ASSESSING AND STRENGTHENING THE PERFORMANCE OF CARDIOVASCULAR AND CANCER CARE PATHWAYS

Co-creating resilient and person-centred systems in the wake of COVID-19

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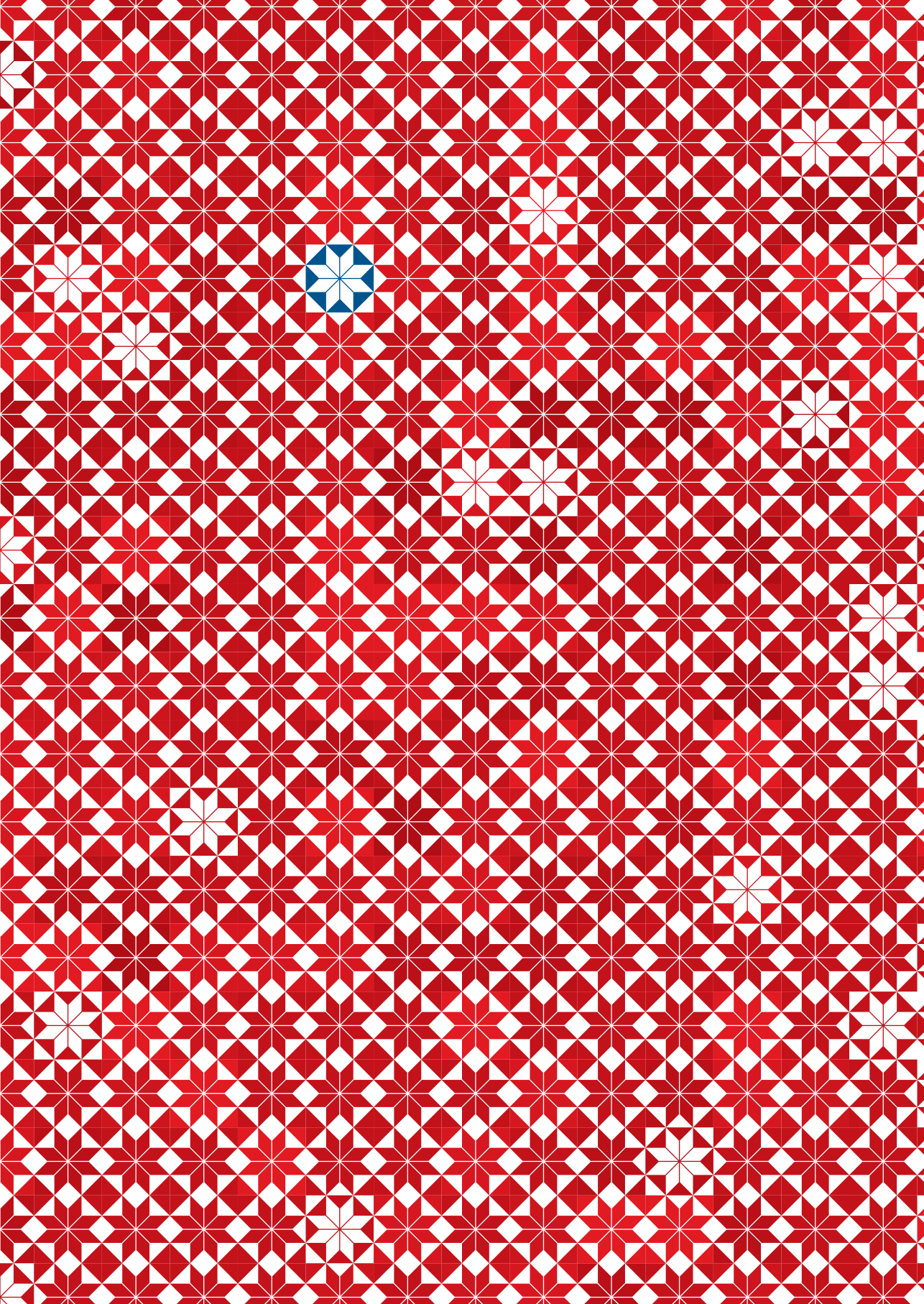
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General introduction

Cardiovascular diseases and cancer pose a substantial burden on health systems globally [1-4], and this burden is expected to increase in the coming decades [5, 6]. The COVID-19 pandemic exposed vulnerabilities in the ability of health systems to maintain access to and quality of care for people living with these conditions during crises [7-9]. In response to the pandemic and to broader global societal challenges, health system objectives have evolved. The concepts of person-centredness and resilience have emerged as essential components of health system performance, calling for robust measurement approaches that can help inform decision-making of varying stakeholders across health system levels [10, 11].

Against this backdrop, this thesis contributes to the field by integrating performance measurement, a care pathway perspective, and co-creation approaches to operationalise resilience and person-centredness in cardiovascular and cancer care.

This thesis aims to inform efforts to strengthen the performance of cardiovascular and cancer care pathways, contributing to the delivery of high-quality care both during crises and in routine care. To achieve this, a whole-system approach is considered, focussing on improving performance measurement across these care pathways. Furthermore, a co-creation approach is applied to develop actionable tools to support decision-making at the micro-, meso-, and macro-levels of health systems.

This General Introduction defines the key concepts that underpin this thesis, including health system performance, with particular attention to the dimensions of resilience and person-centredness, as well as the care pathway and co-creation approaches used to enhance performance measurement. Building on these concepts and the identified knowledge gaps, the aims, research questions and structure of this thesis are then presented.

Cardiovascular diseases and cancer pose a substantial burden on health systems

Cardiovascular diseases (CVD) and cancer are the leading causes of mortality in Europe [12] and in most Member States of the Organisation for Economic Co-operation and Development (OECD) [1]. Their prevalence is expected to rise in the coming years [5, 6], a trend driven by demographic ageing [12]. The crude prevalence of CVD is projected to increase by 36% between 2025 and 2050 in high-income countries globally [5]. Similarly, the number of cancer cases in the European Union (EU) is expected to increase by around 30% over the next 30 years, despite an anticipated overall population decline of about three percent [4]. At the same time, an increasing number of people live with multiple chronic conditions and complex health needs [13], requiring coordinated care across providers and specialties.

In response to these trends, several international policy initiatives have been developed to address the growing burden of non-communicable diseases. These include the 2030 Agenda for Sustainable Development, adopted at the United Nations General Assembly in 2015 [14], further reinforced by a political declaration adopted at the General Assembly in December 2025 [15]. The latter has established measurables goals for 2030, including that at least 80% of countries possess strong surveillance and monitoring capabilities for non-communicable diseases [15]. At the European level, the 'Healthier together'—EU Non-Communicable Diseases initiative includes CVD as one of the five priority strands for 2022-2027 [16], the EU 'Beating Cancer Plan' was launched in 2021 [17] and the EU cardiovascular health plan—the 'Safe Hearts Plan' was launched in December 2025 [18]. Together, these initiatives provide a strong policy foundation for improving cardiovascular and cancer care delivery. Nonetheless, to strengthen health systems performance and optimise health outcomes, further evidence is needed to support decision-making at clinical, organisational, and policy levels.

The COVID-19 pandemic, declared on 11th March 2020 [19], disrupted continuity of care and exposed vulnerabilities in health systems globally [20]. For people living

with CVD and cancer, service delivery was severely affected [7-9, 12, 20, 21]. Across Europe, hospital admissions for heart and cerebrovascular diseases declined by 9–66%, and cardiac procedures decreased by 25-88% [9]. Mortality rates from CVD have increased [9]. In cancer care, patients often presented with clinically more advanced disease than prior to the pandemic, and clinicians reported changes in curative and palliative management [7, 8]. These disruptions highlighted weaknesses in the organisation and coordination of care, demonstrating that strengthening cardiovascular and cancer care pathways is essential to ensure continuity, quality, and resilience during future crises.

Performance measurement: an approach to inform practice and policy

Measuring health system performance is an essential element for assessing and improving care pathways across organisations, regions, and countries. It is key to achieving high-quality care, which can be defined along three core dimensions: effectiveness, patient safety, and person-centredness [22]. In 2008, the Tallinn Charter was adopted by Member States of the World Health Organization (WHO) European region, conveying the need for health systems 'to demonstrate good performance' [23]. Health system performance assessment (HSPA) is therefore recognised as a key approach to systematically assess, monitor, and inform on health systems' ability to meet key goals [24]. It supports monitoring, management and continuous improvement of national health systems [25, 26].

To provide timely and accessible information for decision-making, performance indicators are essential. These indicators are defined as measures that provide information about the effectiveness, safety, and person-centredness of care [22]. They rely on robust health data infrastructures and should meet several quality criteria, including relevance for intended users and uses, scientific soundness, feasibility of measurement (e.g. availability of data), and meaningfulness for their intended

target audience [22]. Importantly, to effectively support decision-makers, indicators need to be actionable, meaning that they should serve a specific decision-making function (fit-for-purpose) and convey the right information to the right person at the right time (fit-for-use) [27].

While identifying actionable performance indicators is an essential starting point for assessing and strengthening performance [27], indicators also need to be embedded within a whole-system perspective. This means linking measurement to decision-making processes across all three system levels: clinical practice (micro-level), organisational management (meso-level), and health policy (macro-level) [27]. Such integration acknowledges the interdependence between services and actors across the health system [28].

A systems approach considers the relationships between inputs, outputs, and outcomes that collectively drive performance [29]. Health system inputs include the necessary resources, such as physical infrastructure, workforce, and finances [30]. Health system outputs refer to the immediate products of service delivery, for example, the number of surgeries, consultations, or diagnostic procedures performed [29]. Health system outcomes, in turn, represent the ultimate goal: a population with improved health [29]. Understanding these linkages provides the foundation for assessing how effectively and efficiently health systems transform resources into better health outcomes.

Key dimensions of healthcare performance studied in this thesis

In the aftermath of the COVID-19 crisis and driven by new global mega-trends, such as climate change, demographic shifts and technological disruption [31], health system objectives have evolved. The need for innovative dimensions in healthcare performance measurement has emerged [11], in particular a renewed focus on resilience and person-centredness. Both are currently considered key dimensions of healthcare

performance [11, 13, 32]. They reflect the growing need for health systems that can adapt to shocks, while consistently responding to people's needs and preferences.

Resilience

12 The combination of demographic, societal, and environmental challenges has underscored the importance of health systems' ability to anticipate and respond to shocks [33, 34]. Health systems resilience is defined by the OECD as 'the ability of systems to prepare for, absorb, recover from and adapt to major shocks' [32]. Originating in material science, the concept of resilience has been applied across disciplines, such as ecology, disaster management, psychology, and economics [35, 36]. Since the early 2000s, a series of global crises such as the financial crisis (2007–2009), the Ebola outbreak in West Africa (2014–2016), and the COVID-19 pandemic (2020–2023) have established resilience as both a research focus [37-40] and a policy priority [33, 41-43]. It is now considered a core component of healthcare performance, and is increasingly viewed as a necessary dimension within health system performance assessment frameworks [11, 35].

At the international level, policy initiatives have sought to strengthen preparedness and systematically measure resilience. The European Commission's Health Emergency Preparedness and Response Authority, established in September 2021, aims to prevent and enhance response capacities for cross-border health crises [44]. More recently, the 'Preparedness Union Strategy', launched in March 2025, focuses on improving Europe's capacity to anticipate and respond rapidly to emerging shocks [45].

Resilience has also been embedded in health system performance assessment frameworks at both international and national levels [26]. The OECD's renewed HSPA framework (2024) considers resilience a cross-cutting dimension, alongside sustainability, efficiency, and equity [11]. National HSPA frameworks in several countries, including Belgium, Italy, and Ireland, have incorporated resilience as a dedicated measurement dimension [46-50]. Complementary efforts have also focused on translating this concept into practice, such as the resilience testing toolkit developed by the European Commission's Expert Panel on Effective Ways of Investing in Health [51]

and the 'Handbook for Resilience Testing', launched in 2024 by the OECD, European Commission, and the European Observatory on Health Systems and Policies [52].

Person-centredness

In parallel, the increased focus on tailoring healthcare delivery to the needs, expectations and preferences of individuals has driven a shift towards person-centred care. People receiving care are now considered active partners in their care teams [10, 53] and their perspectives on symptoms, health-related quality of life, and functional states are increasingly valued [54]. The concept of value in healthcare, understood as both a primary goal of healthcare delivery and a driver of equity and efficiency, places patients' needs, expectations, and preferences at the centre of decision-making and aligns health system actors toward a shared goal [55]. The concept of person-centredness has its roots in the mid-twentieth century [56, 57] and has gained increased relevance in the last decades [58, 59]. Notably, this shift was reinforced through the development of the value-based healthcare framework in 2006 [60]. Two years later, the Institute for Healthcare Improvement proposed the Triple Aim framework [61], which sets out three goals for improving health systems: improving population health and the experiences of care, while decreasing per capita costs [61]. Recognising the increasing complexity of care and societal change, these goals were expanded to include workforce well-being (2014) and health equity (2022), forming the Quintuple Aim [62]. This broader focus on person-centred care has led to extensive efforts to standardise and routinely collect patient-reported data, both on experiences and outcomes. These are measured through Patient-Reported Experience Measures (PREMs) and Patient-Reported Outcome Measures (PROMs), which together provide essential input for assessing person-centredness in healthcare performance [13, 63].

Linking resilience and person-centredness

Together, resilience and person-centredness represent complementary dimensions of health system performance. Resilience ensures that care can be sustained and

adapted during times of crisis, while person-centredness ensures that such care remains responsive to individuals' needs. This thesis brings these dimensions together within the context of cardiovascular and cancer care pathways, using performance measurement and co-creation approaches to strengthen both dimensions simultaneously.

Applying a care pathway approach to measure performance

In line with the increased focus on experiences of care, equity, and cost-effectiveness, health systems performance measurement should not only assess final health outcomes, but also examine the processes and interactions that occur across the continuum of care. Care for individuals living with chronic conditions entails various interconnected components, including prevention, diagnosis, treatment, and long-term support for quality of life. The care pathway concept has evolved in healthcare since the 1970s, building on management theories from the 1950s and 1990s [64]. A care pathway can be defined as a 'complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period' [65]. It is characterised by three aspects: 1) it supports translating evidence into local contexts, 2) it provides organised guidance to define care plans and guide decision-making in care delivery, and 3) it intends to harmonise care delivery for specific healthcare episodes or conditions [22]. This approach emphasises coordination and integration across disciplines, settings, and time points in the patient journey.

A care pathway perspective offers various theoretical advantages for both patients and professionals. It helps to streamline care processes, to improve coherence between care providers, and to reduce the probability of errors and inefficiencies [66, 67]. In turn, this can lower costs and enhance professional satisfaction [64]. Ultimately, a care pathway approach aims to improve the quality of care while optimising the

use of available resources. At the policy level, this approach is increasingly used to design, implement, and monitor integrated care strategies. For example, the EU 'Beating Cancer Plan' applies a pathway perspective across four strategic pillars: prevention, early detection and diagnosis, treatment, and quality of life [17]. Each pillar is supported by specific initiatives and policy reports, reflecting the value of care pathways in aligning efforts across sectors and levels of governance. Similarly, the EU cardiovascular health plan is centred on prevention, diagnosis and treatment and care [18].

Within this thesis, the care pathway approach serves as a unifying framework to assess and strengthen the performance of cardiovascular and cancer care. It enables the analysis of how care is organised and experienced across different stages of the care pathway, and how person-centredness and resilience can be enhanced through measurement and co-creation.

Leveraging co-creation to inform efforts to strengthen the performance of care pathways

The growing emphasis on inclusive and participatory approaches in health systems design [68], combined with broader societal changes, has contributed to the increasing application of co-creation methods in health services research [69]. The principles of a participatory approach have deep political and philosophical roots. Participatory design traditions emerged in Scandinavia in the 1970s, initially in the context of industrial product design [70]. These early approaches were grounded in the democratic involvement of end-users, acknowledging the value of local expertise and lived experience [70].

In the field of health services research, participatory approaches aim to ensure that research is responsive to stakeholder needs and fosters person-centredness. They do so by producing actionable knowledge, thereby ensuring that this knowledge is accessible and usable by those involved in care delivery and decision-making [71].

The development and implementation of HSPA frameworks, both nationally and internationally, particularly in relation to the creation and use of performance indicators, the strengthening of resilience, and the enhancement of person-centredness, increasingly rely on participatory methods to ensure relevance, feasibility and uptake [69, 72].

In light of this, the studies presented in the second part of this thesis apply co-creation as a development approach. Given the cross-sectoral nature of care pathways and the value-laden nature of concepts such as resilience and person-centredness (both of which involve judgments about priorities, trade-offs, and what constitutes good care), co-creation was considered essential rather than optional. These studies aim to produce actionable insights for use in practice and policy within cardiovascular and cancer care, and to advance resilience and person-centredness at the health system level. To this end, each study was embedded in participatory international initiatives that provided the context for stakeholder engagement and tool development.

In this thesis, co-creation serves as both a methodological and philosophical foundation for strengthening the performance of care pathways. It enables the integration of stakeholder perspectives into the design of practical tools and frameworks, advancing person-centredness and resilience within health systems. Through this approach, this thesis aims to bridge research and policy by translating evidence into actionable insights for improving cardiovascular and cancer care performance.

Co-creation to strengthen cardiac care pathway resilience

One study in this thesis was embedded in a Europe-focused project led by a global network of interventional cardiologists, in collaboration with an Italian cardiology society and a regional public health institute in Spain. The project's Advisory Board included organisations representing patients, nurses, allied professionals, and women physicians. As a member of the consortium, our research team led the development of a context-sensitive tool to support stakeholders in strengthening the resilience of cardiac care pathways across Europe.

A stepwise and participatory process was followed to gather experiences and

lessons learned from the COVID-19 pandemic. Stakeholders were engaged from the inception of the project through all stages of its development, piloting, and dissemination. These stakeholders included patient representatives, healthcare professionals such as nurses and cardiologists, hospital managers, and representatives from scientific societies.

Co-creation to advance cancer care performance measurement

Another study employed a co-creation approach in collaboration with a non-profit, multi-stakeholder global organisation dedicated to improving cancer care performanc — All.Can International. As an independent research team, we led the development of an 'Action Guide' designed to support the implementation of cancer care performance indicators across health systems.

The co-creation process involved continuous engagement with the All.Can International leadership and its global cancer stakeholder community, ensuring that the tool reflected diverse perspectives and needs. Stakeholders were involved throughout all phases of the project, from initial concept development to the launch of the final Guide.

Co-creation in the use of patient-reported data

A third study contributed to an OECD initiative aimed at assessing the systematic use of Patient-Reported Outcome Measures (PROMs) across OECD countries. In this work, country officials at the macro-level were consulted to identify barriers and enablers to PROMs implementation within their national contexts. Preliminary findings were shared and discussed with participants, creating opportunities for feedback and cross-country learning. This iterative and participatory process enhanced the validity and applicability of the results, while fostering shared understanding among stakeholders.

Aims, research questions and structure of this thesis

Building on lessons learned from the COVID-19 pandemic, this thesis seeks to advance the measurement and to strengthen the performance of cardiovascular and cancer care pathways. The overall aim is to generate new insights into how the performance of these pathways can be assessed and strengthened, and to provide evidence to support decision-making at the clinical, managerial, and policy levels. To achieve this, the thesis focuses on improving performance measurement and applies co-creation as a practical approach to develop tools that can inform stakeholders across these care pathways.

This thesis focuses on two main research questions: 1) How can the impact of shocks on healthcare delivery for people living with cardiovascular diseases and cancer be monitored through performance measurement and a care pathway approach?, and 2) How can the performance of cardiovascular and cancer care pathways be strengthened to promote more resilient and person-centred healthcare delivery?

Based on these questions, the thesis is organised into two parts (Table 1). Part I addresses the first question and identifies performance indicators to assess the impact of the COVID-19 pandemic on care delivery inputs, processes, and outcomes. It focuses on the cardiovascular and cancer care pathways and analyses key trends in the quality of care during the pandemic. Part II addresses the second question and applies a co-creation approach to develop actionable insights and practical tools that inform efforts to strengthen care performance. The final General Discussion synthesises findings across all studies, reflects on methodological and conceptual contributions, and outlines implications for policy and research.

