main reasons for this: corporate secrecy designed to protect manufacturers' intellectual property, technical illiteracy of users, and the intrinsic complexity of the algorithms being used (Burrell, 2016). The problems that arise from the difficulty of knowing how the algorithms function was illustrated in study where AI could identify pictures of horses not because of their equine characteristics but rather because the pictures used bore a small copyright tag (Lapusckin et al., 2016). When this was attached to other objects, such as cars, it identified them as horses.

One possible solution is explainable AI (XAI), where models are made more transparent so that decisions can be explained to humans interacting with them (Arrieta et al., 2020). This can take at least five forms. First, there can be local, or specific, explanations of an individual prediction (Ribeiro et al., 2016). Second, global explanations present the model's general logic (Wu et al., 2020). Third, counterfactual explanations report a threshold at which the algorithm could change its recommendations. Fourth, confidence explanations report the probability that the prediction is correct (Zhang et al., 2020). Finally, example-based solutions involve the algorithm justifying its decision by providing examples from the same dataset with similar characteristics (Liao et al., 2020).

So far, the evidence on whether XAI can achieve an appropriate level of trust is mixed. Starting with medical imaging, a study from Taiwan found that physicians were more likely to trust and implement AI in clinical practice if results were perceived as explainable, with higher levels of explainability associated with higher levels of trust (Liu et al., 2022). Another study found that 70% of pathologists agreed that their trust increased when the algorithm indicated those areas of images associated with high or low confidence, although 10% disagreed and 20% were undecided (Evans et al., 2022). Yet another study found that adding counterfactual explanations, which indicate how much change would be required in an image to lead to a different conclusion, further increased trust (Mertes et al., 2022). However, other studies have found no association between use of XAI and trust when interpreting images (Cabitza et al., 2020; Gaube et al., 2023). Mixed results have also been found in studies where XAI was used to interpret complex data (Martínez-Agüero et al., 2022; Naiseh et al., 2021).

In thinking about trust and AI, it is important to differentiate cognition-based trust, where trust is derived from the perceived understandability, reliability and technical competence of XAI, rooted in reasoning, from affect-based trust, involving emotional attachment and faith. Most research so far has focused on the former but the limited research available suggests that both play a role, with use

of counterfactuals promoting relaxation and reducing anger (Mertes et al., 2022).

In summary, those involved in implementing AI solutions must consider how they will be received by those who must use them and, especially, whether they will engender the appropriate level of trust, neither too much nor too little. There is some evidence that XAI can help but much more research is needed to understand how it can be most effective and in what circumstances and therefore when it should be seen as trustworthy (and trusted to the extent that is appropriate).

## 5.2 Trust in information

Health systems will often have to communicate crucial public health messages to the population, as happened during the COVID-19 pandemic. However, as soon became clear, they often struggled against others who were promoting disinformation, which differs from misinformation, in that the former is designed to mislead while the latter is inadvertently false (Wang et al., 2019). Previous research had shown how disinformation often spreads more rapidly than factually correct information (Donzelli et al., 2018). In their 1947 basic law of rumour, Allport and Postman proposed that the amount of rumour circulating reflected the importance of the subject to the individuals concerned and the ambiguity of the evidence (Allport & Postman, 1947).

AI can reduce trust in messaging by generating misleading content. Those involved can have a variety of motives. Some believe in the messages they are creating but others are using them as clickbait, to monetize interactions with web pages or to spread malware. Others, in particular state actors, have political objectives, to undermine trust in other governments (Broniatowski et al., 2018).

This false messaging can take many forms, including misleading images (for example, a stock picture purporting to have been taken somewhere it was not), a doctored newspaper headline, or, increasingly, so-called deep fakes, where the image of a well known and trusted individual is manipulated to have him or her say something that is false (Chesney & Citron, 2019).

The impact of disinformation can be increased by selective targeting. The scope for so-called microtargeting was revealed when the advocacy group ProPublica showed that it could use Facebook's algorithms to restrict certain groups, such as African Americans, Jews and disabled people, from viewing advertisements for property in a desirable area (Angwin et al., 2017). Facebook has subsequently limited the ability to identify people based on certain protected characteristics but it is possible to circumvent this restriction.

