Executive summary

The push to make health systems more accountable to the people who use them – in other words, to make health systems more *people-centred* – is not a new effort. Health professionals, policy makers and patients themselves have long realised that the institutions making up health systems today are no longer fit for purpose, neither meeting the needs of those who use them, nor sufficiently adaptable to rapidly developing global trends, including digitalisation, population ageing and pandemic shocks.

This report examines the steps OECD countries have taken to put people-centredness into action across health systems, including their institutions, workforce, governance and decision-making. The OECD Framework for People-Centred Health Systems includes five dimensions – voice, choice, co-production, integration and respectfulness – that can be used to methodically analyse people-centredness. An application of relevant indicators to this framework to benchmark how countries have embedded people-centredness in their health systems reveals that despite broad support for a people-centred health systems agenda, few countries have comprehensively institutionalised people-centred policies across these five key dimensions. Moreover, despite recent progress in developing patient-reported measures, regularly collected indicators for people-centredness are still vastly insufficient.

Policies to address COVID-19 paid little heed to the needs of people-centred health services, especially in the early phases of the pandemic

The health systems response to the COVID-19 pandemic over the last two years was largely *not* people-centred, reflecting the reality that policy changes towards people-centred care have not been deeply embedded into institutions. Yet the speed at which policies were introduced or adapted to deal with the pandemic suggests that with sufficient will, there is opportunity for progress to strengthen a people-centred agenda.

- People-centredness was very weak in public communications about the state of scientific evidence and recommendations for preventive behaviours, such as the use of facemasks and the uptake in vaccination, with misinformation impacting vaccine hesitancy. By late April 2021, the proportion of unvaccinated people who were unwilling to receive a vaccine reached 29% in Germany, 34% in Australia, and 54% in the United States.
- Integration and continuity of care suffered greatly during various waves of the pandemic, with diagnostic services and treatment of patients with non-COVID-19 needs disrupted or delayed. More often than not, there were no instruments to prioritise continuity of care for patients at risk or those living with chronic diseases. Delays in cancer screening and diagnosis have been common, including an average 5 percentage point decline in breast cancer screening over the previous two years in 2020 compared with 2019 across seven OECD countries with available data, and delays in cancer diagnosis reported in at least 12 OECD countries.
- Respectfulness for patients and their families also suffered. For example, all countries adopted strong restrictions on visits to people hospitals and long-term care facilities, in many cases even at

the end of life, upending traditional norms around respectful end-of-life care. These restrictions were implemented to protect long-term care residents and workers from COVID-19 infections but also affected the experience of many who died of COVID-19, given that more than 40% of all COVID-19-related deaths across 25 OECD countries took place among long-term care residents. Although most countries later changed these policies following popular outcry, the experience of deaths among long-term care facilities residents away from their family was dramatic.

- Despite these shortcomings, there were important signs and opportunities for future progress, such as the acceleration of real-time data sharing, linkage of health data to follow patient pathways across health systems, and the adoption of digital technologies to overcome disruptions.
- People's preferences also evolved over the pandemic and digital tools have helped communication and the roll-out of policies to incentivise vaccination rates. Since the start of the pandemic, 34 of 38 OECD countries or subnational regions have adopted variations of COVID-19 passes requiring proof of vaccination status, a negative COVID-19 test, or recovery from previous infection to access public spaces or engage in certain activities.
- The absence of formal patient representation in health decision making was particularly conspicuous when countries needed to make rapid decisions to contain the virus's spread, such as measures restricting mobility and measures implemented in hospitals and long-term care settings. Among 57 patient organisations in Europe, nearly two-thirds of respondents (63%) indicated that there was no patient involvement or consultation in management and decision-making processes during the pandemic.

Despite some progress, no country yet delivers strong, person-centred care across all key policy domains of the OECD Scorecard

The patterns observed during the response to the COVID-19 pandemic are not surprising when the dimensions of people-centredness across countries are examined from a broader health systems perspective. The measured results within the five dimensions of the OECD Framework and Scorecard on People-Centred Health Systems highlight weaknesses that preceded the pandemic and underscore the mixed progress in the journey towards people-centred health systems.

- **With few exceptions, patient voice remains weakly embedded in decision-making processes.** Just 11% (3/27) of countries reported that patients had a formal role in at least four of five key decision-making areas of health policy. While patient voice is broadly recognised as important for personal health decision-making, fewer countries included patients in decision-making around health care research or funding for research.
- **Countries have improved patients choice across many health services, but access and affordability continue to act as barriers for many people.** While provider choice is widespread, access and affordability constraints affect free choice. Across 23 OECD countries, one in six adults reported delaying or foregoing care due to cost.
- **Patients are increasingly seeking control over their health information, to better influence their own health and the health care they receive.** Digital tools offer the potential to greatly expand patient access to their own information. Yet while the majority of OECD countries (70%) say they are implementing ways for people to access their health data electronically, in 2020 just two-fifths (43%) allowed patients to interact with their personal health information. Moreover, health and digital literacy remain low for many people, with poor health literacy reported by more than half of the population in two-thirds of OECD countries.
- **Countries have leveraged digital tools to improve integration.** Despite progress in the uptake of electronic health records, establishing linkages and integration between electronic records has been slow, with primary care often excluded from close electronic integration with other parts of

the health system. Fewer than 40% of countries reported they regularly conducted linkage projects with primary care data.

- **Measurement of patient experience and outcomes is far from systematic in most countries, and international comparability remains limited.** Much recent focus on strengthening people-centred measures of health systems has been on expanding patient-reported measures. Other dimensions, such as including patients in decision-making processes and ensuring patient access and choice, are also important components of people-centred care, and must be measured accordingly. The lack of regularly-collected data to measure progress underscores how far many countries have to go to better embed people-centredness into their health systems.