Table 1 Outline of chapters, aims, study characteristics and scope

Sections	Chapters	Aims	Data sources	Study design	Stakeholder context for co-creation	Scope
Part I Assessing the performance of acute cardiovascular and cancer care pathways during the COVID-19 pandemic	Chapter 1	To assess the impact of the COVID-19 pandemic on hospital cardiac care pathways, as assessed by performance indicators	Scientific literature	Scoping review	Not applicable	OECD countries
	Chapter 2	To assess changes in the quality of acute care during the COVID-19 pandemic through summarising available performance indicators and assessing their trends	Scientific literature	Scoping review	Not applicable	OECD countries
	Chapter 3	To assess changes in the quality of cancer care through the summarisation of performance indicators and assessing their trends	Scientific literature	Scoping review	Not applicable	OECD countries
Part II Co-creation of tools to strengthen resilience and person-centredness in cardiovascular and cancer care pathways	Chapter 4	To develop a resilience assessment tool for cardiac care pathways, providing recommendations to enhance resilience	Scientific and grey literature, survey and focus groups	Mixed-methods: cross-sectional survey and focus groups	Healthcare professionals from the cardiology field from the 27 EU Member States and Ukraine, and patients	European countries
	Chapter 5	To identify barriers and enablers to implementing cancer metrics globally and to describe the co-development of an implementation guide to support the embedding of these metrics into cancer care pathways	Semi-structured interviews	Qualitative study	Multi-stakeholders from All.Can International global cancer community	Global
	Chapter 6	To assess the systematic use of PROMs data and to identify barriers and enablers for system-wide implementation from decision-makers' perspectives	Survey and workshops	Mixed-methods: cross-sectional survey and workshops	Country officials from 38 OECD member and accession countries	OECD countries

Context, scope and methods

Part I—including the studies described in Chapters 1 to 3—aims to provide a structured identification of performance indicators across the care pathways and to identify key trends in changes in the quality of care delivered during the COVID-19 pandemic. Chapter 1 analyses the full cardiac care pathway, while Chapter 2 focuses on the acute phase, with specific attention to timeliness of care, which was particularly affected during the pandemic. Chapter 3 investigates changes in cancer care delivery. These three studies focus on OECD countries, which share a common framework for health system performance measurement [11], including comparable performance indicators and methodological standards, thereby facilitating cross-country learning to improve health outcomes.

All three studies of Part I apply a scoping review methodology, following the framework developed by Arksey and O'Malley [73] and Levac et al. [74]. This methodology allows the systematic mapping of large and heterogeneous bodies of literature [75]. Considering the variety of methodologies applied to assess the impact of the COVID-19 pandemic in healthcare delivery and the broad range of contexts being studied, the scoping review methodology is particularly suitable. Moreover, it is considered a helpful methodology to identify and assess knowledge gaps in a specific field [75].

Part II includes three empirical studies, which are described in Chapters 4 to 6. In Part II, co-creation approaches are employed to strengthen the cardiovascular and cancer care pathways, with particular emphasis on resilience and person-centredness in healthcare delivery. Chapters 4 and 5 engage multi-level stakeholders to develop tools for improving the performance of cardiac and cancer care, respectively. Chapter 4 describes the development of a tool to enhance resilience in cardiac care pathways in Europe, while Chapter 5 focuses on co-developing a guide to support the implementation of performance indicators in cancer care at the system level. Chapter 6 explores how PROMs can be used at the macro or policy level to advance patient involvement and person-centredness across OECD countries.

In Part II, the principles of Participatory Action Research (PAR) [71] are applied.

PAR is a collaborative approach that involves relevant communities and stakeholders in generating practical knowledge and driving change [71]. Although participatory research can require substantial time and resources and may lead to differing perspectives between researchers and end-users [76], it offers major benefits. It enhances the relevance and applicability of research, fosters trust and engagement, and advances person-centredness by meaningfully integrating stakeholder perspectives throughout development, implementation, and evaluation. In this thesis, the PAR framework provides the foundation for Part II, ensuring that the knowledge produced supports effective and sustainable health system performance strengthening.

Within this participatory framework, co-creation is used as the main methodological approach. Co-creation involves the active collaboration of stakeholders across all phases of a project to develop solutions to identified problems and to ensure their usability in practice [77]. The term encompasses related participatory methods such as co-design and co-production, which focus respectively on developing and implementing these solutions. This operational understanding of co-creation guides the design and conduct of Chapters 4–6, which apply participatory methods to build tools and guidance for strengthening cardiovascular and cancer care performance.

Part II combines qualitative and mixed-methods approaches, including surveys, focus groups, interviews, and workshops, to engage stakeholders in developing practical tools and insights. These methods support a participatory research design and ensure that findings are relevant, trustworthy, and applicable to real-world healthcare settings.

The data types handled included scientific and grey literature, survey data, interview notes and transcriptions of focus group discussions, as well as transcribed video recordings of interviews and focus groups. The types of analysis employed include descriptive statistics, inductive and deductive thematic analysis [78], and qualitative content analysis [79]. Quality assurance strategies such as piloting, reflexivity, and co-coding [80] were applied to enhance rigour. Reporting adheres to established methodological standards, including the PRISMA extension for scoping reviews [81], the mixed-methods criteria by Lee et al. [82], the COREQ checklist for qualitative studies [83], and the CROSS checklist for survey studies [84].

Together, the studies in Parts I and II combine complementary methodological approaches —systematic evidence synthesis and participatory research— to provide a comprehensive understanding of how health system performance in cardiovascular and cancer care pathways can be assessed and strengthened.

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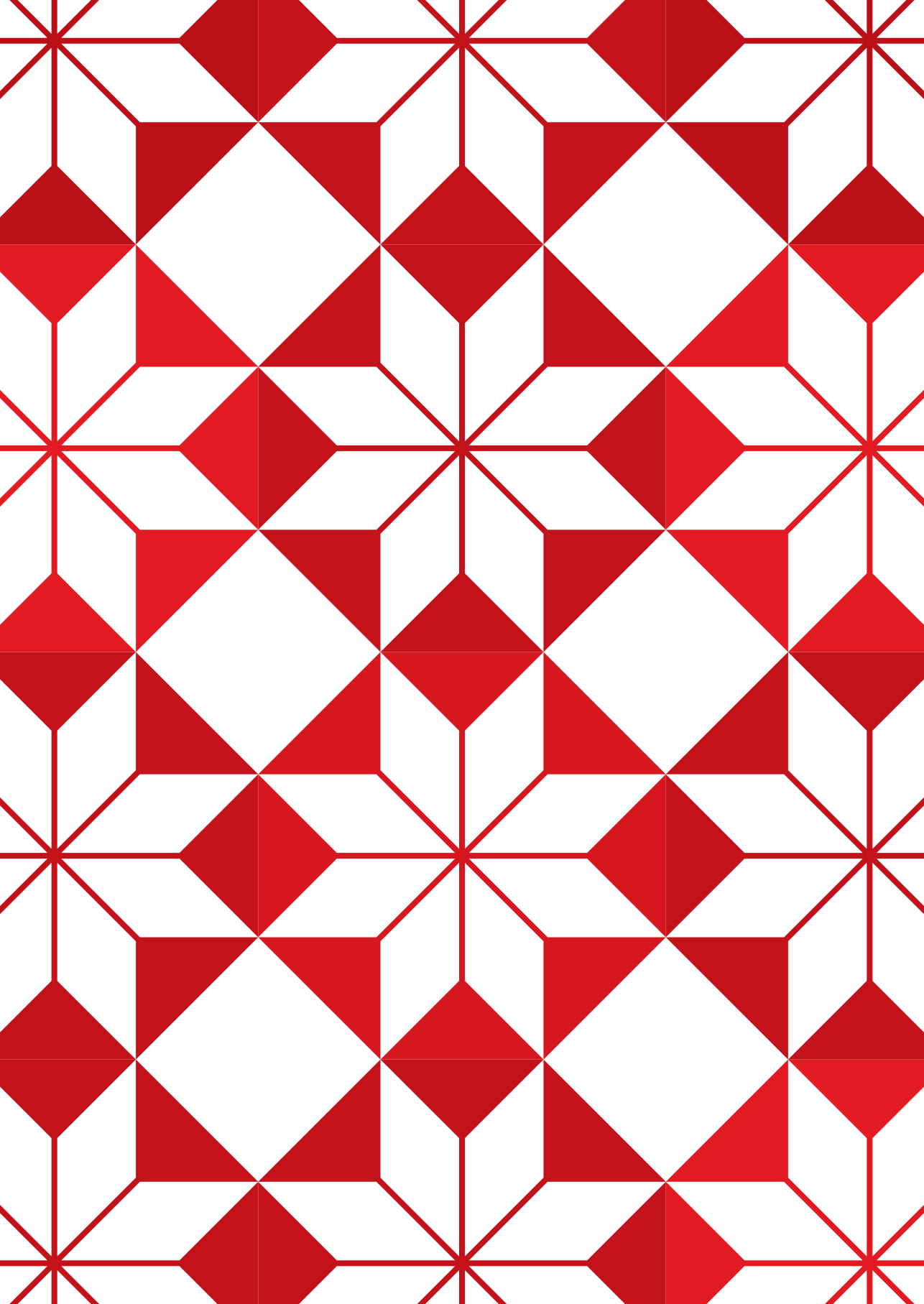
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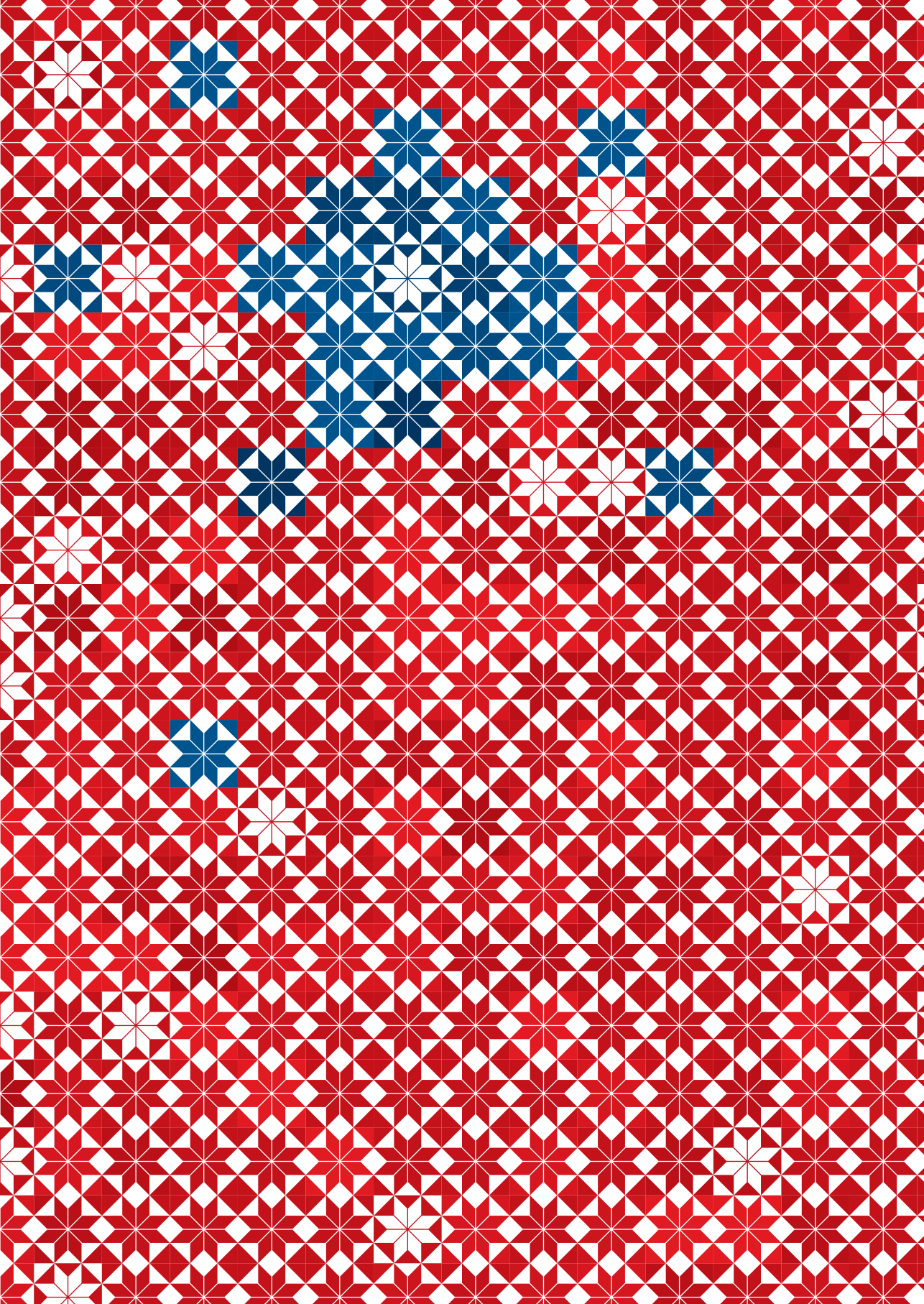
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Part I

Assessing the performance of acute cardiovascular and cancer care pathways during the COVID-19 pandemic



Chapter 1

The Impact of the COVID-19 Pandemic on hospital services for patients with cardiac diseases: a scoping review

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Abstract

This study aims to assess the impact of the COVID-19 pandemic on hospital cardiac care, as assessed by performance indicators. Scoping review methodology: performance indicators were extracted to inform on changes in care during January–June 2020. Database searches yielded 6277 articles, of which 838 met the inclusion criteria. After full-text screening, 94 articles were included and 1637 indicators were retrieved. Most of the indicators that provided information on changes in the number of admissions (n=118; 88%) signaled a decrease in admissions; 88% (n=15) of the indicators showed patients' delayed presentation and 40% (n=54) showed patients in a worse clinical condition. A reduction in diagnostic and treatment procedures was signaled by 95% (n=18) and 81% (n=64) of the indicators, respectively. Length of stay decreased in 58% (n=21) of the indicators, acute coronary syndromes treatment times increased in 61% (n=65) of the indicators, and outpatient activity decreased in 94% (n=17) of the indicators related to outpatient care. Telehealth utilization increased in 100% (n=6). Outcomes worsened in 40% (n=35) of the indicators, and mortality rates increased in 52% (n=31). All phases of the pathway were affected. This information could support the planning of care during the ongoing pandemic and in future events.

Introduction

As of 12 January 2022, the virus causing COVID-19 disease, SARS-CoV-2, has infected 313 million people globally and caused 5,5 million deaths [1–3]. The use of health resources for non-COVID care was minimized and elective procedures and appoint-

ments were postponed since the beginning of 2020 [4, 5]. The impact of COVID-19 on health care services for patients with non-communicable diseases (NCDs) seems to be severe and involves multiple clinical areas [6–12].

According to the World Health Organization, cardiovascular diseases, which include cardiac diseases, are the leading cause of death globally [13]. Before the pandemic, a decelerating pace in the improvement of cardiovascular disease mortality was already identified as a major contributor to the slowdown of life expectancy gains in several Organization for Economic Co-operation and Development (OECD) member countries [14]. The continuity of care for patients with cardiac diseases during a crisis is a major concern among healthcare providers [15, 16], who seek to strengthen referrals and care pathways and establish and maintain novel models of care. Given the burden of cardiac diseases in healthcare systems globally [13, 14], attention to the impact of the COVID-19 pandemic on cardiology patients is justified. Previous studies noticed a decrease in patients presenting with (acute) cardiac conditions and mentioned delays in those patients who eventually did present for hospital care [17–19], which could lead to worse clinical outcomes [20].

In a relatively short period, large amounts of scientific evidence have become available on the impact of the pandemic on patients with cardiac diseases in varying countries. This literature is scattered, which makes it difficult to draw conclusions regarding the impact on cardiac care delivery and the use of data to steer health care service delivery improvements during the current pandemic and future public health crises. Hence, reviewing the existing literature that quantifies the magnitude of this impact during the first half of 2020 helps to systematize, synthesize, and consolidate the evidence and to formulate recommendations for policy and practice.

This scoping review is part of a larger project that focuses on performance indicators used for a range of clinical areas during the COVID-19 pandemic. In this study, we aim to assess the impact of the pandemic on hospital care for cardiac patients in OECD countries, focusing on the different phases of the hospital cardiac care pathway (admission, diagnosis, treatment, outpatient care, outcomes).

Methods

We pursued a scoping review methodology, considering the extensive number of scientific articles, their heterogeneous character, and the lack of a clear and structured overview of the large sums of literature that have become available on the impact of the pandemic on patients with cardiac conditions. A scoping review can be used to examine emerging evidence and give an overview of the literature and studies available on a certain theme [21]. We followed the methodological framework developed by Arksey and O'Malley [22], further developed by Levac et al. [23], and the PRISMA extension for scoping reviews to report our methodology [24] (Supplementary Material S1).

Search Strategy

The MEDLINE and Embase databases were selected to search for this scoping review, as we considered them to sufficiently cover the literature related to the delivery of health care services. Pilot searches were conducted to identify a list of suitable search terms. A medical research librarian was consulted to improve the search strategy and adapt it to both databases. The final search strategy included the following key terms and synonyms: COVID-19, pandemic, non-communicable disease, chronic disease, performance indicator, healthcare quality, healthcare utilization, healthcare delivery, and other closely related terms. The full search strategy for Embase and MEDLINE can be found in Supplementary Material S2. The comprehensive search was conducted by the research librarian on 17 March 2021. No limitations were set regarding language or year of publication. Duplicates were removed using EndNote software. Additional articles of relevance were added by hand-searching the reference lists of the included studies.

Study Selection

The following inclusion criteria were set: (1) studies using empirical data on the use of health services; (2) studies describing health outcomes and/or performance

indicators during the COVID-19 pandemic; (3) studies that are presented as original journal articles using quantitative or qualitative methods, such as cohort studies, case-control, cross-sectional designs, case reports, systematic reviews, surveys, and meta-analyses. The following exclusion criteria were set: (1) non primary studies (such as editorials and commentaries); (2) prediction models; (3) clinical case reports; (4) diseases management or health services organization guidelines; (5) studies about the impact on healthcare workers, patients diagnosed with COVID-19, children, or pregnant women; (6) studies primarily performed in non-OECD countries; (7) articles from which only an abstract was available.