Ways to combat the use of AI to spread disinformation and thus undermine trust in health messaging go beyond the scope of this policy brief. The challenges are considerable, not least because there may be reluctance by officials to challenge those politicians that are spreading disinformation in what has come to be known as a post-truth world, where some politicians know that they can lie with impunity (Higgins, 2016). In addition, in some countries, most notably the United States, concepts such as trust in

science have become politically highly polarised (Bruine de Bruin et al., 2020; Rao et al., 2022). A further complication is that everyone is subject to cognitive biases, including those where strong prior beliefs may not only make authoritative corrections ineffective but may even render them counterproductive (McKee & Stuckler, 2015). However, there is now a strong case for all health organizations that make use of public messaging to have processes to actively combat disinformation and misinformation, employing both traditional methods to tackle false information, including corrective messages and factchecking information, and novel ones that tackle the creators of this information, employing evidence from psychology and communication science (Wang et al., 2022).

## 5.3 Trust in data systems

The modern health system depends on access to clinical information. It is intuitive that clinicians will make better decisions if they have comprehensive medical records. Moreover, legitimate surveillance activities, such as cancer registration, can be compromised where people opt out or where data linkage is not possible (Rahu et al., 2020). Yet, in some places, there has been a backlash against the collection of such information, in part reflecting a lack of trust that the patient's data will be adequately safeguarded.

Some groups may have well founded concerns about the use of their data, based on previous experience. Ethnic minority populations may fear the potential for discrimination (López et al., 2011). Migrants may have concerns if their health data is linked to immigration enforcement (Hiam et al., 2018).

AI complicates this issue because of its ability to deanonymize data, combining disparate items in ways that can identify individual patients (Murdoch, 2021). Concerns are further exacerbated by other developments that compromise individuals' expectations of privacy, such as facial recognition technology (Van Noorden, 2020).

Similar concerns are arising in the relationship between staff and employers. Thus, in some areas, such as warehouse and delivery operations, staff are being tracked and their productivity monitored. This is, so far, less common in health care but there is some potential, for example in tracking those working in the community. This also risks eroding trust and exacerbating shortages in a sector that, in many countries, already struggles to recruit and retain staff.

Finally, trust in information systems can be damaged by hacking or cyberattacks, which like the generation of disinformation can have many motives, from the use of ransomware to acts by hostile states.

## 6 The challenges of measuring trust in European health systems

### 6.1 Measuring trust

Despite its importance, there is no single source of data on trust in health systems and related issues in Europe. Instead, there are a variety of sources that track levels of interpersonal trust and trust in certain institutions. These collate data from household surveys using various methodologies. Caution is, however, needed.

The methodological challenges involved have been reviewed in detail in a publication from OECD (OECD, 2017). The best questions are easily understood, unambiguous and place minimal burden on the respondent. It is also necessary to consider how words, concepts and meanings translate across languages and subgroups within those using a particular language, such as ethnic minorities or by social class or education.

The OECD report emphasises the importance of question wording, citing evidence, mostly relating to questions on interpersonal trust, that relatively minor changes can have a large effect. Thus, the addition of a caution rider, such as adding to a question “do you think most people can be trusted” the words “or do you need to be careful in dealing with people” the percentage expressing trust can fall substantially. Importantly, the effect is different for male and female respondents. The literature is less extensive on institutional trust but the report cites evidence that adding

to the question “do you think x can be trusted” the words “to act in the national interest” increases reported trust with national institutions, with the exception of the banks (noting that the research in question was conducted in the aftermath of the financial crisis).

Other considerations include response formats, with evidence that an 11-point scale (0–10), accompanied by scale anchors (completely, not at all, etc.) is optimal, and placement of questions within surveys. In general, the report argues, asking questions on trust after ones that may cause the respondent to recall negative experiences yields lower reported trust. Hence, it recommends placing them early in a survey and beginning with trust in general before moving to more specific questions.