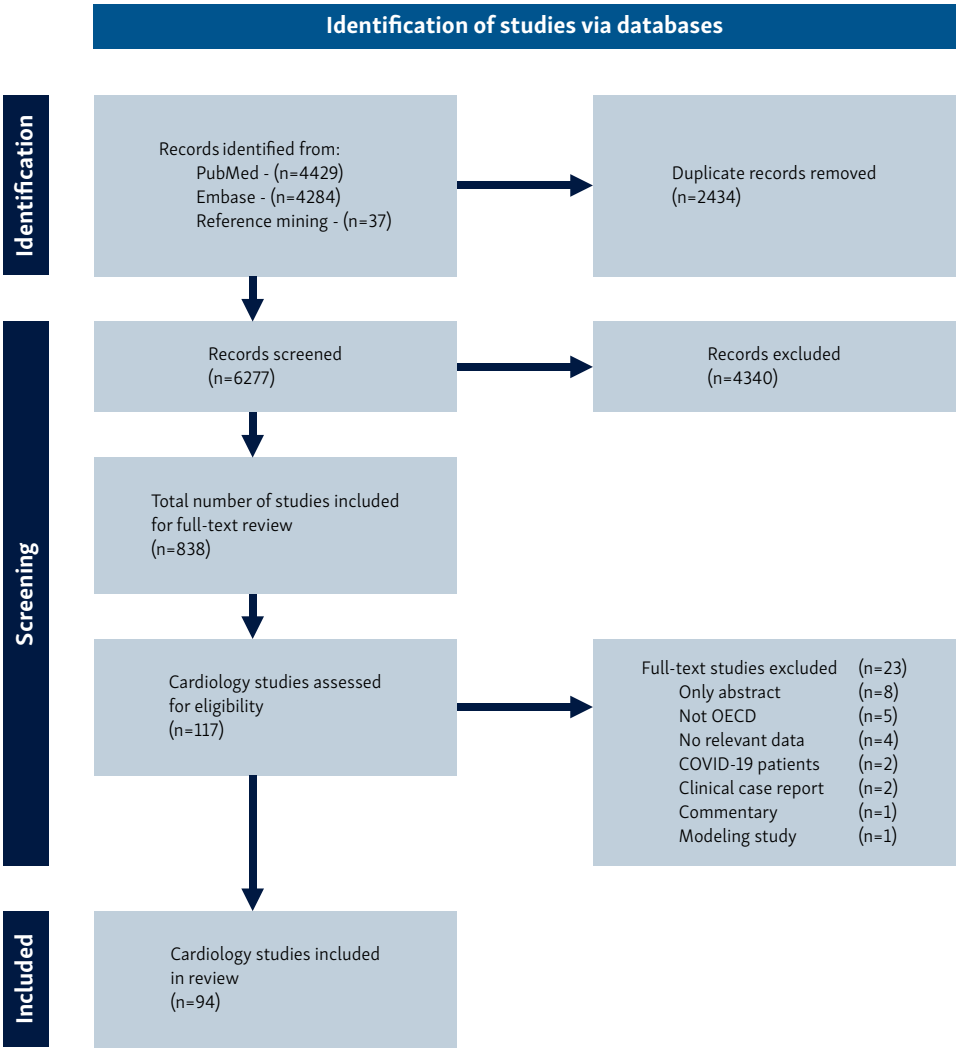
Methods of Selection

An initial screening of the retrieved studies based on title and abstract was performed independently by two researchers (ASC, OBF) using Rayyan [25]. Studies considered relevant after this phase were exported to a spreadsheet to support full-text screening, which was performed independently by three researchers (MdL, ASC, OBF). For this study, only articles on cardiac diseases were analysed. The reason for the exclusion of articles was recorded at this point. In case of doubt, the other co-authors were consulted, and a decision was made.

Data Extraction and Charting

Data extracted from the included articles were collated in a spreadsheet informed by a pilot on 15 studies (Supplementary Material S3). Data extraction was performed independently by three researchers (MdL, ASC, OBF). Extracted data included information on generic and methodological aspects of the article (e.g., authors, title, setting) and information about the indicators reported (e.g., indicator title, and data inclusion/exclusion considerations). For every indicator, we identified the trend reported in the articles (increase/decrease/stable).

Figure 1 PRISMA flow diagram of the literature search. Abbreviations: OECD—Organization for Economic Co-operation and Development



Synthesis of the Results

Indicators were grouped and categorised according to the different phases of the hospital cardiac care pathway by MdL, followed by a review conducted by ASC (Supplementary Material S4). The percentages of indicators showing a decreasing,

increasing, or stable trend were computed for each category. Results are presented in line with the hospital cardiac care pathway.

Results

Database searches yielded 6277 articles. Of these, 838 articles focusing on non-communicable diseases met the inclusion criteria. After full-text screening of 117 articles focused on cardiac hospital care, a total of 94 articles were included in this review (Figure 1). Twenty-three full-text studies were excluded.

General Characteristics of the Included Articles

The included articles reported on 109 different countries (Figure 2). Eighty-six articles provided information on one country only. Eight articles involved multiple countries, of which seven also included non-OECD countries. Most articles reported on Italy (n=20; 21%), followed by the United Kingdom (n=17; 18%) and Germany (n=14; 15%).

Most of the studies used a retrospective cohort design (n=66; 70%), while other studies used a prospective cohort (n=13; 14%) or survey design (n=12; 13%). The included studies used three different time periods when comparing pandemic versus pre-pandemic indicators. Most studies compared a COVID-19-affected period in 2020 to the same period in the previous year (n=54; 56%). Other studies (n=34; 36%) compared the COVID-19 affected period to a period immediately before. Lastly, a COVID-19-affected period was compared to the average of the same period in several previous years (n=27; 29%). The general characteristics for each article can be found in detail in Supplementary Material S5.

Impact of COVID-19 on the Hospital Cardiac Care Pathway

The grouped and categorized indicators were collated according to the different phases of the hospital cardiac care pathway (Figure 3) to visualize their combined trends.

Figure 2 Countries reported on in the included articles (including articles reporting on multiple countries), color-graded according to the number of included papers (n=109).

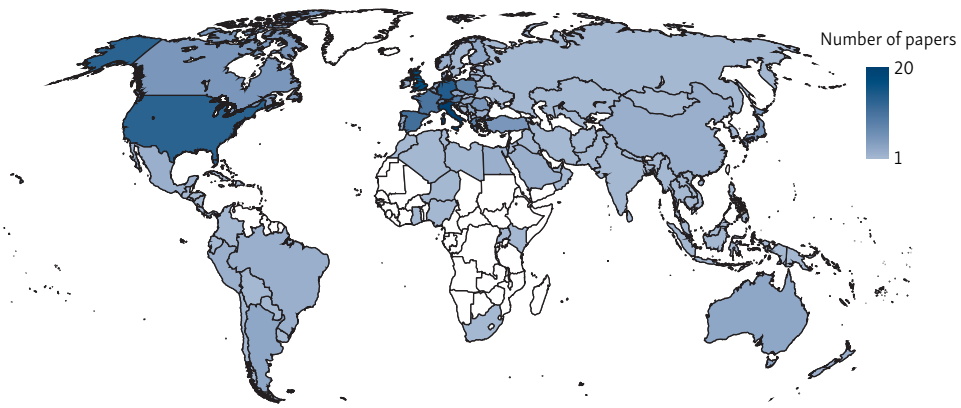
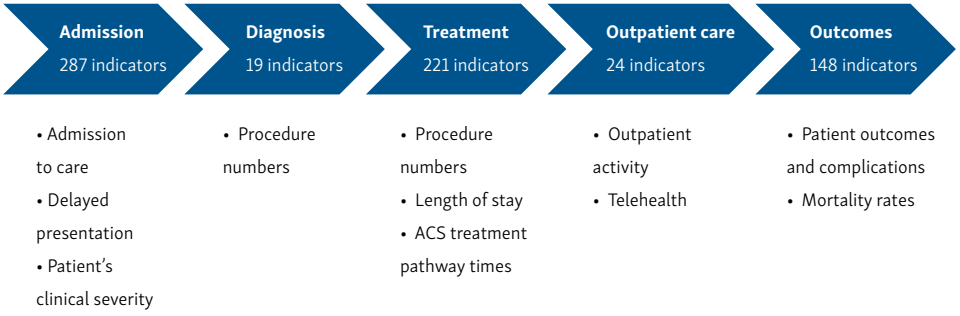


Figure 3 Categorization of indicators according to different phases of the hospital cardiac care pathway. Abbreviations: ACS—Acute Coronary Syndrome.



Admission

A total of 287 indicators regarding the 'admission' phase of the hospital cardiac care pathway were identified. These indicators were grouped into three separate categories: 'admission to care', 'delayed presentation', and 'patients' clinical severity at presentation'.

Admission to care

Regarding the number of admissions for cardiac diseases to hospital services, 134 indicators were identified from 49 articles [10, 26-73]. Most of the indicators concerned patients with acute coronary syndrome (ACS), heart failure, or cardiac arrythmia (Figure 4). Of these indicators, 118 (88%) reported a decrease in the number of admissions, compared to a non-COVID-19 period, 13 indicators (9,7%) reported a stable number of admissions, whereas 3 indicators (2,2%) reported an increase in admission numbers.

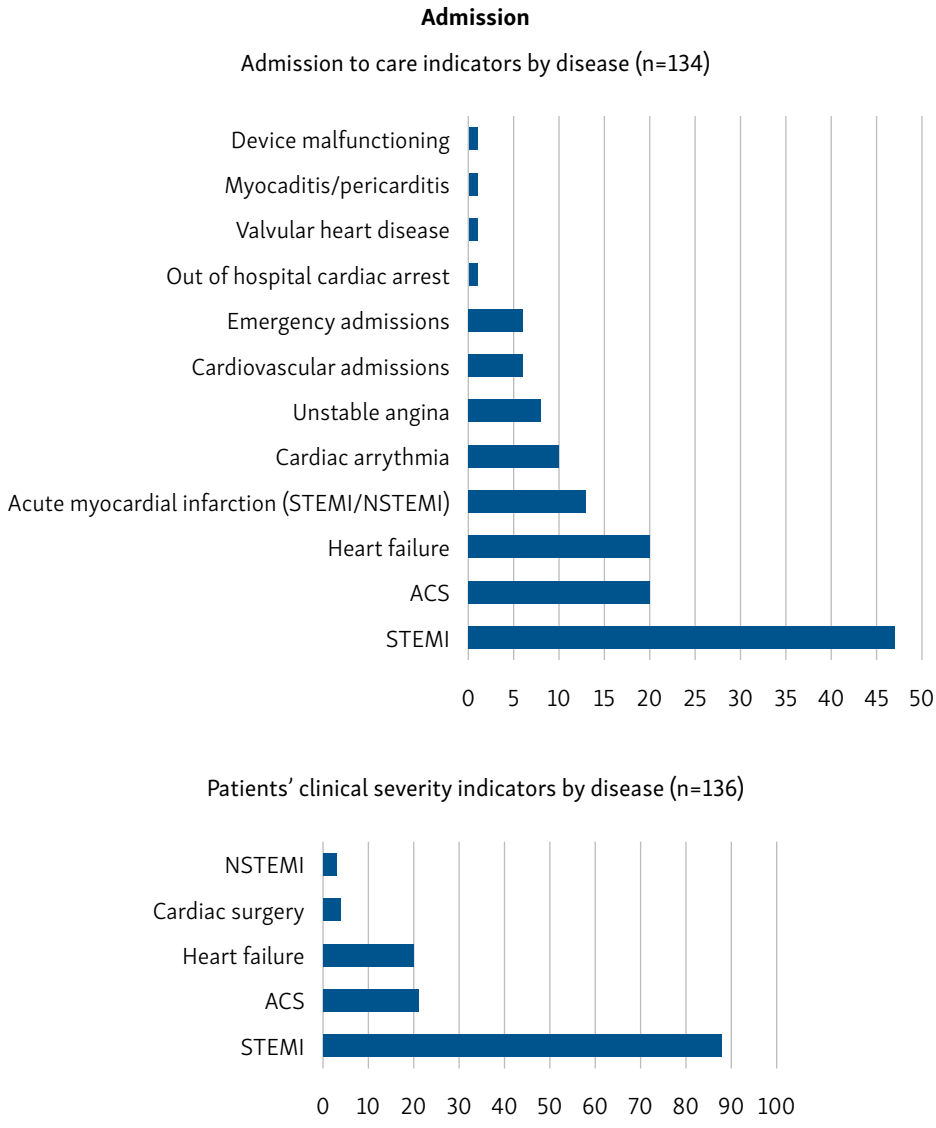
Delayed presentation

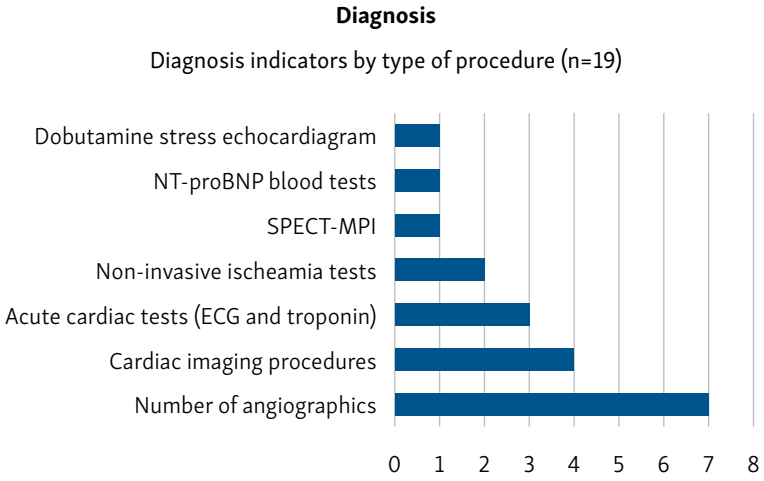
Regarding the patients' timing of presentation to hospital services, 17 indicators were identified from 12 articles [36, 43, 48, 61, 71, 74-80]. All the indicators in this category reported on patients with ACS. Most indicators defined delayed presentation as more than 12 h after symptom onset. Of these indicators, 15 (88%) reported an increase in the number of patients with a delayed presentation to hospital services for cardiac care compared to a non-COVID-19 period. One indicator (5,9%) reported a stable number of patients with a delayed presentation and another indicator a decrease.

Patients' clinical severity

Regarding the patients' clinical severity, 136 indicators were identified from 38 articles [19, 27, 31, 36, 37, 39, 41, 43, 46, 48, 50, 52, 54, 59, 61-63, 66, 69, 71, 73, 75, 76, 79, 81-94]. Most of the indicators were markers for patients with ACS (Figure 4), such as left ventricular ejection fraction, Killip class, or biomarkers at admission. Other indicators reported on heart failure and cardiac surgery. Of these indicators, 54 (40%) reported a worse clinical condition at admission when compared with patients during the COVID-19 period, 72 indicators (53%) reported a stable clinical condition, and 10 indicators (7,4%) reported a better clinical condition.

Figure 4 Admission and diagnosis indicators by disease. Abbreviations: ACS—Acute coronary syndromes; NSTEMI—Non-ST-elevation myocardial infarctions; SPECT-MPI—Single-photon emission computed tomography myocardial perfusion imaging; STEMI—ST-elevated myocardial infarctions.





Diagnosis

A total of 19 indicators regarding the 'diagnosis' phase of the hospital cardiac care pathway were identified from 11 articles [42, 51, 54, 58, 64, 71, 73, 82, 95-97]. All the indicators reported on the same category: the number of diagnostic procedures, including transthoracic and transoesophageal echocardiograms, non-invasive ischemia tests, and coronary angiographies (Figure 4). Of these indicators, 18 (95%) reported a decrease during the COVID-19 period. One indicator (5,3%) reported a stable number of diagnostic procedures performed.

Treatment

A total of 221 indicators regarding the 'treatment' phase of the cardiac care pathway were identified. These indicators were grouped into three separate categories: 'procedure numbers', 'length of stay,' and 'ACS treatment pathway times'.

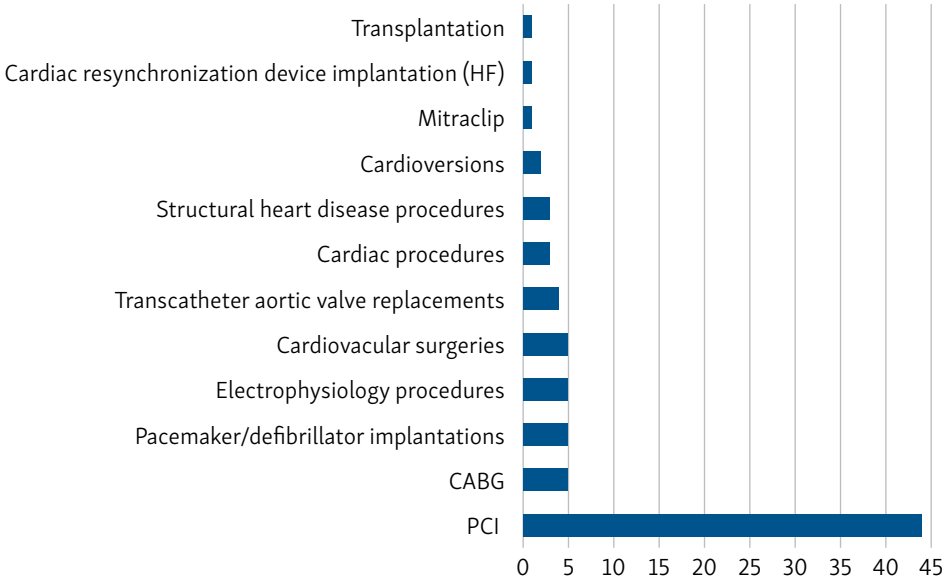
Procedure numbers

Regarding the number of treatment procedures, 79 indicators were identified from 32 articles [28, 30, 36, 42, 43, 51-54, 57, 58, 60, 64, 65, 71, 76, 78-80, 82, 83, 85, 88, 90, 97-104].

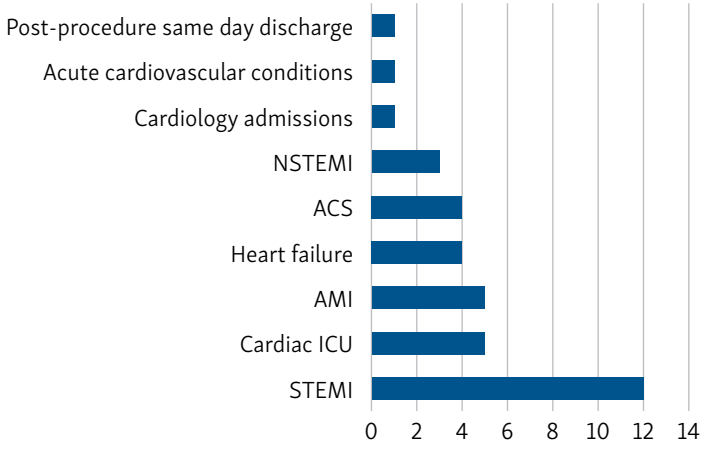
Figure 5 Treatment and outcome indicators by disease. Abbreviations: ACS—Acute coronary syndromes; AMI—Acute myocardial infarction; CABG—coronary artery bypass graft; HF—Heart failure; ICU—Intensive care unit; NSTEMI—Non-ST-elevation myocardial infarctions; PCI—Percutaneous coronary intervention; STEMI—ST-elevated myocardial infarctions; SPECT-MPI—Single-photon emission computed tomography myocardial perfusion imaging.

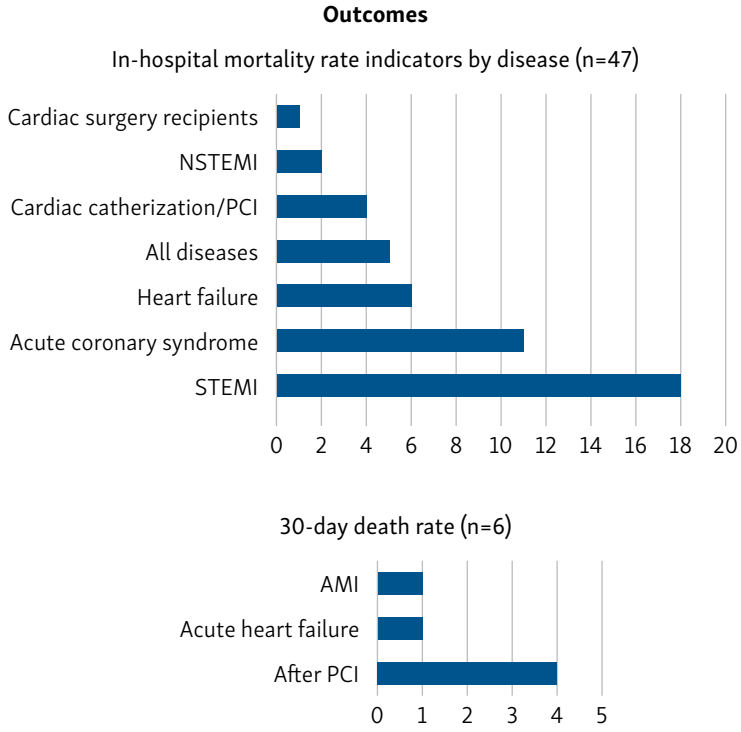
Treatment

Procedure numbers by procedure type (n=79)



Length of stay indicator by disease (n=36)





The indicators collected mainly concerned the number of percutaneous coronary interventions (Figure 5). Of these indicators, 64 (81%) reported a decrease in the number of treatment procedures performed during the COVID-19 period, and 15 indicators (19%) reported a stable number of procedures.

Length of stay

Regarding the patients' in-hospital length of stay, 36 indicators were identified from 25 articles [10, 29, 32, 39, 43, 47, 48, 50, 52, 54, 57, 61, 69, 71, 73-77, 80, 85, 87, 88, 102, 105]. Most of the indicators reported on patients with ACS (Figure 5). Of these indicators, 21 (58%) reported a decrease in the length of stay during the COVID-19 period, 13 indicators (36%) reported a stable length of stay, and 2 indicators (5,6%) reported an increased length of stay.

Acute Coronary Syndrome treatment pathway times

Regarding the treatment times for ACS care, 106 indicators were identified from 35 articles [27, 30, 33, 36, 40, 41, 48, 57, 61, 63, 66, 69, 71, 73-78, 81-89, 91-95, 105, 106]. Treatment pathway times reported in the papers were symptom-to-contact, symptom-to-door, symptom-to-diagnosis, symptom-to-balloon, contact-to-door, contact-to-balloon, door-to-ECG, door-to-balloon, ECG-to-balloon, diagnosis-to-balloon, first medical contact-to-catheter laboratory arrival, catheter-to-puncture, catheter laboratory arrival-to-balloon, puncture-to-balloon, and procedure time. Of these indicators, 65 (61%) reported an increase in ACS treatment pathway times during the COVID-19 period, 37 indicators (35%) reported stable treatment pathway times, and 4 indicators (3,8%) reported decreased treatment pathway times.

Outpatient Care

A total of 24 indicators regarding the 'outpatient care' phase of the cardiac care pathway were identified. These indicators were grouped into two separate categories: 'outpatient activity' and 'telehealth'.

Outpatient activity volume

Regarding outpatient activity, 18 indicators were identified from eight articles [11, 42, 53, 55, 73, 107-109]. Most of the indicators were concerned only with in-person outpatient activity. Of these indicators, 17 (94%) reported a decrease in outpatient activity volume during the COVID-19 period. One indicator (5,6%) reported a stable number.

Telehealth

Regarding the use of telehealth, six indicators were identified from six articles [11, 42, 55, 107, 109, 110]. All the indicators reported increased use of telehealth.

Outcomes

A total of 148 indicators regarding the 'outcomes' phase of the cardiac care pathway were identified. These indicators were grouped into two categories: 'outcomes and complications' and 'mortality rates'.

Outcomes and complications

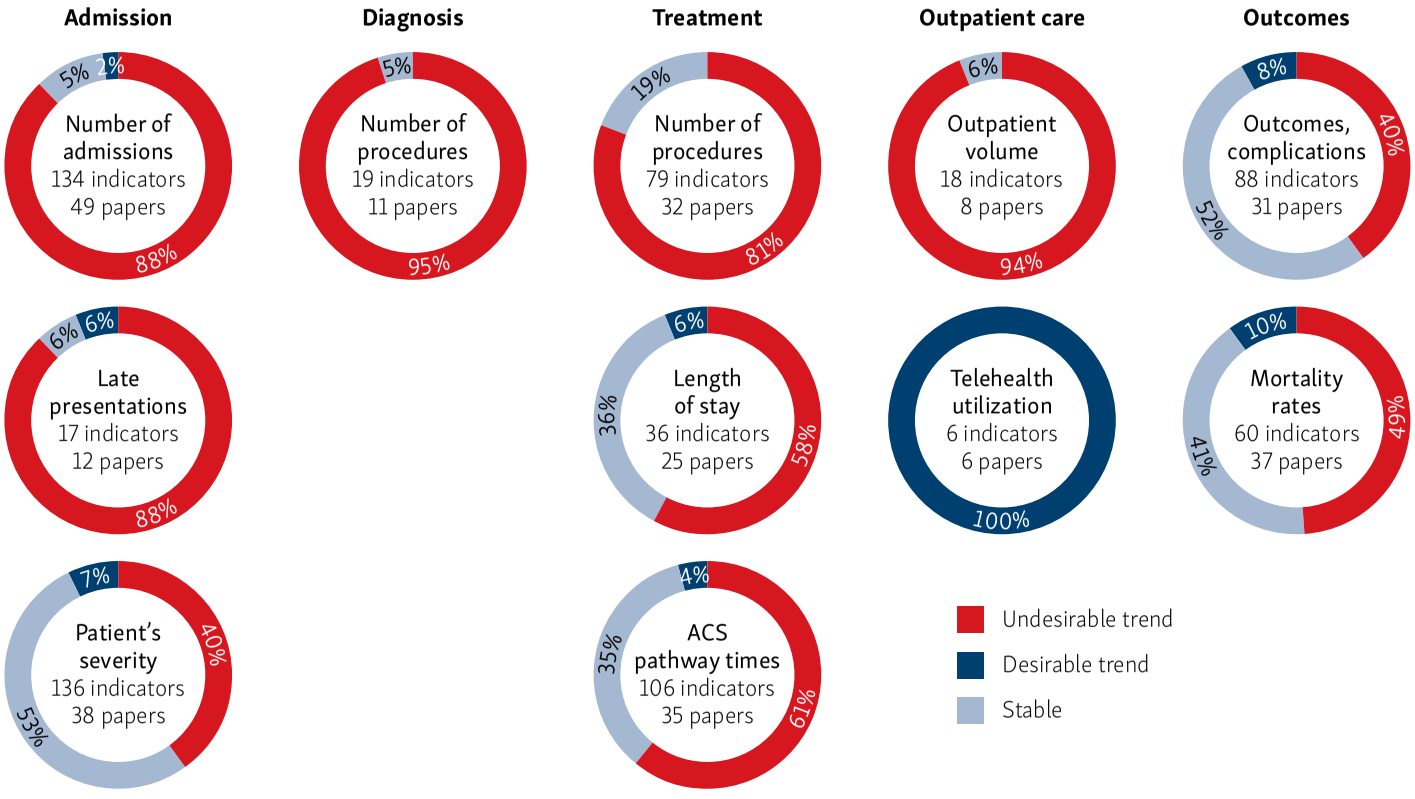
Regarding patients' outcomes and complications, 88 indicators were identified from 31 articles [19, 27, 30, 34, 40, 43, 48, 52, 59, 61, 63, 64, 66, 69, 74-77, 81-84, 87, 88, 91-94, 102, 103, 109]. Most indicators were on patients with ACS, in particular ST-elevated myocardial infarctions (STEMI), such as left ventricular ejection fraction at discharge, thrombolysis in Myocardial Infarction (TIMI) risk score after percutaneous coronary intervention, and major adverse cardiovascular events. Of these indicators, 35 (40%) reported worse outcomes during the COVID-19 period, 46 indicators (52%) reported a stable outcome, and 7 (8,0%) reported a better outcome.

Mortality rates

Regarding mortality rates, 60 indicators were identified from 37 articles [10, 19, 31-34, 36, 37, 39-41, 43, 47, 48, 50, 52, 54, 57, 59-61, 66, 69, 71, 73, 74, 79, 84, 87-90, 93, 94, 102, 103, 111]. Forty-seven indicators reported on in-hospital mortality rate (Figure 5), from which 22 indicators (47%) signalled an increase, while the same number (22,47%) reported a stable trend and 3 indicators (6%) signalled a decreasing trend. Six indicators reported on the 30-day death rate (Figure 5), from which five (83%) signalled an increasing trend and one (17%) a stable trend. There were seven indicators reporting changes in mortality rates without any specific interval provided or with a different interval.

Of all the indicators regarding mortality, 31 (52%) reported an increase in mortality rates during the COVID-19 period, 26 (43%) reported stable mortality rates, and 3 indicators (5%) show decreased mortality rates.

Figure 6 Hospital Cardiac Care Pathway Indicators' Trends during the COVID-19 Pandemic's early stages (January–June 2020).



An overview of the trends reported by the indicators in each phase of the hospital cardiac care pathway (defined as desirable, undesirable, or stable, following clinical reasoning) is shown in Figure 6. The trends reported for each indicator of the care pathway, by country, are available in Supplementary Material S6.

Discussion

This study aimed to provide an overview of the impact of the COVID-19 pandemic on hospital services for patients with cardiac diseases. We analysed more than 1600 indicators that were used in 94 papers, reporting on 109 different countries. Our findings show that all phases of the hospital care pathway for patients with cardiac diseases (admission, diagnosis, treatment, outpatient care, and outcomes) were, to different degrees, affected during the pandemic. Admission numbers dropped substantially, and patients arrived later and in a worse clinical condition at the hospital. The number of diagnostic and treatment procedures decreased, ACS treatment pathway times increased, and patients were discharged from the hospital after a shorter length of stay. Outpatient activity decreased, whereas the use of telehealth services increased. Finally, worse clinical outcomes and an increase in mortality rates were reported. Although future crises could lead to different consequences, and even though this study's results refer to a period without immunisation of the population to the SARS-CoV-2 virus, we consider that this information could help to plan future phases of the current pandemic or future events. This study's results can inform which indicators to monitor closely, support the standardization of indicators, and bolster their embeddedness in health information systems towards enhancing health systems' resilience and adaptability, allowing to avoid or minimize disruption and postponement of care during crises. This information can inform clinicians and policy-makers on the main areas affected in the cardiac care pathway, contributing to the monitoring and improvement of health care delivery. Additionally, these results can be helpful in planning the recovery of care for patients with cardiac diseases.

The drop in admissions to hospital services reported in almost all included arti-

cles is probably signaling healthcare avoidance, caused by patients afraid of being infected with SARS-CoV-2 in the hospital [112]. Another explanation could be an actual reduction in the incidence of cardiac diseases during the pandemic. Several explanations have been opted for this reduction in incidence, such as changes in physical activity during lockdowns or a reduction of air pollutants [113-116]. Patients with cardiac diseases presenting later to the hospital and arriving in a worse clinical condition than before the pandemic could also have been caused by the fear and avoidance mentioned before, with patients waiting for longer periods before seeking care.

Following the drop in admission numbers and decreased outpatient activity, a decrease in the number of diagnostic and treatment procedures was to be expected. On top of patients potentially avoiding care and a possible lower incidence rate of cardiac diseases, elective procedures and surgeries were cancelled [117]. These three factors together have likely contributed to reducing procedure volume. The decreased length of hospital stay that we found in most indicators is explained by several authors by a shortage of hospital bed capacity or the physicians' intention to minimize the risk of patients' exposure to the virus. For instance, the European Society of Cardiology recommended that patients 'should stay in the hospital for the shortest time possible' [118], and healthcare providers in the United Kingdom were advised to reduce non-ST-elevation myocardial infarction inpatient stays to 36–48 h if normal pathways could not be followed [54]. The increased ACS treatment pathway times and the decreased length of stay together indicate that the hospital cardiac care pathway was under pressure during the COVID-19 pandemic and the delivery of care got squeezed.

The reduction in outpatient care volume that we show in this study mostly comes from indicators reporting on in-patient visits. Therefore, it is probably an underestimation of the actual outpatient care provided. The change towards using telehealth shows that innovative measures were taken during the pandemic to avoid the risk of SARS-CoV-2 infection and health systems adapted quickly to reach out to patients with other means than in-person consultations. In theory, strengthening the use of telehealth to provide continuity of care is beneficial. However, little is known about the quality of care provided and potential inequalities that may have risen from the

use of telehealth (e.g., access for all patient groups).

Our findings suggest that patients with cardiac conditions are showing worse outcomes and increased mortality rates during the COVID-19 pandemic. The indicators that reported changes in mortality mostly concerned short-term mortality rates (up to 30 days). An even larger impact on mortality might be found when long-term mortality rates are assessed in later studies. These studies will have to contribute to capturing the real impact that this paper has outlined. The repercussions of care avoidance and cancelled or delayed diagnostic and treatment procedures could reveal themselves in the years to come.

To our knowledge, this is the first scoping review that gives an overview of the impact of the COVID-19 pandemic on the hospital cardiac care pathway in OECD countries. The scoping review methodology gives the benefit of mapping the published literature that became available during the early stages of the COVID-19 pandemic (January–June 2020). While earlier works assessed the impact of the pandemic on specific cardiac diseases care [119], in a specific country [120] or nation-wide, and previous authors have mentioned some of the impact revealed in this work based on earlier articles [121], this study has the strength to present an overview of performance indicators' trends collated in a systematic way, which capture the impact throughout the hospital cardiac care pathway with an international scope. This methodology, while it constitutes an innovative approach, allowed to map performance indicators that could be used by countries to assess the impact of the pandemic as it evolves, in a more uniform and comparable way.

However, a scoping review has its limitations. Despite efforts to accelerate the time of scientific publication, there is still a relevant time lag between the occurrence of events and their reporting. The time it takes to perform a review related to a broad clinical area justifies why this study only reports results from the first semester of 2020. Nonetheless, our findings provide a thorough overview of performance indicators across the cardiac care pathway, which can contribute to better monitoring the quality of cardiac care provided. Ideally, a systematic review with meta-analyses would be performed. For the articles included in this paper, this would be extremely difficult, given their different methodologies, indicators, indicators' definitions, and

comparison periods. The heterogeneity in study characteristics and indicators make it hard to compare data in a reliable way. In July 2020, the International Training Network for Healthcare Performance Intelligence Professionals (HealthPros) [122] suggested that to compare, manage, and improve health systems responsiveness to the pandemic, commonly agreed-upon standardized data and indicators are necessary [123]. We recommend devising a uniformly accepted set of indicators with clear definitions to use in future pandemics.

Another limitation is that only articles reporting on OECD countries were included in this scoping review. The global repercussions of the COVID-19 pandemic on hospital services for cardiac care will therefore likely be larger than reported in this paper, given the smaller capacity to handle changes in hospital care in low-income countries. On the other hand, publication bias may have played a role in portraying a more severe impact of the pandemic. Physicians might publish sooner when the effects of the pandemic are being clearly noticed in their hospital. It could also be the case that the overload with clinical tasks did not allow physicians to find the time to do scientific work, which may counterbalance this limitation. Regardless, we consider our findings to be useful and signaling major trends.

Based on the included articles, we are not able to provide an analysis of what caused these changes in the hospital cardiac care pathway. Being able to contextualize these results with future research will be of use for implementing measures to improve care during the current and future pandemics or disasters. Studies systematically assessing the following phases of the pandemic are necessary to evaluate whether the cardiac patients' management improved. We also welcome studies on the quality and access of telemedicine. It would be relevant to study if and how this could improve quality and access of services delivery for the better, also in non-crisis times.

Conclusions

These results signal that the hospital services delivery process for cardiac care came under pressure in the first half of 2020 and all phases of the hospital cardiac care pathway were affected. Lessons should be learnt and steps taken to be able to safeguard the continuity of care during the ongoing COVID-19 pandemic and in future crises. Furthermore, to guide the decisions of health system actors on the implementation of measures to ensure the continuation of essential care during future crises, fostering the use of an international standardized set of indicators is paramount, making optimal use of existing health in-formation infrastructures.

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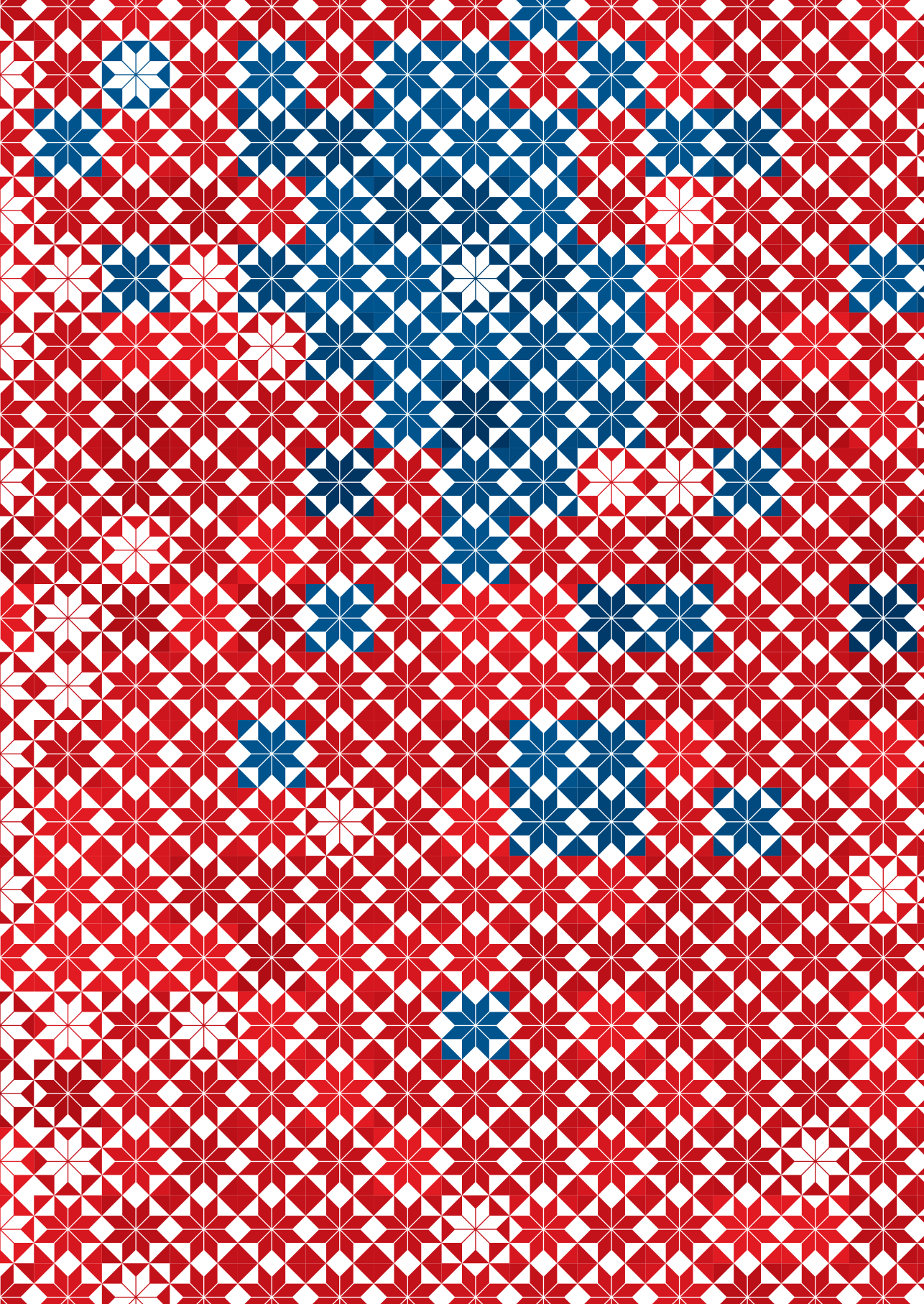
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Supplementary Material

Available at *https://tinyurl.com/Chapter1SM*

Supplementary Material S1—Preferred Reporting Items for Systematic reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) Checklist
Supplementary Material S2—Search strategy
Supplementary Material S3—Data Extraction Form
Supplementary Material S4—Collected and grouped indicators
Supplementary Material S5—Characteristics of the studies included in the review from which indicators were extracted and collated
Supplementary Material S6—Number of indicators and indicator trends reported by each indicator, presented by country



Chapter 2

Acute care pathway assessed through performance indicators during the COVID-19 pandemic in OECD countries (2020–2021): a scoping review

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Abstract

Background: The COVID-19 pandemic severely impacted care for non-COVID patients. Performance indicators to monitor acute care, timely reported and internationally accepted, lacked during the pandemic in OECD countries. This study aims to summarize the performance indicators available in the literature to monitor changes in the quality of acute care in OECD countries during the first year and a half of the pandemic (2020-July 2021) and to assess their trends.

Methods: Scoping review. Search in Embase and MEDLINE (07-07-2022). Acute care performance indicators and indicators related to acute general surgery were collected and collated following a care pathway approach. Indicators assessing identical clinical measures were grouped under a common indicator title. The trends from each group of indicators were collated (increase/decrease/stable).

Results: A total of 152 studies were included. 2354 indicators regarding general acute care and 301 indicators related to acute general surgery were included. Indicators focusing on pre-hospital services reported a decreasing trend in the volume of patients: from 225 indicators, 110 (49%) reported a decrease. An increasing trend in pre-hospital treatment times was reported by most of the indicators (n=41; 70%) and a decreasing trend in survival rates of out-of-hospital cardiac arrest (n=61; 75%). Concerning care provided in the emergency department, most of the indicators (n=752; 71%) showed a decreasing trend in admissions across all levels of urgency. Concerning the mortality rate after admission, most of the indicators (n=23; 53%) reported an increasing trend. The subset of indicators assessing acute general surgery showed a decreasing trend in the volume of patients (n=50; 49%), stability in clinical severity at admission (n=36; 53%), and in the volume of surgeries (n=14; 47%). Most of the indicators (n=28; 65%) reported no change in treatment approach and stable

mortality rate (n=11,69%).