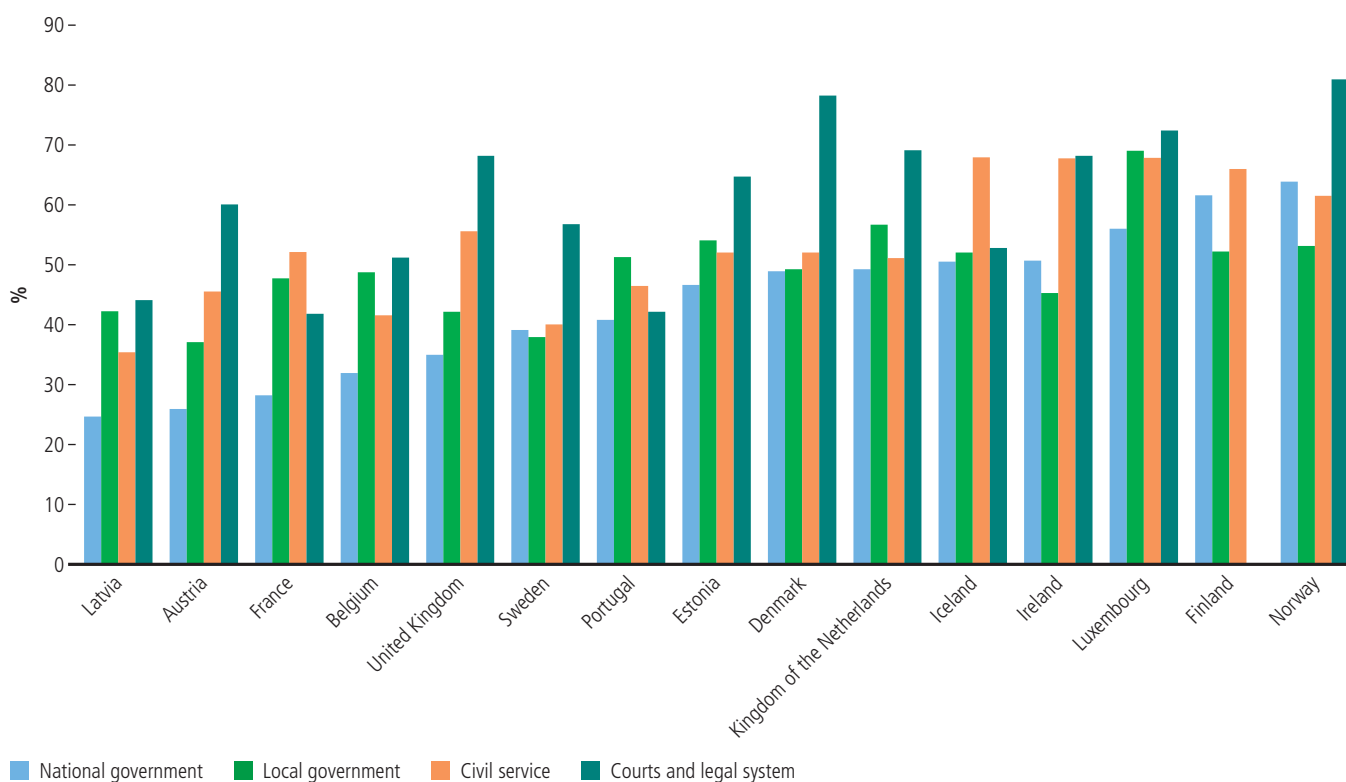
### 6.2 The state of knowledge

Although there are a number of cross-country surveys conducted regularly in Europe, such as the Eurobarometer (Eurobarometer, 2007) and EU-SILC (Survey of Income and Living Conditions) (Arora et al., 2015), they rarely ask about trust in health systems.

Recognizing the importance of trust in governance more generally, OECD has begun to survey public trust in certain institutions. However, the number of countries in Europe that are included remains limited (Fig. 3). Moreover, there are as yet no time series.

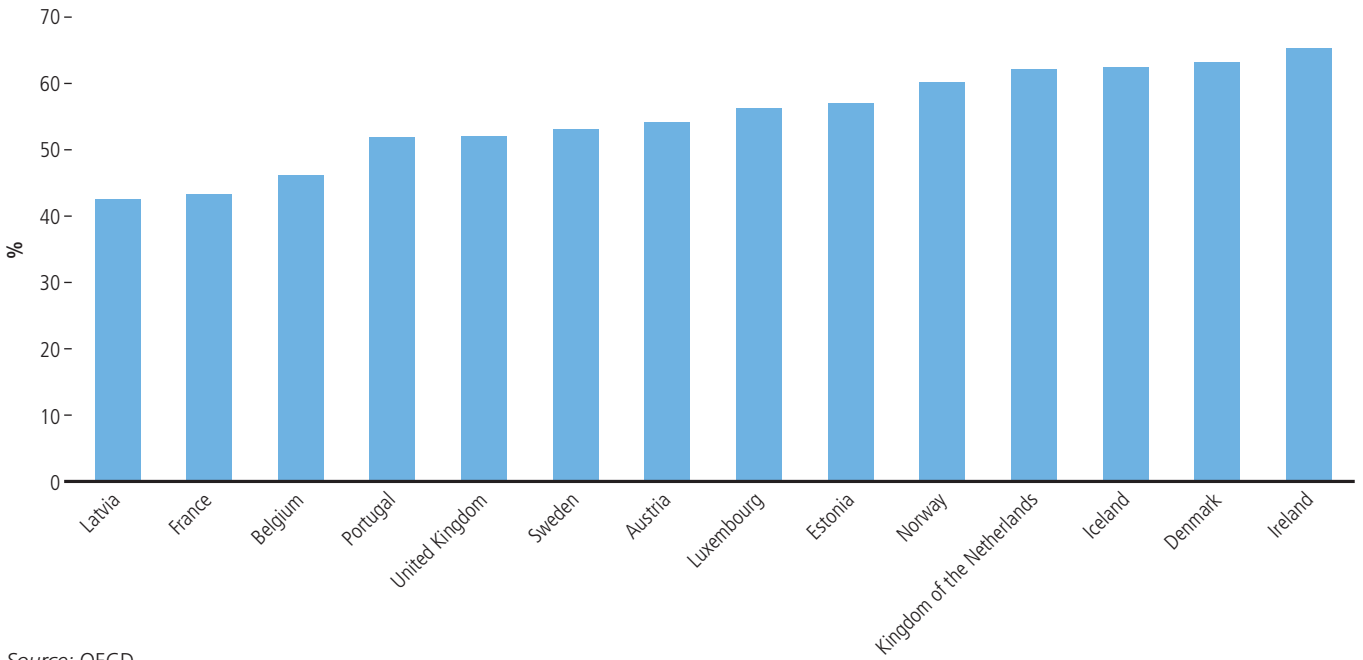
The OECD also surveys trust that personal data will be used appropriately, an important concern given the increasing dependence of health systems on data. Again, the data