Conclusions: This review signals relevant disruptions across the acute care pathway. A subset of general surgery performance indicators showed stability in most of phases of the care pathway. These results highlight the relevance of assessing this care pathway more regularly and systematically across different clinical entities to monitor disruptions and to improve the resilience of emergency services during a crisis.

Background

Since the World Health Organization (WHO) declared the COVID-19 outbreak a 'Public Health Emergency of International Concern' [1] on the 30th of January, 2020, the COVID-19 pandemic has severely impacted health systems worldwide [2], alongside far-reaching economic and societal impact [3]. The surge of patients infected with SARS-CoV-2 led to staff deployment and reduced hospital capacity [4]. Furthermore, the containment measures enforced by national governments [5], patients' hesitance to seek care [6, 7], and postponements of elective care contributed to disruptions in care pathways for non-COVID-19 patients, notably patients with noncommunicable diseases (NCDs) [8–10]. A care pathway is 'a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period', which ultimate aim is to improve quality of care [11]. Deleterious consequences of delayed care were reported among the Organization for Economic Co-operation and Development (OECD) member countries [9], such as increased mortality rates following hospital admissions with an acute cardiac event in several European countries in 2020 [8].

Emergency and trauma care are recognized by the WHO as part of Universal Health Coverage [12]. Emergency departments (EDs) are key to ensuring accessible, effective, and time-sensitive healthcare services, notably during crises [12, 13]. The WHO Emergency Care System Framework [14] provides a structured tool to appraise the essential functions of an emergency care system at the national level. During the pandemic, EDs worldwide faced the need to adapt quickly: services have reconfigured

their structure to separate (potentially) infected from non-infected patients, build additional capacity, ensure physical distancing, and introduce new operational pathways, among others [15–19]. However, many OECD countries presented substantial data gaps to evaluate health services performance during this period [8], such as access and quality of ambulance and emergency care. To prepare emergency care systems in maintaining essential functions during crises, and ensure quality and equity of care [20], improvements in the regular monitoring of performance are paramount.

Healthcare performance measurement allows for regularly appraising health systems and informing policy-making [21]. Quality indicators can be defined as 'quantitative measures that provide information about the effectiveness, safety and/or people-centeredness of care' [22]. Previous authors pursued efforts to identify indicators that could be used to monitor ED's performance, from the literature and/or with consensus-based techniques [23–26]. Nonetheless, indicators that are fit for purpose and use [27], reported transparently, timely, internationally accepted, and grounded on robust health information systems lacked during the COVID-19 pandemic and are urgently needed to guarantee the continuous monitoring of the quality of acute care provided and to tailor policy responses during a crisis [28, 29]. This scoping review intends to contribute to this knowledge, considering OECD member countries, which share a conceptual framework for performance measurement [30]. Therefore, we set out: 1) to summarize the performance indicators available in the literature, according to the phases of the acute care pathway, to monitor changes in the quality of acute care in OECD countries during the first year and a half of the COVID-19 pandemic (2020 – July 2021) and 2) to assess their trends during this period.

Methods

Study design

We performed a scoping review following the methodological framework developed by Arksey and O'Malley [31] and Levac et al. [32]. Considering the heterogeneous methodologies of the studies assessing changes in the quality of care during the

COVID-19 pandemic and the diversity of settings being studied [33], applying a scoping review methodology allows mapping the literature [32, 34, 35], specifically the performance indicators used to evaluate healthcare and the information they provide regarding changes in the quality of care [36]. Furthermore, it enables the synthesis and communication of emerging evidence [31, 34] and the identification of knowledge gaps [36]. This methodology has been described by the authors in two previous studies [37, 38], where different clinical areas were studied. The PRISMA checklist—extension for scoping reviews [39] was used for reporting (Additional file 1).

Eligibility criteria

The following inclusion criteria were considered: 1) original scientific articles providing empirical data on the use of health services (including literature reviews); 2) studies displaying performance indicators related to NCDs during the COVID-19 pandemic; and 3) studies applying quantitative and/or qualitative methods. Studies were excluded when they did not provide empirical data on health services, namely: 1) editorials and commentaries; 2) prediction models; 3) clinical case reports; 4) health services organization or diseases management guidelines; 5) studies assessing the impact on healthcare workers, patients diagnosed with COVID-19, children, or pregnant women; 6) studies primarily performed in non-OECD countries; 7) conference abstracts. No limitations were set regarding language or year.

Information sources & search strategy

The literature search was performed in Embase and MEDLINE databases. These two databases retrieve the most unique references in systematic reviews [40]. Relevant search terms were identified through pilot searches. The search strategy was elaborated by an experienced medical information specialist and refined following internal discussions among the research team. Search terms were grouped by key concepts: COVID-19, pandemic, noncommunicable disease, chronic disease, performance indicator, healthcare quality, healthcare utilization, and healthcare delivery.

The information specialist conducted the search on 17-03-2021, which was updated on 14-12-2021 and 07-07-2022. The entire search strategy for Embase is available in Additional file 2. Duplicates were removed using EndNote reference management software.

72 **Study selection**

Two reviewers (ASVC, OBF) screened titles and abstracts independently with Rayyan [41]. Disagreements were solved through discussion or consultation with a third reviewer (NK). Following the updates of the search strategy, one reviewer (ASVC) screened titles and abstracts. The records deemed relevant were exported to a spreadsheet. Only articles related to healthcare utilization of emergent and urgent care were considered for this study. Articles focusing exclusively on acute neurological, cardiac diseases, and trauma were excluded, considering that previous publications have extensively studied these subjects [37, 42–46]. Taking into consideration that most of the patients presenting with surgical diseases in the emergency department are evaluated by general surgeons, surgical diseases not evaluated in the general surgery setting were excluded. Full-text articles were independently screened for eligibility by two reviewers (ASVC, BB). Disagreements were solved through discussion and the reasons for exclusion were recorded at this stage. Articles in a language other than English, Dutch, French, Spanish, or Portuguese were translated to English with Google Translate, considering its accuracy [47].

Data extraction and charting

A spreadsheet form was developed to collect data. First, we performed a pilot test with 10 studies, from which data were collected by one reviewer (BB) and revised by another (ASVC) (Additional file 3). Then, the spreadsheet form was consolidated through discussion. Subsequently, two reviewers (ASVC, BB) collected data independently, which were revised by one another. Extracted information from the studies comprised: generic and methodological aspects (e.g., title, country, study

design), data regarding the indicators collected (e.g., indicator title as stated in the studies, numerator/denominator, inclusion/exclusion considerations), and the trend reported for every indicator (increase/decrease/stable). The trends regarding each indicator were collected as reported by the authors in each of the included studies. When the computation and/or the interpretation was not available, it was computed as: *((value during the COVID-19 pandemic) – (value before the COVID-19 pandemic)) / (value during the COVID-19 pandemic) × 100*. The positive values were considered an increasing trend, the negative values were considered a decreasing trend, and values close to zero were considered stable.

Data synthesis

Indicators collected from studies assessing emergent/urgent care without focusing on specific diseases were collated together. Indicators collected from studies explicitly related to general surgery in the ED were analyzed separately.

Indicators assessing identical clinical measures were grouped. Given the heterogeneity of indicator titles referring to equivalent measures, the authors attributed a common indicator title to each group of indicators assessing similar aspects of healthcare (eg, 'volume of patients contacting emergency medical services'). The trends from each group of indicators were collated, and the percentage of indicators reporting each trend (increase/decrease/stable) was computed. For groups of indicators retrieved in low numbers (<10 indicators), a trend was not computed. The groups of indicators and their combined trends were reported according to the phases of the acute care pathway: pre-hospital setting, access to the ED, diagnostic and treatment in the ED, and outcomes.

Results

Database searches retrieved 15454 records. Following screening of titles and abstracts, 2393 studies met the inclusion criteria. From those, 624 acute care studies were as-

sessed for eligibility, from which 319 were excluded, considering the clinical areas excluded for this review. A total of 305 acute care studies focusing on healthcare utilization and general surgery were considered for full-text screening. Two records were identified via hand-searching. Following the full-text screening, 152 were included and 155 studies were excluded (reasons for exclusion detailed in Figure 1).

Studies characteristics

A total of 152 studies were included (Additional file 4), conveying information from 27 countries. The most frequent study design was the retrospective cohort (n=141; 92,8%), followed by 5 prospective cohort studies (3,3%), 4 systematic reviews (2,6%), and 2 surveys (1,3%). Administrative data (n=92; 56,8%) and clinical data (n=49; 30,2%) were the most frequent data sources, followed by registries (n= 8), claims (n=4), population-level data (n=3), and surveys (n=2). The most frequent countries reported on, excluding the literature reviews, were the United States of America (USA) (n=39; 26,4%), Italy (n=21; 14,2%), Canada (n=12; 8,1%) and the United Kingdom (UK) (n=10; 6,8%) (Table 1). The magnitude of the indicators in the year 2020, in each study, were compared to their magnitude in 2019 (n= 240; 36,9%), to the period immediately before the beginning of the pandemic (n= 162; 24,9%), or to the average in previous years, ranging from 2018 to 2019 (n=111; 17,1%). Some studies compared the first half of the year 2021 to 2019 (n= 103; 15,8%) or the first half of the year 2021 to the previous years (n= 34; 5,2%).

Figure 1 PRISMA flow diagram—literature search (17th March, 14th December 2021 and 07th July 2022). From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

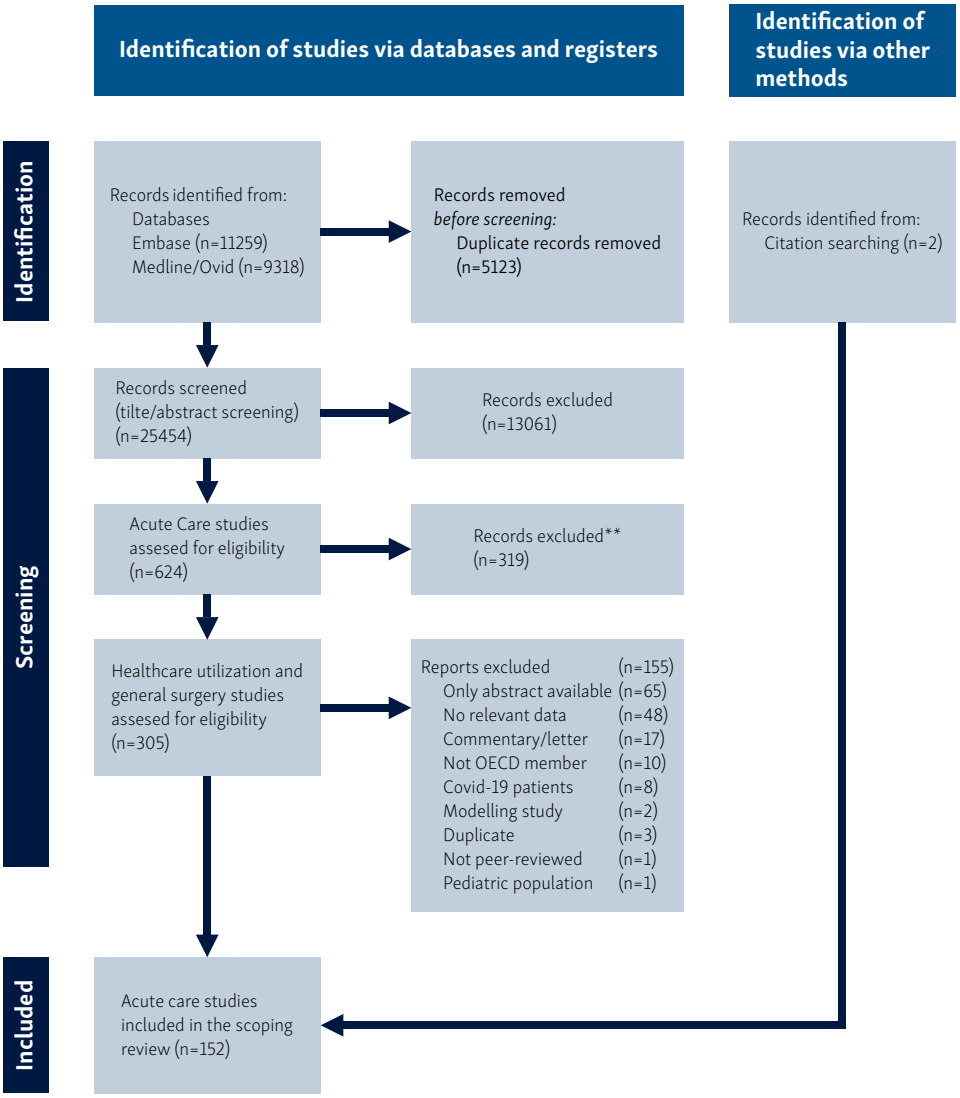


Table 1 OECD countries included in the analysis, excluding literature reviews (n=148 studies)

Country	Number of studies included	
	n	%
United States of America	39	26,4%
Italy	21	14,2%
Canada	12	8,1%
United Kingdom	10	6,8%
Turkey	9	6,1%
Germany	8	5,4%
United Kingdom	5	3,4%
Israel	5	3,4%
Australia	5	3,4%
Japan	4	2,7%
France	4	2,7%
Ireland	4	2,7%
Spain	3	2,0%
Finland	3	2,0%
Switzerland	3	2,0%
Greece	2	1,4%
Scotland	1	0,7%
Austria	1	0,7%
Slovenia	1	0,7%
Croatia	1	0,7%
Korea	1	0,7%
Netherlands	1	0,7%
Belgium	1	0,7%
New Zealand	1	0,7%
Hungary	1	0,7%
Norway	1	0,7%
Portugal	1	0,7%

Acute care indicators

A total of 2953 indicators related to acute care were collected: 2354 indicators from 124 studies focusing on general emergent/urgent healthcare and 301 indicators from 28 studies related to acute general surgery (Table 2).

Table 2 Groups of performance indicators across the acute care pathway (n=2953 indicators)

	Number of indicators [a]		Number of studies
	n	%	n
General emergent/urgent healthcare			
1. Pre-hospital services		**13,6%**	
1.1. Volume of patients contacting Emergency Medical Services	225		20
1.2. Volume of bystander cardiopulmonary resuscitation	26		10
1.3. Proportion of patients with out-of-hospital cardiac arrest witnessed by bystanders	12		9
1.4. Pre-hospital treatment times: from call to care provided	59		12
1.5. Survival rate of patients with out-of-hospital cardiac arrest	81		14
2. Admission to the Emergency Department		**46,2%**	
2.1. Volume of Emergency Department visits	1066		87
2.2. Arrival mode to the Emergency Department	78		22
2.3. Level of urgency by triage system	186		34
2.4. Clinical severity at admission	26		8
2.5. Duration of symptoms prior to presentation[b]	9		5
3. Diagnosis		**5,5%**	
3.1. Volume of diagnostic procedures	131		16
3.2. Rate of positive findings after diagnostic testing	32		4
4. Treatment		**4,9%**	
4.1. Volume of therapeutic interventions	106		18
4.2 Operational times	17		10
4.3 Length of stay (Emergency Department / in-hospital)	22		16
5. Outcomes		**9,3%**	
5.1 Disposition after visit to the Emergency Department	228		49
5.2 Unscheduled returns / re-admissions[b]	3		3

5.3 Scheduled follow-up visit after Emergency Department visit[b]	2		2
5.4 Mortality rate after Emergency Department admission	43		23
General surgery in the ED			
1. Admission to the Emergency Department		**5,7%**	
1.1. Volume of Emergency Department visits	101		17
1.2. Clinical severity at admission	68		19
2. Diagnosis		**0,3%**	
2.1. Volume of diagnostic procedures	8		4
3. Treatment		**3,3%**	
3.1. Volume of emergency surgeries	30		10
3.2. Change in treatment approach	43		19
3.3. Length of hospital stay	19		20
4. Outcomes		**0,9%**	
4.1 Post-operative complications	10		8
4.2 Mortality rate	16		12

a A total of 298 indicators were not included in the analysis since they were too specific to be grouped into categories.
b Indicator retrieved in low numbers therefore it is not mentioned in the text and a trend was not computed.

Indicators related to general emergent and urgent care

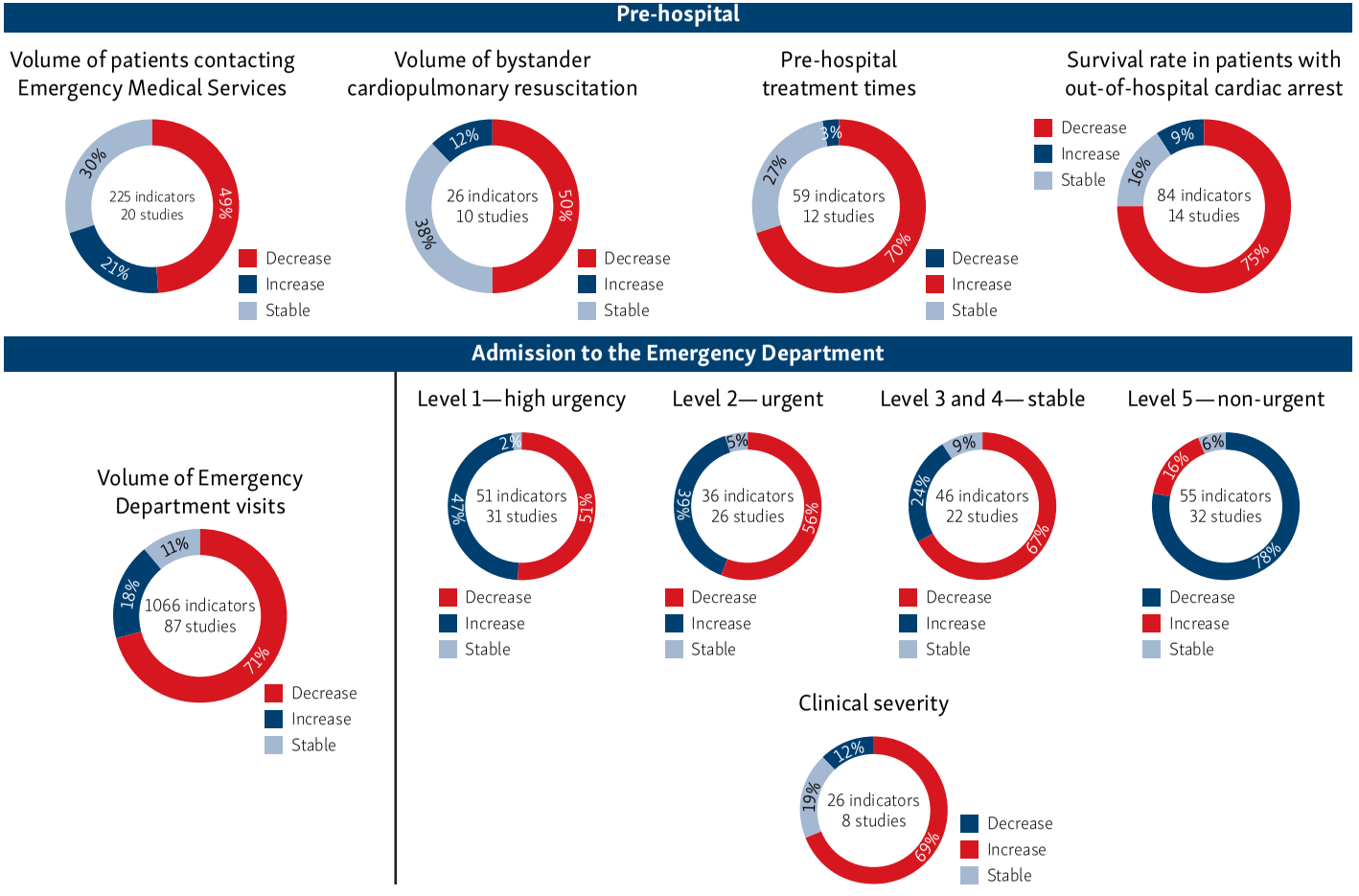
Indicators and their trends were collated according to the acute care pathway (pre-hospital services, admission to the emergency department, diagnosis, treatment, and outcomes), which are outlined as follows (Figure 2).

1. Pre-hospital services

Volume of patients contacting Emergency Medical Services

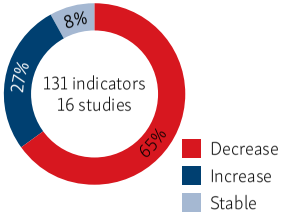
A total of 225 indicators from 20 studies [48–67] assessed the volume of patients contacting Emergency Medical Services (EMS). From those, most of the indicators (n= 110; 49%) showed a decreasing trend. These data came predominantly from Australia (n= 73 indicators; 33%) and Canada (n= 55 indicators; 24%).

Figure 2 Group of general acute healthcare indicators and their respective trends: OECD countries (2020 – July 2021)

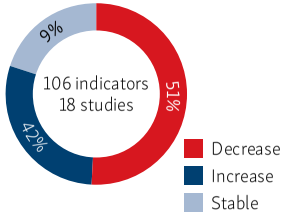


Diagnosis & treatment in the Emergency Department

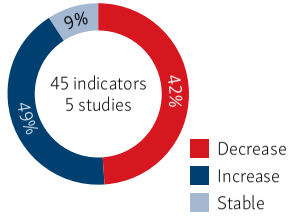
Volume of diagnostic procedures



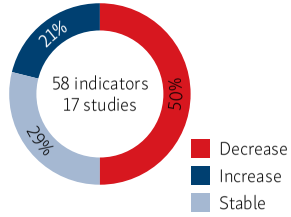
Volume of therapeutic interventions



Volume of therapeutic invasive procedures

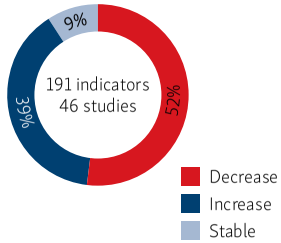


Volume of urgent surgical interventions

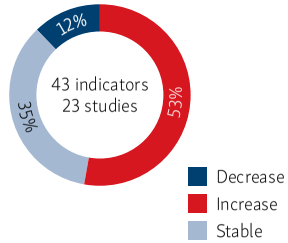


Outcomes after Emergency Department admission

Volume of hospital admissions after ED presentation (includes ICU)



Mortality rate after ED visit



One systematic review [68] reporting data from Australia, France, Italy, Spain, and the USA showed an increase of 120% in the number of out-of-hospital cardiac arrest (OHCA) events when comparing the year 2020 with a previous period.

Volume of bystander cardiopulmonary resuscitation

Twenty-six indicators from 10 studies [48, 56, 59, 60, 65, 66, 69–72] evaluated the volume of bystanders providing first aid in collapsed patients out-of-hospital. These indicators revealed, in most cases, a decreasing trend (n=13; 50%). Most data were from the USA (n=9; 35%) and France (n=6; 23%). Similarly, one systematic review [68] documented a decrease in bystander cardiopulmonary resuscitation (BCPR) rates during the pandemic, although not statistically significant. Two meta-analyses [73, 74] revealed no statistical difference in BCPR rates.

Proportion of patients with OHCA witnessed by bystanders

Twelve indicators from 9 studies [48, 56, 59, 60, 65, 66, 69–71] reported on the proportion of patients with OHCA witnessed by bystanders, most of those (7; 59%) showed stability in this proportion.

Pre-hospital treatment times

The analysis of the treatment times in the pre-hospital setting revealed 59 indicators from 12 studies [48, 50, 52, 55, 57, 59, 63, 65, 69–72], predominantly from Australia (n=14; 27%) and Finland (n=12; 20%). Most indicators (n=41; 70%) signaled an increasing trend. The treatment times assessed included: 'response time: start of an emergency call to the arrival of the first ambulance at the scene' [63], 'activation time: from the time someone reports to EMS to the time EMS departure' [72], 'on-scene time: from the time arrival at scene to the time of departure for hospital' [72], 'transport time: departure from the scene to arrival at the hospital' [63], among others. Similarly, the systematic reviews that assessed pre-hospital treatment times [68, 73, 75] documented

significantly increased times from OHCA to ambulance arrival during the pandemic.

Survival rate of patients with out-of-hospital cardiac arrest

Concerning the survival rate of patients with out-of-hospital cardiac arrest, 81
82 indicators from 14 studies [48, 51, 52, 55–57, 59, 60, 64–66, 70, 72, 76] were identified. These indicators included the following sub-categories of indicators: 'on-scene death rate', 'rate of pre-hospital return of spontaneous circulation (ROSC)', 'survival rate to hospital admission', and 'survival rate to hospital discharge'. Most indicators (n=61; 75%) signaled a decreasing trend in survival rates. Data came predominately from Spain (n=44; 62%) and the USA (n=20; 26%). Similarly, three of the systematic reviews documented a significant increase in the mortality rate following OHCA during the pandemic [68], lower rates of pre-hospital ROSC [74, 75], decreased survival rates to hospital admission [74] and to hospital discharge [74, 75].

2. Admission to the Emergency Department

Volume of Emergency Department visits

A total of 1066 indicators from 87 studies [50, 52, 61, 67, 76–158] provided information on the volume of patients admitted to the Emergency Department. From these, 752 (71%) indicators displayed a decreasing trend. Most of the data came from the USA (n=309; 29%), Italy (n=163; 15%), and the UK (n=122; 11%).

Arrival mode to the Emergency Department

Three indicator categories were identified regarding the arrival mode of patients to the ED. A total of 16 indicators from 9 studies [67, 77, 81, 86, 93, 110, 124, 133, 137] assessed the volume of patients arriving with their own transport, from which 15 (94%) indicators showed a decreasing trend. Twenty-two indicators from 12 studies

[52, 67, 77, 81, 86, 91, 110, 112, 124, 133, 137, 159] evaluated the volume of patients reaching the ED with the Emergency Medical Services. Most indicators (13;57%) signaled a decreasing trend. One study from Germany [110] displayed 40 indicators evaluating the number of ED admissions with a referral by a doctor related to different diseases; of those, 29 (72%) indicators showed a decreasing trend.

Level of urgency by a triage system

A total of 51 indicators from 31 studies [52, 62, 77, 80–82, 86, 88–91, 97, 98, 102, 103, 105, 108, 113, 116, 119, 123, 124, 126, 130–132, 134, 137, 142, 144, 158] were identified regarding patients presenting with level 1/highly urgent conditions to ED, mainly from the USA (n=21; 41%) and Italy (n=13; 25%). Of these indicators, 51% (n=26) signaled a decreasing trend. Of 36 indicators from 26 studies [52, 62, 77, 80–82, 86, 88, 91, 97, 98, 102, 103, 105, 108, 113, 123, 124, 126, 130, 134, 137, 142, 151, 157, 158] reporting on the volume of patients presenting with level 2/urgent conditions to ED, 56% (n=20) reported a decreasing trend. These data came predominantly from the USA (n=14; 39%) and Italy (n=6; 16%). Concerning the stable conditions/levels 3 and 4, 46 indicators from 22 studies [52, 62, 77, 81, 86, 91, 97, 98, 102, 108, 113, 116, 119, 123, 126, 130, 131, 134, 137, 142, 144, 158] provided information on indicators' trends from 7 countries. Most of these indicators reported a decreasing trend (n=31; 67%). Data came mainly from the USA (n=23; 50%). Concerning non-urgent/level 5 conditions, a total of 55 indicators from 32 studies [52, 62, 77, 80–82, 86, 88–91, 97, 98, 102, 108, 113, 116, 119, 123, 124, 126, 130–132, 134, 137, 142, 144, 151, 156–158] were identified. Of these, 78% (n=43) reported a decreasing trend in the volume of these patients. Data were reported predominantly from the USA (n=20; 36%) and Italy (n=15; 27%).

Clinical severity at admission

Regarding patients' clinical severity at admission, 26 indicators from 8 studies [83, 103, 120, 136, 143, 159–161] were identified. Most indicators reported an increasing

trend (n=18; 69%). Data were reported mainly from the UK (n=8,31%) and Switzerland (n=5; 19%). The indicators retrieved were related to the overall severity of medical admissions [120], clinical severity of patients diagnosed with urolithiasis [136], diverticulitis [160], pyelonephritis [83], pulmonary embolism [103], chronic obstructive pulmonary disease [143], and appendicitis [159].

3. Diagnosis

Volume of diagnostic procedures

Information on the volume of diagnostic procedures in the ED was retrieved from 131 indicators from 16 studies [82, 86, 92, 95, 103, 113, 125, 145, 160–167] reporting on 8 countries. They displayed information regarding laboratory testing [162, 168], ultrasound imaging [86, 166], radiological examinations [86, 92, 103, 125, 145, 160–167], nuclear imaging [86, 166], and biopsies [95]. Most of the indicators reported on computed topographies (CT) (n=64; 49%) and laboratory testing (n=16; 6%). The predominant trend was a decrease in the volume of diagnostic procedures (n=85,65%) (trends for each diagnostic procedure are detailed in Additional file 5). Data came predominantly from the USA (n=74 indicators; 56%) and Italy (n=19; 14%).

Rate of positive findings after diagnostic testing

A total of 32 indicators from 4 studies reporting on 4 countries were retrieved regarding the rate of positive diagnostic findings, namely positive blood cultures [162] and positive CT findings [92, 161, 162, 164]. Of these, 9 (58%) indicators displayed an increasing trend. Most indicators were from the USA (n=18; 55%) and Ireland (n=7; 21%).

4. Treatment

Volume of therapeutic interventions

A total of 106 indicators from 18 studies [67, 82, 83, 88, 92, 93, 95, 98, 99, 108, 136, 148, 151, 155, 159, 161, 169, 170] and 11 countries reported on therapeutic interventions in the ED. Most indicators signaled a decreasing trend (n=54; 51%). The therapeutic interventions assessed were invasive procedures (e.g., endoscopy, endovascular intervention, endoscopic retrograde cholangiopancreatography, paracentesis/thoracentesis), acute surgical interventions, and other procedures, such as bedside procedures.

Operational times

Seventeen indicators from 10 studies and 7 countries reported on the average operational times for emergent and urgent care, such as average waiting time for triage [123, 167], from triage to first medical assistance [52, 123, 126, 130], from consultation to treatment [52, 90, 148, 161, 162], and for hospital ward admission [131]. Of these, 9 (53%) indicators signaled a decreasing trend.

Length of stay

A total of 14 indicators from 11 studies [52, 86, 91, 98, 114, 120, 126, 130, 145, 151, 157] reported on the length of stay (LOS) in the ED, from which 11 (79%) indicators displayed a decreasing trend. Concerning the in-hospital LOS after ED admission, 8 indicators from 5 studies [127, 130, 139, 143, 159] were retrieved, from which 62% (n=5) reported a decreasing trend.

5. Outcomes

Disposition after ED visit

Concerning the volume of patients discharged home, a total of 26 indicators from
86 15 studies [52, 82, 86, 98, 102, 112, 113, 116, 117, 120, 130, 136, 151, 157, 158] and 5 countries were retrieved. Most indicators (n=15; 58%) reported a decreasing trend. Regarding the volume of hospital admission after ED presentation (including admission to intensive care unit), from the 191 indicators from 46 studies [52, 67, 77, 78, 81, 83, 85–88, 90–94, 96, 98, 100, 102, 103, 107, 108, 112–117, 120–123, 127, 128, 130, 131, 134, 137, 144, 145, 147, 149, 151, 152, 157, 158] collected, 52% (n=100) signaled a decreasing trend, and 39% (n=74) showed an increasing trend. Most of the indicators were from the USA (n=43; 23%), Italy (n=35; 18%), and Croatia (n=23; 12%). Eleven indicators from 7 studies [77, 98, 113, 130, 151, 157, 171] and 3 countries reported on the volume of patients leaving the ED without completing treatment, including patients that left the ED without being seen, completing treatment, and against medical advice; of these, 9 (82%) indicators signaled a decreasing trend.

Mortality rate

A total of 43 indicators from 23 studies [50, 52, 67, 76, 85, 91, 92, 96, 98, 107, 113, 120, 123, 127, 130, 133, 137, 139, 143, 149, 153, 157, 162] reported on the mortality rate after an ED visit. Most of the indicators signaled an increasing trend (n=23; 53%). Data came predominantly from Canada (n=9; 21%), Turkey (n=6; 14%), and Norway (n=5; 11%).

Trend analysis by country and clinical entity did not show recognizable tendencies in any of the indicators retrieved (Additional file 5). The trends of the indicator categories related to general acute care comparing the COVID-19 period to a previous period are displayed in Figure 2.

Indicators related to acute general surgery care

Indicators on acute general surgery care were collected and grouped following the care pathway (admission, diagnosis, treatment, and outcomes), and their respective trends are summarized in Figure 3.

1. Admission

Volume of Emergency Department visits

A total of 101 indicators from 17 studies [172–188] and 10 countries reported on the volume of ED visits related to acute general surgery. Of those, almost half of the indicators (n=50; 49%) signaled a decreasing trend. Most of the data were from Canada (n=19; 18%), the UK (n=14; 14%), and New Zealand (n=12; 12%).

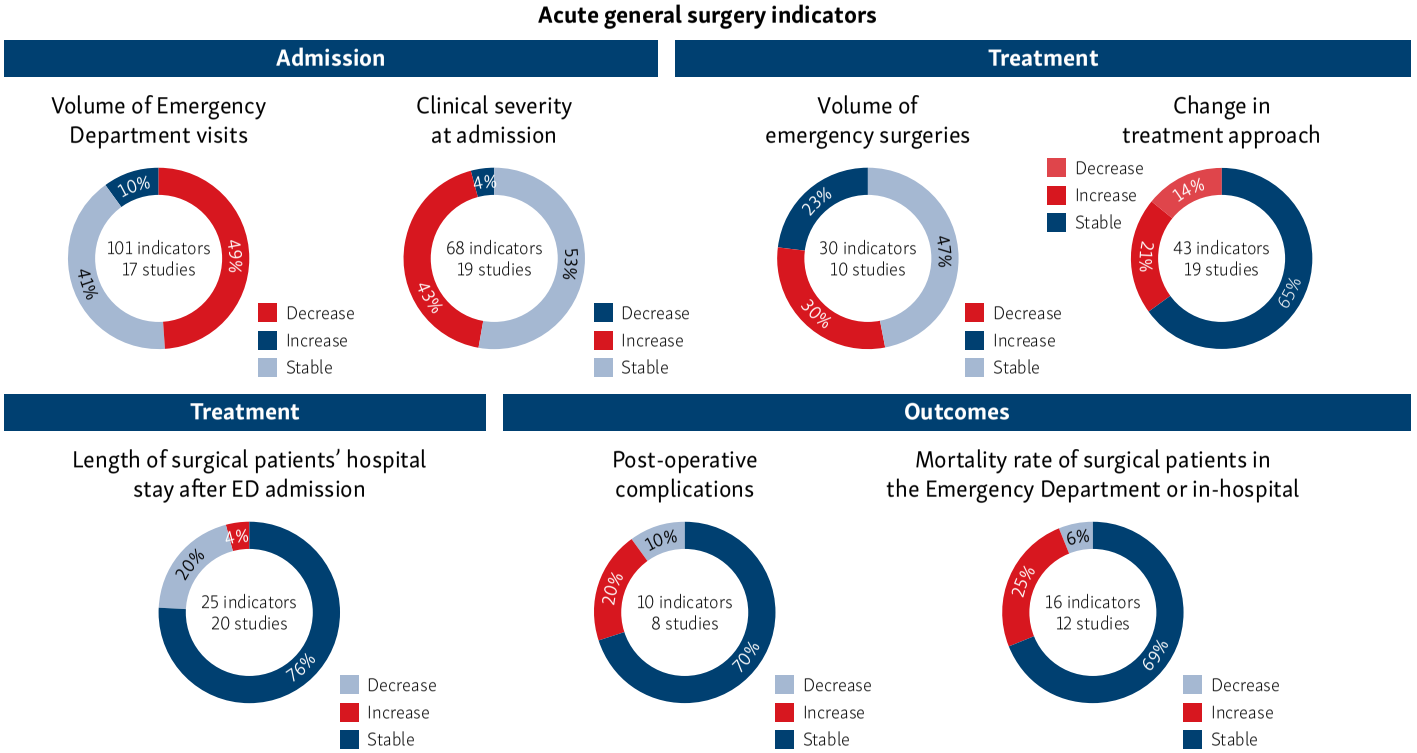
Clinical severity at admission

Indicators assessing patients' clinical severity included clinical, laboratory and imaging features at admission, severity grading according to diseases-specific scores, operative findings, and the American Society of Anesthesiologists (ASA) score. Sixty-eight indicators were retrieved from 19 studies; of those, 36 (53%) indicators showed a stable clinical severity and 29 (43%) indicators signaled increased severity. The countries most represented were the USA (n=19; 28%), Israel (n=15; 22%), and the UK (n=11; 16%).

2. Diagnosis

Eight indicators from four studies evaluated the diagnosis phases of the pathway, which did not provide sufficient information regarding trends.

Figure 3 Groups of acute general surgery indicators and their respective trends: OECD countries (2020 – July 2021)



3. Treatment

Volume of emergency surgeries

Data related to the volume of acute surgeries was retrieved from 30 indicators and 10 studies [174, 176, 185, 186, 188–193], from 8 countries. Most of the indicators [n=14; 47%] signaled stability in the volume of acute surgeries. Data came predominantly from Italy (n=16; 54%).

Change in treatment approach

A total of 43 indicators from 19 studies [173–177, 179, 180, 182, 183, 186, 188–191, 194–198] were retrieved. These indicators evaluated the treatment strategy in the acute surgical setting related to diseases such as appendicitis, acute cholecystitis, and bowel obstruction. Most of the indicators (n=28; 65%) signaled no change in the treatment approach. Data were predominantly from the UK (n=12; 28%) and Germany (n=9; 21%).

Length of hospital stay

Concerning the LOS in-hospital (including in the intensive care unit), 25 indicators from 20 [175–181, 183, 184, 186, 189–191, 193–199] studies were collected. Most of the indicators showed stability of the LOS (n=19; 76%). Data came mostly from the UK (n=7; 28%), USA (n=4; 16%), and Ireland (n=4; 16%).

4. Outcomes

Post-operative complications

Ten indicators from 8 studies [174, 175, 179, 182, 186, 194–196] reported on post-operative complications. Most of these indicators (n=7; 70%) signaled stability in this outcome.

Mortality rate

Concerning the mortality rate, 16 indicators from 12 studies [174, 176–178, 182, 183, 186, 187, 189, 190, 195, 198] were collected. Of these, 69% (n=11) signaled stability.

Discussion

In this scoping review, we aimed to summarize the performance indicators available in the literature to monitor changes in the quality of acute care in OECD countries and to assess their trends for the first year and a half of the COVID-19 pandemic (2020-July 2021). A total of 2953 indicators were collected from 152 studies reporting on 27 countries. Concerning access to acute care, indicators signaled a decreasing trend in the volume of patients, as well as increased clinical severity at presentation, and treatment delays. Trends regarding acute diagnostic and treatment procedures showed decreases in volume, as well as worsened outcomes. Similarly, the subset of indicators focusing on acute general surgery signaled a decrease in the volume of patients and increased clinical severity. Conversely, our results showed stable trends in acute general surgery regarding the volume of surgeries, length of hospital stay, treatment approaches, and outcomes.