Fig. 3: Trust in institutions in selected countries, 2021



Source: OECD Trust Survey (2021).

**Fig. 4: Percentage of respondents saying it is likely that their personal data will be used for legitimate purposes**



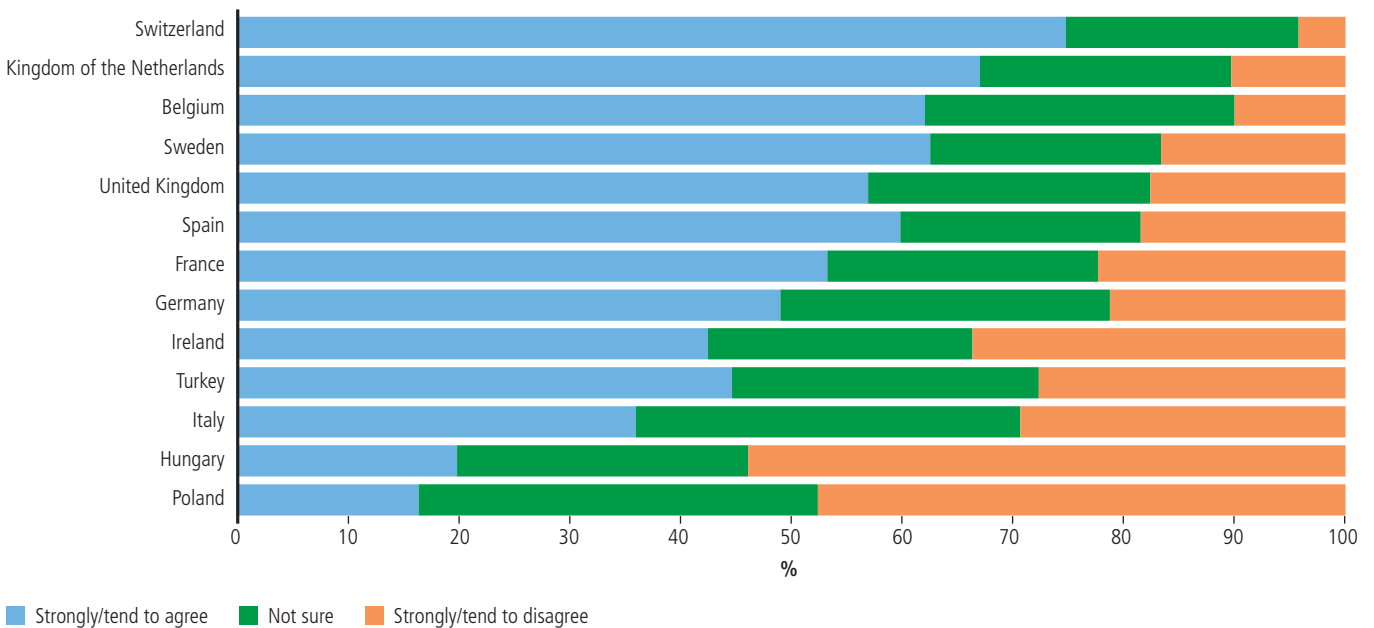
Source: OECD.

are limited in coverage and time but do offer some insights (Fig. 4).