Looking in detail at the stages of the acute care pathway, starting from the pre-hospital setting, our results showed a decrease in the volume of patients contacting EMS, which is in line with findings of other studies reporting reductions in access to primary care [8] and to hospital care by patients with acute myocardial infarction (AMI) [8], cancer [200], and stroke [201]. Our findings support patients delayed care considering the increased time from symptom until calling the EMS, as reported in previous studies [202]. The decision to delay care might be related to fear of overwhelming the health system [7, 142] or getting infected with SARS-CoV2 [203]. This fear could also explain the decreasing trend in bystanders providing first aid that our results show. The possibility of reductions in the incidence of some diagnosis is a hypothesis to consider. However, it is difficult to quantify the exact

number of 'missed' diagnoses during the COVID-19 pandemic, as these are affected by several factors, such as changes in the mortality rates, lifestyle, or migration in each country. A study from the UK, conducting an analysis between March 2020 and December 2021, found a persistent decrease in the incidence rate of some respiratory diseases (such as asthma and chronic obstructive pulmonary disease), strokes, and heart diseases (such as coronary heart disease and atrial fibrillation), when compared to pre-pandemic levels [204]. Concerning stroke, the avoidance in care seeking is generally hypothesized as one of the justifications rather than the hypothesis of a real decrease in the incidence of stroke [205, 206]. Regarding the respiratory conditions, the social distance measures may have led to a reduced number of acute exacerbations of these diseases. Nonetheless, the restrictions in access to diagnostic testing (spirometry) could also have contributed to this decrease [204]. The impact of the pandemic in the outcomes of patients with cardiac diseases remains unclear. Factors such as the misclassification of cardiovascular deaths as COVID-19 deaths, the lack of population data and the lack of regular monitoring of the quality of cardiovascular care and outcomes makes it difficult to formulate accurate conclusions [207].

Despite the reduced demand, our results signaled an increasing trend in pre-hospital times, suggesting the timeliness of acute care was compromised. Delays triggered by patients, as signaled by our results, and insufficient timely response have most likely contributed to the worsening of survival rate trends in patients with OHCA that we report. Some authors have also reported increased pre-hospital times and worsened outcomes in patients with acute stroke [202] and AMI [208].

Regarding access to the ED, our results also signal substantial disruptions. We found a decreasing trend in the volume of patients regardless of triage classification or mean of arrival. This decrease was neither condition- nor country-specific, suggesting that fear and delay were relevant for patients with different clinical conditions and across different countries. Our results also signal a trend toward increased clinical severity at admission to the ED, as previous studies reported for specific diseases such as acute stroke [203]. These delays in access to pre-hospital care and to the ED highlight the need to improve communication strategies directed to patients with

symptoms related to time-sensitive and life-threatening conditions during crises. Care provided at the ED should primarily focus on the most urgent patients, therefore the decreasing trend in access by non-urgent patients could provide a window of opportunity to avoid unjustified use of the ED, emphasizing the need to strengthen and integrate primary care support.

The reduced demand for access to acute care settings resulted in decreasing trends in acute diagnosis and treatment procedures. Noteworthy, our results also showed higher rates of positive findings after diagnostic testing, which is in line with the more severe clinical condition displayed in our results.

Our results feature a small sample of indicators concerning the timeliness of care in the ED that signal a decreasing trend in operational times and in LOS in the ED. Although this small sample of indicators was insufficient to compare trends among different periods, previous studies reported variations in the LOS during 2020 [209, 210] and for different clinical severities [211].

Regarding the outcomes after ED admission, we report a decreasing trend in the volume of patients discharged home and in the volume of hospital admissions, which are most likely related to the reduced demand. Additionally, our results signal a trend towards increased mortality rates after admission to the ED. This adverse outcome could be a consequence of delays in seeking care and increased pre-hospital treatment times. Worse clinical outcomes were previously reported for specific acute diseases during the pandemic, such as acute stroke [202] and AMI in several European countries [8, 212].

The analysis of the subset of indicators assessing acute general surgery care did not show similar disruptions. We found a decreasing trend in the volume of patients at the ED, however our results display no change in treatment approaches, length of stay, and outcomes. The small sample of indicators needs to be taken into consideration to interpret these findings. Notwithstanding, these results suggest that the quality of care provided to these patients has not substantially changed during the pandemic. The difference of these results compared to the general acute healthcare justify the need to monitor the pathways of acute diseases separately to identify and act upon changes in the quality of care regarding different clinical

entities in a timely manner.

The disruptions signaled by these results highlight that the inclusion of this performance information as part of the continuous monitoring and more systematic assessment of emergency care systems is pivotal to tailoring policy responses timely and to building more resilient health systems. Performance intelligence, defined as 'the structured approach to acting on health policies, using knowledge and information generated by the application of scientific methods to comparable healthcare data to systematically measure indicators of health systems performance' [28], can be a valuable tool to prepare for future crises [28]. Investment in data infrastructure is an essential component to enable performance intelligence [28] and to improve healthcare systems resilience [213]: the 'ability of systems to prepare for, absorb, recover from and adapt to major shocks' [213].

Substantial advancements to health information systems were triggered by the COVID-19 pandemic, such as improved data linkage between data sets in the public sector, improved timeliness of national datasets, and adoption of digital tools [29]. Nonetheless, relevant hindrances still need to be addressed, namely related to regulatory barriers, data interoperability, quality and linkage, as well as the need for a skilled workforce in health information [29]. Good practices to inform further improvements are, for instance, Korea's Emergency Medicine Monitoring System, a nationwide information network constructed in 2013 that links public sources to calculate key indicators at the entire acute care pathway, providing real-time information [168, 214, 215]. The Israeli National Hospital Discharge Register [216] also assesses performance indicators related to stroke and AMI regularly.

Our results expose only a few of indicators reflecting the impact on outcomes and experiences of patients or patient safety culture in hospitals, both recognized as relevant for international benchmarking and healthcare quality improvement [8, 217]. Future research is needed to provide a deeper analysis of the impact on specific acute clinical entities in a comparable way across countries. Moreover, stratified analyses of these indicators by patients' sociodemographic characteristics will be useful to enhance the understanding of the trends we report and assess possible inequalities. Future studies to develop performance intelligence that is actionable

to decision-making will be crucial in the years to come.

Strengths and limitations

Previous studies have investigated the impact of the COVID-19 pandemic in the acute care setting on specific countries [24, 218, 209, 211], phases of the pathway [142, 211], or diseases [203, 212, 219]. This scoping review provides a comprehensive overview of the changes reported on the quality of acute care during the first year and a half of the COVID-19 pandemic, covering OECD countries, multiple diseases, and following a care pathway approach. In addition, this review provides a summary of performance indicators from pre-hospital to in-hospital outcomes, which could be useful tools, if further developed and systematically collected, to inform policy-making. Some national and international reports [9, 220] proposed standards for acute care, where some of the performance indicators we retrieved were proposed to drive care improvements.

This study has some limitations. First, the heterogeneity of study designs, sample sizes, and indicators definitions did not allow to perform a meta-analysis to quantify the impact of the COVID-19 pandemic on the indicator categories identified, or to assess inequalities related to gender or socio-economic status. Secondly, despite the inclusion of all OECD countries, the heterogeneity in the number of studies per country comprised a skewed sample. Therefore, it needs to be considered that the professionals experiencing the most severe disruptions were likely the ones that were more inclined to report it.

Conclusion

This study signals relevant disruptions across the acute care pathway during the first year and a half of the COVID-19 pandemic, such as decreasing trends in the volume of patients, in the volume of diagnostic and treatment procedures, increased clinical severity at presentation, treatment delays, and worsened outcomes. A subset of

general surgery indicators showed stability in most of phases of the care pathway. This evidence underscores the relevance of monitoring the acute care pathway more regularly and systematically to assess the care processes and outcomes of these patients. This would allow to monitor care disruptions more efficiently. Furthermore, our results could contribute to strengthening health information infrastructures worldwide, which is an urgent step to monitor structure, process, and outcome information regarding patients with time-sensitive and life-threatening conditions. This is of paramount importance to improve the resilience of health systems during a crisis.

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Supplementary Material

Additional file 1—Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

Available at *https://tinyurl.com/Chapter2SM1*

Additional file 2—Search strategy

Available at *https://tinyurl.com/Chapter2SM2*

Additional file 3—Data Extraction Form

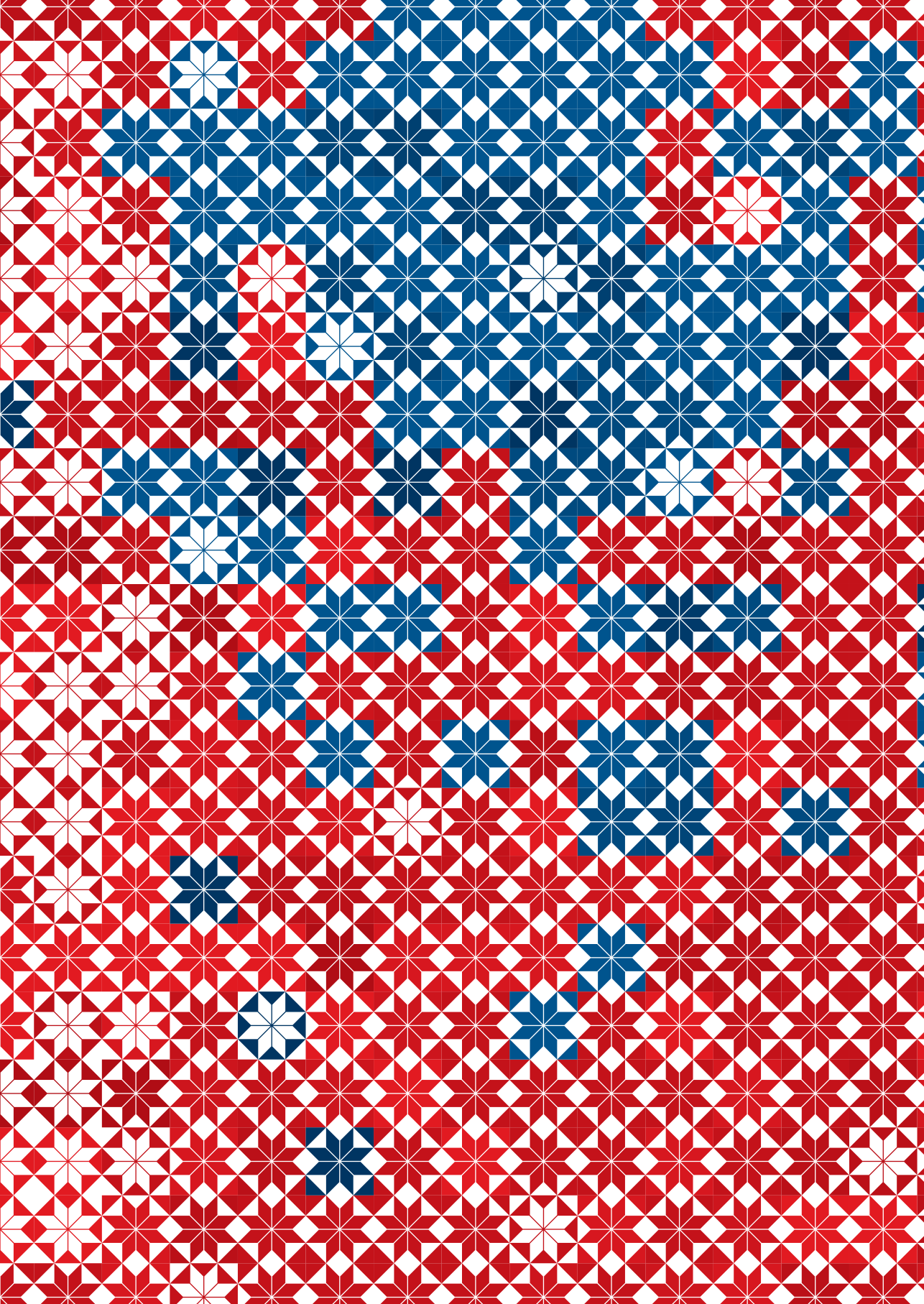
Available at *https://tinyurl.com/Chapter2SM3*

Additional file 4—List and characteristics of the studies included, from which indicators were extracted and collated

Available at *https://tinyurl.com/Chapter2SM4*

Additional file 5—Analysis of specific indicator trends by country, clinical entity, and/or diagnostic procedures

Available at *https://tinyurl.com/Chapter2SM5*



Chapter 3

Changes in the quality of cancer care as assessed through performance indicators during the first wave of the COVID-19 pandemic in 2020: a scoping review

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Abstract

Background: Cancer comprises a high burden on health systems. Performance indicators monitoring cancer outcomes are routinely used in OECD countries. However, the development of process and cancer-pathway based information is essential to guide health care delivery, allowing for better monitoring of changes in the quality of care provided. Assessing the changes in the quality of cancer care during the COVID-19 pandemic requires a structured approach considering the high volume of publications. This study aims to summarize performance indicators used in the literature to evaluate the impact of the COVID-19 pandemic on cancer care (January-June 2020) in OECD countries and to assess changes in the quality of care as reported via selected indicators.

Methods: Search conducted in MEDLINE and Embase databases. Performance indicators and their trends were collated according to the cancer care pathway.

Results: This study included 135 articles, from which 1013 indicators were retrieved. Indicators assessing the diagnostic process showed a decreasing trend: from 33 indicators reporting on screening, 30 (91%) signalled a decrease during the pandemic (n=30 indicators, 91%). A reduction was also observed in the number of diagnostic procedures (n=64; 58%) and diagnoses (n=130; 89%). The proportion of diagnoses in the emergency setting and waiting times showed increasing trends (n=8; 89% and n=14; 56%, respectively). A decreasing trend in the proportion of earliest stage cancers was reported by 63% of indicators (n=9), and 70% (n=43) of indicators showed an increasing trend in the proportion of advanced-stage cancers. Indicators reflecting the treatment process signalled a reduction in the number of procedures: 79% (n=82) of indicators concerning surgeries, 72% (n=41) of indicators assessing radiotherapy, and 93% (n=40) of indicators related to systemic therapies.

Modifications in cancer treatment were frequently reported: 64% (n=195) of indicators revealed changes in treatment.

Conclusions: This study provides a summary of performance indicators used in the literature to assess the cancer care pathway from January 2020 to June 2020 in OECD countries, and the changes in the quality of care signalled by these indicators. The trends reported inform on potential bottlenecks of the cancer care pathway. Monitoring this information closely could contribute to identifying moments for intervention during crises.

Background

The COVID-19 outbreak was declared a public health emergency of international concern by the World Health Organization on the 30th of January, 2020 [1]. Since the beginning of the pandemic, health systems have struggled to cope with the high numbers of people infected with SARS-CoV-2, while maintaining adequate care for people with other conditions [2].

Cancer is the second cause of death in Organisation for Economic Co-operation and Development (OECD) countries [3], comprising a high burden on OECD's health systems. The COVID-19 pandemic has widely affected cancer care delivery in these countries. Substantial declines in the number of cancer diagnoses have been reported in the Netherlands [4–6], Spain [7], Belgium [8], and Denmark [9]. While trying to minimize the risk of COVID-19 disease in cancer patients, changes in practice were pursued by oncologists, according to each setting's capacity and recommendations released by oncology societies [10–12]. Changes in the treatments prescribed were also reported [13].

Improving cancer care was already on the international health agenda before this pandemic, namely in the 2030 Agenda for Sustainable Development adopted in 2015 at the United Nations Sustainable Development Summit [14], in the Resolution 'Cancer prevention and control in the context of an integrated approach' approved in 2017 by the World Health Assembly [15]. At the same time, systematic efforts to capture the

outcomes of cancer care globally are in place such as the CONCORD study [16, 17] (via cancer registries), OECD reports on cancer care as part of its Health at a Glance series [3] and several European Union (joint) actions [18]. During the COVID-19 pandemic, efforts continued to be pursued to improve prevention, diagnostics, treatment, and the quality of life of cancer patients and to monitor and report upon inequalities, such as the 'Europe's Beating Cancer Plan' [19], the European Cancer Inequalities Registry [20] and the launch of the European Commission's Knowledge Centre on Cancer [21]. These efforts are necessary to address the backlog this pandemic is creating [22–24].

Healthcare performance measurement is key to evaluate and improve healthcare systems, informing policy decisions and quality of care improvement initiatives [25]. Healthcare quality indicators are 'quantitative measures that provide information about the effectiveness, safety and/or people-centeredness of care' [26]. The development of performance indicators following fit for purpose and use considerations [27] underpinned by robust health information systems is key to monitoring changes in care quality during crises, allowing for comparisons within and between countries' health systems [28]. A common conceptual framework for health system performance measurement developed by the OECD aims to help member countries to prioritize areas to improve quality of care [29]. Indicators monitoring cancer patients' outcomes, like 5-year survival, are already routinely used in OECD countries [3]. However, although improving outcomes is the ultimate aim, for guiding health care delivery systems towards that goal, process and cancer-pathway based information is essential. Therefore, indicators should ideally inform on the whole pathway of care, which is a reality in a few OECD countries [30]. Additionally, only a small percentage of scientific literature assessed in a previous review focused on hospital performance indicators [31] considered a clinical pathway perspective.

In this study, we focus on the cancer care pathway in OECD countries, which share a common conceptual framework for health system performance measurement [29]. Additionally, considering that the literature published on the consequences of the pandemic on cancer care is vast, assessing its impact requires a structured approach. Thus, this study aims to: 1) provide a structured summary of cancer care performance indicators used in the literature, regarding various cancers, across the

care pathway, from early detection to outcomes, within OECD member countries; 2) assess the main trends of the changes in the quality of cancer care during the first wave of the COVID-19 pandemic, from January to June 2020, in these countries.

Methods

We conducted a scoping review, following Arksey and O'Malley methodological framework [32], further developed by Levac et al [33]. Given the heterogeneous methods across countries for data collection on health care system performance and their translation to indicators [28, 34], a scoping review methodology allows to map large sums and heterogeneity of literature available [33, 35, 36], namely cancer care performance indicators. It also enables the reporting of emerging evidence [35], to summarize, and communicate findings [32], including trends revealed by indicators. The PRISMA extension for scoping reviews [37] was used for reporting (Additional file 1).

Eligibility criteria of studies

We considered the following inclusion criteria: 1) studies using empirical data on the use of health services in OECD countries, 2) studies that described health outcomes and/or performance indicators related to NCDs during the COVID-19 pandemic, 3) original journal articles using quantitative or qualitative methods (cohort studies, case-control, cross-sectional, case reports, systematic reviews, surveys, and meta-analyses). Studies were excluded if they did not provide empirical data on health services and NCDs, namely: 1) editorials and commentaries, 2) prediction models, 3) clinical case reports; 4) diseases management or health services organization guidelines, 5) studies about the impact on healthcare workers, patients diagnosed with COVID-19, children, or pregnant women; 6) studies primarily performed in non-OECD countries. No limitations were set regarding language or year of publication.

Data sources and search strategy

MEDLINE and Embase databases were selected to search for this study, given the large number of articles and their comprehensive coverage of the literature [38]. Pilot searches were conducted to identify a list of relevant search terms. An experienced medical information specialist was consulted to improve the search strategy, which was refined with discussion among co-authors. The comprehensive search included search terms grouped by key concepts (COVID-19, pandemic, non-communicable disease, chronic disease, performance indicator, healthcare quality, healthcare utilization, healthcare delivery and other closely related terms). The search was adapted to both databases and conducted by the information specialist on 17-03-2021. The full search strategy for Embase can be found in Additional file 2. Duplicates were removed using EndNote software. Additional articles of relevance were added by hand-searching the reference lists of the included studies.

Study selection

Title and abstract screening was performed independently by two researchers (ASC, OBF) using Rayyan [39]. Studies considered relevant were exported to a spreadsheet to support full-text screening. For this study, only articles related to cancer care were analysed. Full-text screening was performed independently by two researchers (ASC, MdL). The reason for the exclusion of articles was recorded at this point, and both researchers agreed on the excluded studies. In case of doubt, the other co-authors were consulted.

Data collection

Data extracted were collated in a spreadsheet (Additional file 3) piloted on 15 studies. Before extracting data from all studies, two researchers (ASC, MdL) compared data collected from a sample of 10 selected articles to enhance data extraction consistency among researchers. Then, data was charted independently by ASC and MdL.

Extracted data included information on generic and methodological aspects of the article (e.g., authors, title, setting) and information about the indicators collected (e.g., indicator title and data inclusion/exclusion considerations). We identified the trend reported in the articles (increase/decrease/stable) for every indicator, if any.