There are other surveys that capture selected characteristics of health systems in smaller groups of countries that could be used to measure trust. One is the Commonwealth Fund International Health Policy Survey (Commonwealth Fund, 1998), which seeks insights into public opinions on health

care. This survey examines issues like access to care, and health care costs, although it tends to focus on questions that are of most interest to American audiences. Perhaps the most relevant, for the purposes of this publication, is data published commercially by Statista, which covers a small number of European countries (Fig. 5).

**Fig. 5: Share of individuals who trust the health care system in their country to provide them with the best treatment in select European countries in 2023**



Notes: Responses to question "To what extent do you agree or disagree with the following statement? – I trust the health care system in my country to provide me with the best treatment." Sample size: 1000 per country. Fieldwork July/August 2023.

Source: Statista (2023).

The Wellcome Trust Global Monitor, conducted by Gallup, is the world's largest study into how people around the world think and feel about science and major health challenges (Wellcome Trust, 2020). It surveys over 140 000 people from more than 140 countries, including over 40 000 from Europe. It includes important data on public trust in science and medicine, which has emerged as a key issue during the pandemic. The findings reveal substantial variations even, in some cases, between seemingly similar countries (Fig. 6 and 7).

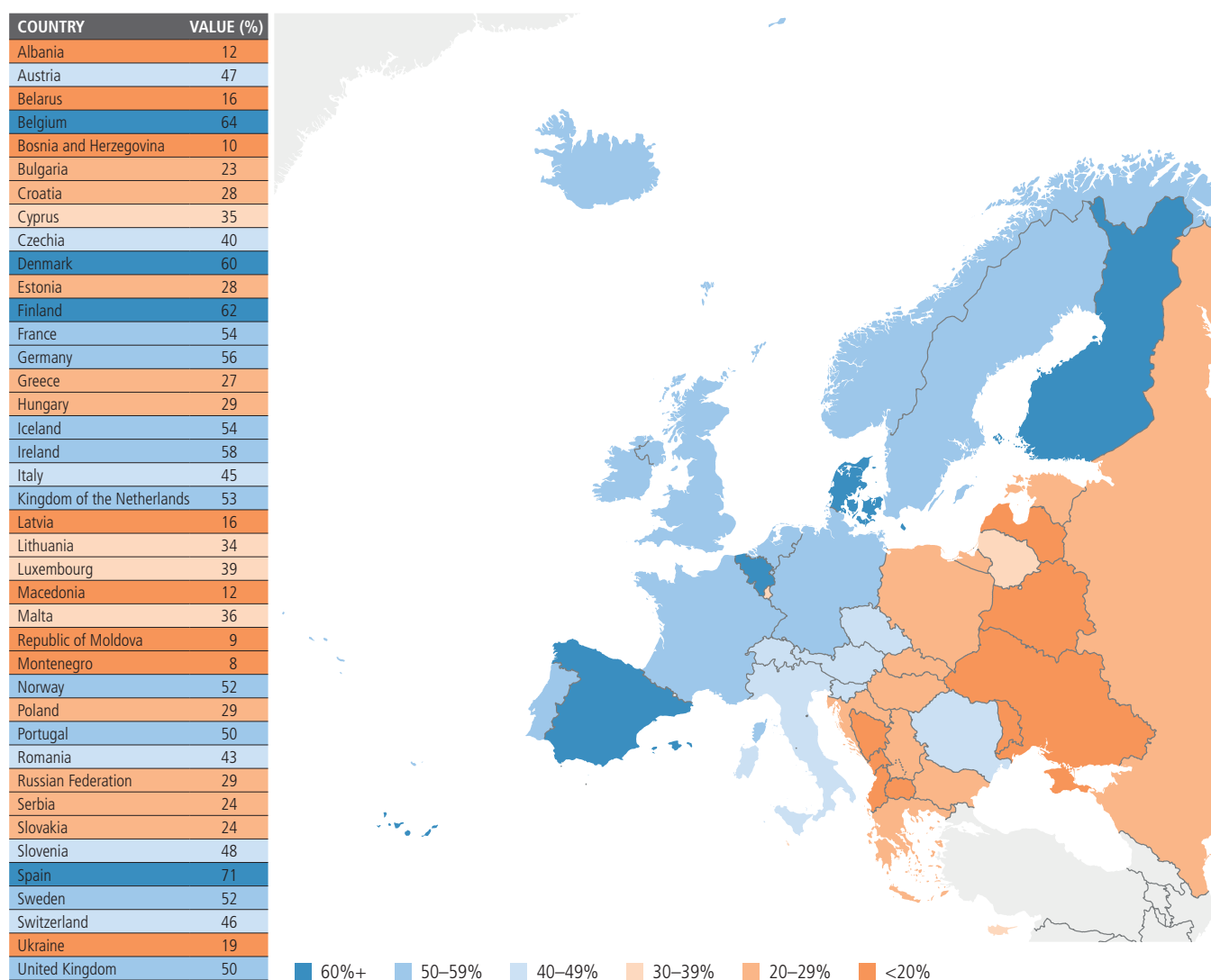
Looking ahead, an international team of researchers is implementing the Peoples' Voice Survey, which seeks to capture public perceptions of health systems, including experience of care and confidence in the health system (Lewis et al., 2023).

There are, however, many important gaps in data on trust in European countries. One example is trust in particular institutions. Although there are examples of surveys of public perceptions, such as that on the United Kingdom

National Health Service conducted by the Health Foundation (Wise, 2023), they have not been standardized and brought together in one place. The importance of regular monitoring is apparent from analyses using data from the RAND American Life Panel that have shown declining trust in the United States Centers for Disease Control during the pandemic (Pollard & Davis, 2022). This noted the known low level of trust among the African American population but also that levels of trust among Hispanics and non-Hispanic Whites declined to the level seen in African Americans. This decline was closely aligned with political affiliation, reflecting the tenor of political discourse at the time.

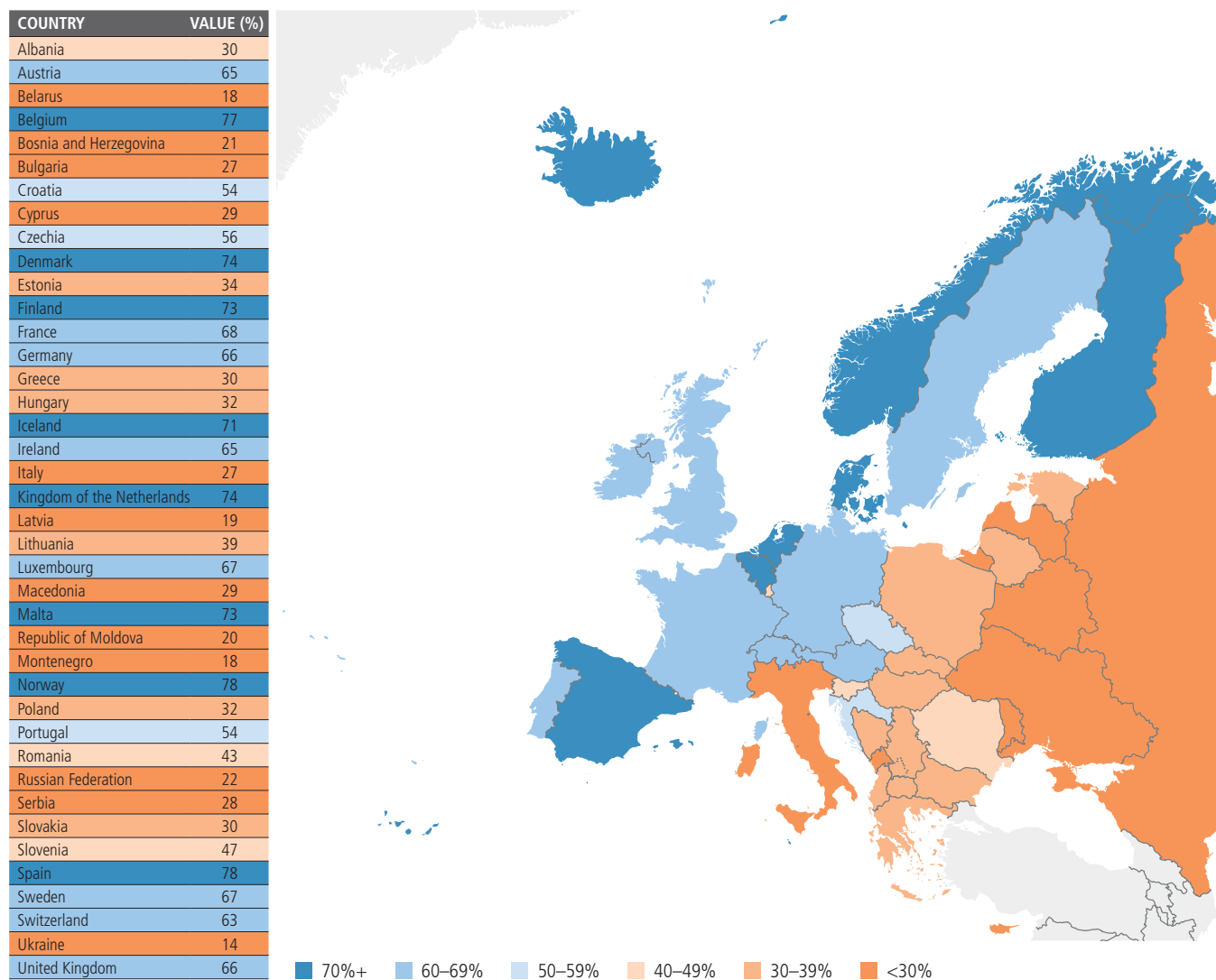
In summary, the state of knowledge on trust in health systems in Europe remains fragmentary. Given its importance for health systems, especially as they seek to implement the transformations that will be necessary to adapt to future challenges, there is a need to collect appropriate data with sufficient granularity to assess differences within populations and sufficient regularity to track changes over time.

**Fig. 6: Share of respondents who answered "a lot" to the question: "How much do you trust scientists in this country?"**



Source: Authors' analysis of data from Wellcome Global Monitor (2020).

Fig. 7: Share of respondents who answered “a lot” to the question: “How much do you trust doctors and nurses in this country?”



Source: Authors' analysis of data from Wellcome Global Monitor (2020).



## 7 Future directions

The previous sections have set out the case for taking measures to restore and sustain trusted relationships throughout health systems. So what needs to happen next? This section cannot hope to offer a comprehensive way forward, for several reasons. First, trust is strongly influenced by context. Even though the evidence is fragmentary, levels of trust in governments, in health systems, in health workers and in science itself vary markedly among countries. It also varies within countries, shaped by the previous experiences of groups within society and their expectations about how they will be treated. Trust can also change rapidly, as happened on occasions during the pandemic. It varies according to what or who is being trusted. Trust in one set of state institutions, such as the health system, does not necessarily translate into trust in another, such as the police. Second, as noted earlier, the evidence on what works to increase trust, either in general or in different circumstances is limited.

What can be said, however, is that even if trust is complex and multifaceted, it matters. Trust serves to bind communities and ensures their smooth operation (Delhey et al., 2018). It fosters cooperation and the sharing of resources, promoting social cohesion and harmony. When individuals trust one another, they are more likely to work together for the greater good, leading to the collective benefit of all. This trust extends to governance and institutions which also ensure that societal norms, regulations, and rules are upheld, contributing to order and stability (Gilson, 2003). People are more willing to pool their resources and efforts when they trust that their contributions will be valued and reciprocated (Schiefer & Van der Noll, 2017).

On an individual level, trust is a fundamental pillar of emotional and mental well-being. Trusting bonds with friends, family, and colleagues provides a sense of security and support, fostering mental resilience and happiness. A lack of trust reduces service utilization, worsened treatment outcomes, and creates stigmatized and strained relationships between individuals seeking care and health providers, especially in mental health. Organizing services around understandings of trust, rather than risk, may be more effective both at meeting need and managing risk (Brown et al., 2009).

### 7.1 Building and sustaining trust

So, what can the health system do to build and sustain trust? A first step is to systematically measure the different aspects of trust, conducting regular surveys that can capture both overall levels of trust and its distribution within populations. This should be coordinated internationally to ensure comparability of results and should be complemented by a range of qualitative and mixed methods measures that explore some of the aspects of trust discussed previously and by a programme of research to improve the ability to measure trust. But measurement can only describe the problem. The next step is to solve it.

This will not be easy. Those in the health sector, the intended readership of this publication, must regrettably accept that they are constrained by what they can do. Trust, in the institutions that make up the health system and in those who work in it, is influenced by many factors in the broader environment, such as the rule of law, the scrutiny that those in power are subject to, and much else. These lie outside the scope of health policy-makers. That does not, however, mean that they should ignore them. Rather, as was set out in the evidence reviewed for the Pan-European Commission on Health and Sustainable Development, a comprehensive strategy for health and health system resilience and preparedness must include advocacy for action on things that reduce trust, such as corruption (recalling that health systems are often perceived as among the most corrupt), organized crime and access to justice, as well as collaboration across sectors and actions that can be taken within the health sector (McKee, 2021).

This publication explicitly does not set out detailed policies to build and sustain trust. These must be developed on the basis of a detailed understanding of the reasons for lack of trust, an understanding that will require a range of study methods and disciplinary methods. It is particularly important to consider differences in levels and determinants of trust in different groups within a population. This will require high levels of cultural competence and a willingness to confront historical issues, such as the legacy of colonialism and discrimination. It is, however, important to incorporate some long-established principles into measures that are being considered. These are transparency and honesty, empathy and care, dedication and commitment, and competence and expertise (Covello, 1993), and they should underpin all interactions at all levels within health systems.

There is a rich literature on institutional trust, from which certain principles emerge (Fuglsang & Jagd, 2015; Hudson, 2006; Sønderskov & Dinesen, 2016). This literature points to the importance of employing a combination of strategies and actions consistent with the principles above. These demonstrate reliability, integrity, transparency, and a commitment to the well-being of stakeholders. A first step is to establish and pursue a clear mission and values. These should align with accepted ethical standards and be communicated effectively to stakeholders. Leadership is crucial. Leaders should exemplify ethical behaviour, place integrity at the heart of their decisions and hold themselves accountable. So is competence, demonstrating the ability to deliver care of high quality to those whose trust is sought. This must be delivered consistently. As noted previously, reliability is not trust but is a core element of it. Inconsistencies can erode trust quickly. There should be clear mechanisms for accountability within the institution. When mistakes or problems occur, those in charge must assume responsibility and take steps to rectify them.

Resolute action is required when actions undermine trust. Perhaps the most pervasive example in some countries in Europe is that of informal payments, used to obtain preferential treatment, or even to access any care. Clearly, those involved in this practice are acting at best unethically and at worst illegally. However, it is important

to recognize that they are often acting in this way because they are working within a dysfunctional system. One conceptualisation of this phenomenon notes that it often arises where patients lack the conventional responses to poor quality care of exit (for example, going to the private sector) or voice (for example, complaining). Instead, such payments offer an informal exit (which they called INXIT) (Gaal & McKee, 2004). More recent work has viewed corruption from a developmental governance perspective, exploring the role of structures and networks, who benefits, and who is simply seeking to make a dysfunctional system work (Hutchinson et al., 2020).

Sharing information about the activities of the health system has become much easier as a consequence of the internet. However, what is published must be honest and there should be no suspicion that information is being withheld. Freedom of information legislation can help but it is important to obey the spirit and not just the letter of the law. Laws to protect whistleblowers are important, although this can be difficult in societies characterized by widespread use of political patronage.

## **7.2 Widening participation in policy**

Trust will only be delivered if those involved can see that they are being listened to. This requires involvement of a wide range of stakeholders in key decisions.

While many governments seek the views of stakeholders through formal consultations, these have limitations. They can be manipulated, especially in a world where it is possible to deluge websites with responses that give a misleading impression of the breadth of opinion. Responses to such consultations can also be shaped by phrasing of questions. There are better alternatives, employing deliberative decision-making, such as the use of citizens' assemblies in which a group of individuals, say 100, are selected purposively to be representative of the range of views on a subject. They meet together over a period of time, alongside experts and others who can supply evidence and opinions and make recommendations. In some cases, these have been a valuable prelude to legislation on contentious issues, such as abortion in Ireland (Farrell et al., 2019).

At the clinical front line, there is enormous scope for co-production, an approach that is now informed by a rapidly growing literature. This allows those most affected, whether patients, carers or clinicians, to find solutions that are practical in a given context (Turk et al., 2021). An example was a cluster randomised trial seeking optimal packages of care for hypertension in two middle-income countries (Schwalm et al., 2019). Although the packages shared certain features such as the use of simplified treatment regimes, mid-level health workers and peer support, the actual packages were developed by working with the communities over a year, and they both achieved significant improvements in outcomes. This requires trust, built through shared values, mutual respect and open communication, but just as important, acknowledging and addressing power imbalances in co-production, which can undermine trust and lead to unequal outcomes (Romsland et al., 2019).

Civil society organizations can play an important role in these processes and should be encouraged. There is now an extensive literature on social accountability, highlighting the importance of active and engaged civil society organizations, supportive interlocutors within institutions and access to information.

A free and active media is also important, with many examples of activities that undermine trust being exposed by investigative journalists (O'Donovan et al., 2019). When this happens, the reaction should not be defensive. Rather, those in charge should make clear that they will learn from what happened and implement change.

Similar principles apply to the other relationships involving trust. Given the challenges currently facing health workforces, measures that increase staff retention must be a high priority. These must include a commitment to build the trust of those whom the system seeks to retain. It is beyond the scope of this publication to discuss the literature on industrial relations. It is, however, within its scope to note that strikes by health workers should never happen and, when they do, it is a sign that something has gone very badly wrong (Weil et al., 2013).

It is much less clear what can be done to restore trust of politicians in health systems, reassuring them that any additional resources will be spent wisely. Robust health technology assessment functions may help but, ultimately, success is likely to emerge from shared visions and excellent communication, including when it is realistic to expect an impact.

Finally, this publication has discussed a series of more specialized issues, of which the most important, given the pace of technological change, is likely to be AI. This will require those engaged in health policy to develop and continually update new sets of skills.

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