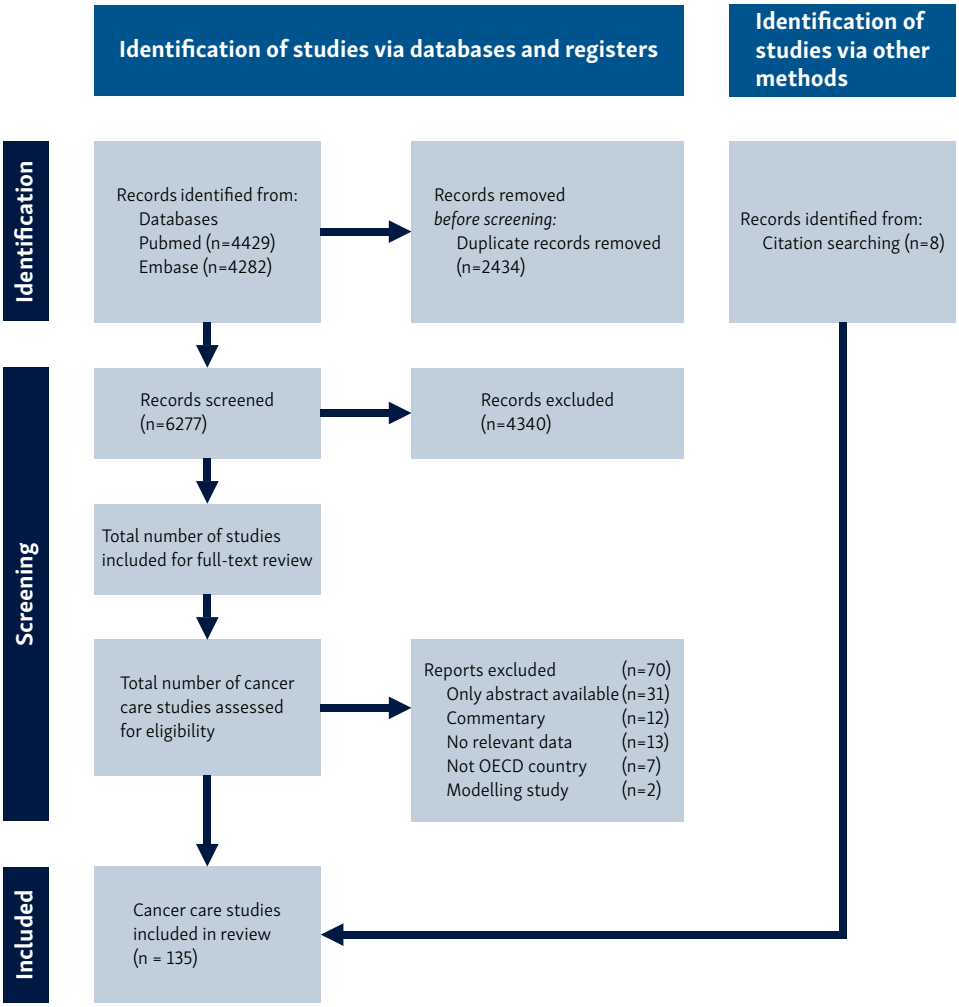
Synthesis of results

The indicators collected that measured similar clinical procedures, identical patients' characteristics, or similar outcomes were grouped together. Since there was some heterogeneity in indicators' titles referring to identical measures, a common indicator title was given by the authors to each category of similar indicators (e.g.: 'Number of screening procedures'), using the language from the studies as much as possible. Then, these indicators' categories were organized and reported according to the different phases of the cancer care pathway, namely: early detection, diagnosis, treatment, and outcomes. Quantitative indicators' trends were collated, and the percentage of indicators reporting each trend (increase/decrease/stable) computed for each category. This evidence is presented in the text of this study, in a table and in a diagram informing about each phase of the cancer care pathway. Qualitative information extracted from surveys is presented in the text, and it was not considered to compute trends. In the category 'changes in treatment' quantitative indicators and qualitative information were grouped and categorized according to clinical reasoning to present an overview of the modifications in cancer treatment reported.

Results

Database searches retrieved 6277 articles. Of these articles, 838 met the inclusion criteria, from which 197 articles on cancer care were identified. Eight records were identified via hand-searching. After full-text screening, 135 articles were included in this study (Fig.1).

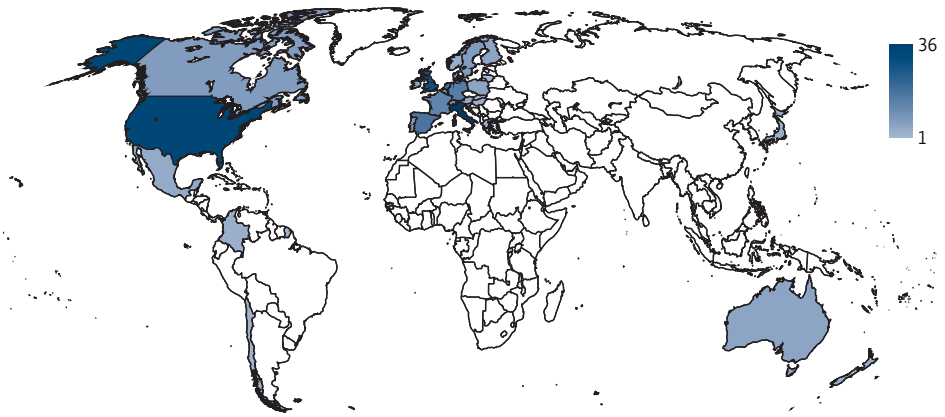
Figure 1 PRISMA flow diagram of the literature search performed on 17th March, 2021. [From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: *http://www.prisma-statement.org/]*



General characteristics of the included articles

In total, 135 studies were included, reporting on 94 countries (Additional file 4). Of these studies, 26 (19%) provided information on multiple countries, from which

Figure 2 OECD countries reported on, color-graded according to the number of papers (n=122; 90% of included articles).



14 (10%) specified all the countries included. Of those, 8 (6%) included non-OECD countries. Most of the studies including more than one country were surveys (n=23; 89%). The most frequent countries reported on were Italy (n=36; 29%), US (n=32; 26%) and UK (n=27; 22%) (Fig. 2). Most articles used a retrospective cohort design (n=82; 61%), followed by surveys (n=44; 33%). Surveys were often directed to health professionals (n=37/44, 84%) and to patients (n=6/44, 14%) to a lesser extent. Other study designs that were applied included prospective cohorts (n=5), observational retrospective cohorts (n=3), and a combination of prospective and retrospective cohorts (n=1). Studies reported indicators' trends during the first phase of the COVID-19 pandemic (from January to June 2020) and, in some cases, after the (in many countries implemented) lockdown period (from May to October 2020). The magnitude of each indicator in 2020 was compared with its magnitude in the same period of 2019 (n=51; 38%), to a period immediately before (n=33; 24%) or to the average of the same period in previous years (ranging from 2017 to 2019) (n=26; 19%).

Cancer Care Indicators

A total of 1013 quantitative indicators from 91 articles were retrieved and grouped into categories (Table 3).

Table 3 Number of quantitative indicators retrieved, grouped in categories according to the cancer care pathway (n=1013)

	Number of indicators with quantitative information[a]		Number of studies
	n	%	n
Early detection	**59**	**6%**	
Number of screening procedures	33		13
Early diagnosis and predisposition exams	12		7
Screening detection rates	14		5
Diagnosis and staging	**418**	**41%**	
Delay in access to diagnostic procedures	9		2
Clinical severity at diagnosis	14		7
Changes in cancer staging	110		21
Proportion of urgent/emergent referrals and procedures	25		5
Number of diagnostic, surveillance, and staging exams/ procedures	90		17
Number of cancer diagnoses	157		40
Cancer detection rate	13		5
Treatment	**497**	**49%**	
Delay in treatment	42		18
Number of treatments			
· Surgeries & loco-regional therapies	104		30
· Radiotherapy	57		8
· Systemic therapy	71		12
Number of referrals / first encounters	41		9
Outpatient volume	47		14
Changes in treatment	119		21
Number of visits and hospital admissions	12		4
Telemedicine utilization	4		4
Outcomes	**39**	**4%**	
Surgical and procedures outcome measures	15		8
Mortality	24		4
	1013	100%	

a A total of 338 indicators were not included in the analysis since they were too specific to be grouped into the defined categories.

The first stage of the care pathway looks at early detection. Regarding the 'number of screening and other early diagnosis procedures', a total of 33 indicators from 13 articles [40–52] have been reported. Most indicators on the number of screening procedures signaled a decreasing trend (n=30; 91%), namely in US, UK, and Italy. One international survey answered by physicians [53] (including Italy, Iran, Spain, UK, US, China, Denmark, Sweden, and Switzerland) reported the suspension of breast screening programs in all countries, except 2. Only one American paper [45] addressed cervical cancer screening, showing a decrease in number of screenings during stay-at-home order, compared with 2019. Three articles [42, 46, 49] addressed colorectal cancer screening, from US, UK and Spain and have also revealed a reduction when compared with previous year.

Seven papers [40, 41, 43–45, 47, 49] (12 indicators) reported on 'early diagnosis and predisposition exams', namely: screening visit for prostate cancer (US), gBRCA testing (Italy), human papillomavirus tests rate, low-dose computed tomography and prostate-specific antigen measurement (all from the US). All these indicators have shown a decreasing trend in the number of diagnostic procedures.

'Screening detection rates' were reported by 14 indicators from 5 articles [22, 43, 44, 54, 55], from the US and Italy. Most of the indicators (n=9; 75%) showed an increase in screening detection rates. These included an increase in high-risk adenomas and colorectal cancer detection rates during the lockdown period, along with a decrease in low-risk adenoma detection rates in one Italian study [54].

The next stage of the care pathway focuses on diagnosis and staging. The 'number of diagnostic, surveillance and staging procedures' was reported in 17 articles [48, 50–52, 55–67] (from the UK, Italy, US, France, Australia, the Netherlands, Turkey, Ireland, and Slovenia), comprising a total of 90 indicators. Most of those indicators (n=58; 64%) showed a decreasing trend in the number of procedures, namely cystoscopy, diagnostic mammograms, breast cancer wire-guided biopsy, gastroscopy, colonoscopy, computed tomography (CT), magnetic resonance imaging (MRI), and endoscopic retrograde cholangiopancreatography.

A total of 147 indicators from 35 articles [9, 42, 46, 54, 55, 59, 61, 62, 66–90] reported on the 'number of cancer diagnosis'. Most of these indicators (n=130; 89%)

signalled a decrease in the number of cancer diagnoses. Data came from registries in the Netherlands, Denmark, Germany, and Italy, cytology laboratories, tumor boards numbers, and administrative sources. One international survey to laboratories from 23 countries [73] showed an absolute reduction in the number of cytological samples regarding all anatomic sites.

Five studies [44, 62, 74, 82, 89] (from the US, UK, France, and Italy) addressed the number of cancer diagnoses after the lockdown period (10 indicators). Three of these indicators (30%) showed a higher number of diagnoses, when compared with the period of lockdown.

Five surveys [91–95] reported 'delays concerning different aspects of cancer diagnostics'. One international survey [92] focusing on colorectal cancer care, with professionals from 84 countries, reported delays in radiologic exams and endoscopic procedures. Other surveys mentioned limited access to hospital facilities (Italy) [96], delays in tissue diagnosis (UK) [95], delays in diagnostics of patients with neuroendocrine tumors (Germany, Austria, Switzerland) [94], and genetic testing or counseling (US) [93]. The other two articles [50, 97] addressed the delays in access to diagnostics, comprising a total of 9 quantitative indicators, from which 8 (89%) signalled an increase in the waiting time to diagnostic procedures.

The 'cancer detection rate in referrals and diagnostic exams' was assessed in 5 articles, from UK [66, 98], Italy [55], Ireland [50], and one international survey of 23 laboratories worldwide [73]. The 13 indicators collected signalled an increasing trend in cancer detection rate in 9 indicators (69%). The survey reported an increase of 5,5% in the malignancy rate in nongynecological samples, when compared with the corresponding period in 2019.

Twenty-five indicators from 5 studies [46, 64, 66, 99, 100] (from Spain, UK, Australia, and Croatia) reported on the proportion of 'urgent/emergent referrals and procedures'. Most of these (n=14; 56%) showed an increase in the proportion of urgent procedures (endoscopy and colonoscopies), diagnosis in emergency setting or operations that followed an emergency admission.

The indicators that reported on 'changes in cancer staging' were grouped in 3 different categories: general staging indicators (14 indicators from 8 articles [82, 84,

88, 101–105]), proportion of earliest-stage cancers (35 indicators from 9 articles [48, 78, 88, 106–111]), and proportion of advanced-stage cancers (61 indicators from 17 articles [46, 64, 70, 73, 84, 86, 94, 99, 100, 102–109]).

Most of the general staging indicators (n=9; 64%) showed stability in cancer stages distribution at diagnosis, when comparing the pre- and post-lockdown periods (data from Italy, US, UK, France, US, and Portugal). These indicators included stages of gynecological cancer, breast cancer, lung cancer, and hepatocellular carcinoma. With respect to the proportion of earliest stage cancers, most of the indicators (n=9; 63%) showed a lower proportion of these cancers when compared with pre-pandemic period, 9 (26%) signalled a stable trend, and 4 (11%) showed an increasing trend. From the indicators reporting on the proportion of advanced-stage cancers, 43 (70%) showed an increasing trend in this proportion after the beginning of the pandemic, 14 (23%) signalled a stable proportion, and 4 (7%) reported a decreasing trend.

Fourteen indicators from 7 articles [48, 54, 64, 76, 104, 107, 112] evaluated the 'clinical severity at diagnosis', which included symptoms, scores, and biomarkers. The majority (n=8 indicators, 57%) showed patients presenting in a more severe clinical condition than before the pandemic, namely in US (endometrial cancer), Portugal (hepatocellular carcinoma), Italy, and Turkey (colorectal cancer).

The following stage of the care pathway reported on is cancer treatment. A total of 41 indicators (from 9 articles [42, 67, 72, 79, 98, 103, 110, 113, 114]) reported on the 'number of cancer patients' referrals'. Most of the indicators (37, 90%) signalled a decrease in the number of first encounters for oncological examination, namely in Slovenia, UK, US, France, Spain, and the Netherlands. Four surveys (from UK [95], US, Italy [115] and one international study [116] reported a decrease in the number of new referrals.

A total of 47 indicators were identified from 14 articles [42, 49, 51, 59, 62, 67, 72, 97, 98, 100, 103, 113, 117, 118] regarding the outpatient volume of patients diagnosed with cancer. Of these indicators, 46 (93%) showed a decrease in the number of outpatient visits (in Korea, US, France, UK, Spain, Slovenia, and Italy). Thirteen surveys [13, 53, 77, 93, 94, 96, 115, 119–124] disclosed information concerning outpatient care. Ten were answered by oncologists and 3 were answered by patients. The latter studies

reported consequences on treatment or follow-up (Netherlands) [121], namely treatment adjustment, postponement, delay, or discontinuation; delay in routine or follow-up clinic appointment (US) [93] and postponements of physician appointments (Germany). A substantial percentage of physicians reported cancellation or deferral of follow-up visits.

Regarding the 'volume of cancer treatment', indicators regarding the 3 main therapeutic components were reported: surgeries and loco-regional therapies, radiotherapy, and systemic therapy.

Concerning surgeries and loco-regional therapies, 104 indicators were identified from 30 articles [49, 55–58, 62, 69, 72, 72, 82, 88, 97, 99–101, 104–106, 108–110, 118, 125–132]. Of those, 82 indicators (79%) showed a reduction in the number of treatment procedures, namely in Italy, France, Germany, Ireland, Netherlands, Spain, Turkey, UK, US, Australia, and in 1 international study. Nineteen articles were surveys directed to physicians [53, 65, 77, 85, 91, 92, 95, 97, 115, 122, 133–141], out of which 8 were international. All have shown significant reductions in surgical activity regarding different cancers.

Regarding radiotherapy treatments, 57 indicators from 8 articles [62, 97, 99, 128, 142–145] were identified. Most of these indicators signalled a reduction of the number of treatments (n=41,72%), namely in UK, US, and Canada. Five international surveys to physicians [119, 121, 133, 139, 144] also reported that this type of cancer therapy was affected.

With respect to systemic anticancer therapy, 43 indicators were identified from 9 articles [49, 60, 62, 79, 103, 113, 118, 146, 147], concerning Italy, France, UK, Spain, and the US. The majority (n=40,93%) showed a decrease in requests for initial treatment and in the number of chemotherapy administrations. Six surveys [65, 116, 119, 122, 141, 148] reported on this treatment modality. One study including 54 countries [53] showed that 88,2% of centers reported a reduction in their usual level of care, while 9,83% of those reported lack of access to medications. A European study with 29 countries [116] reported that 6% of centers revealed shortages of drugs.

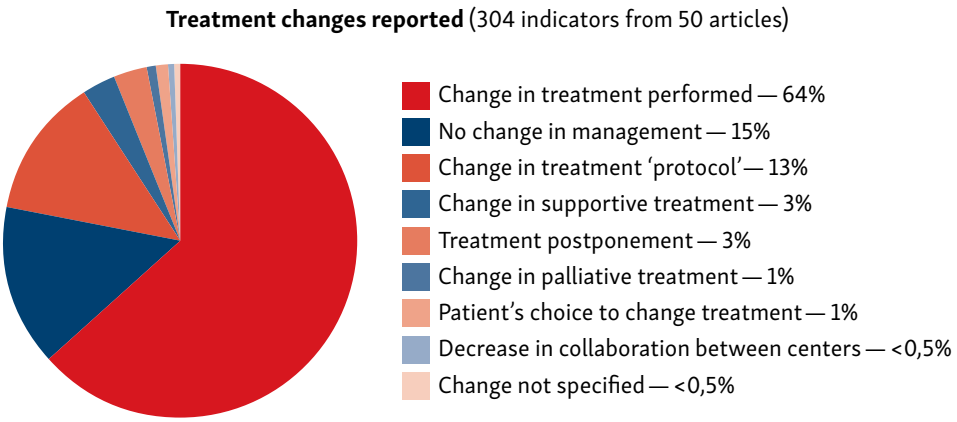
A total of 28 indicators (from 3 articles) [62, 146, 147] reported on systemic anticancer therapy after lockdown ending (from May to October 2020). Of these indica-

tors, 14 (50%) reported an increase in the number of treatments (in UK and France).

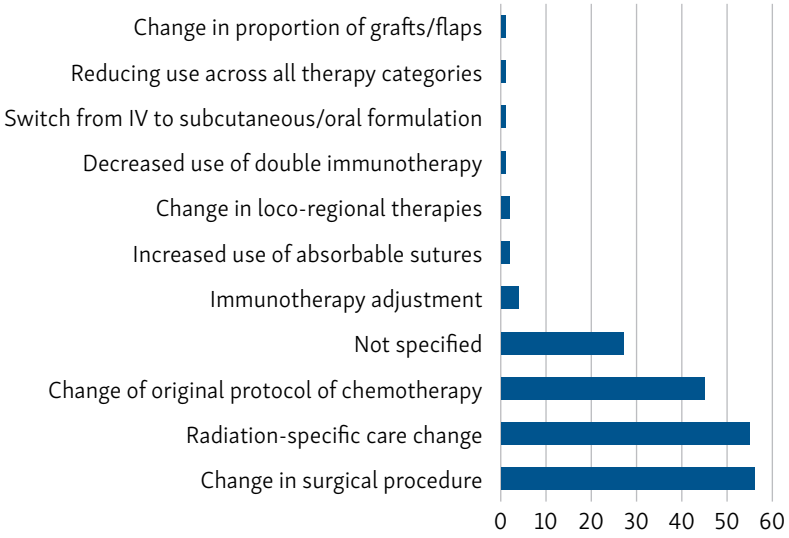
Regarding 'delay in treatment', a total of 42 indicators from 18 articles [46, 59, 79, 84, 88, 96, 98, 99, 103, 104, 106, 108, 145, 149–153] were identified. Of those, 18 (43%) reported an increasing trend in waiting time to treatment, namely in France, Portugal, Canada, US, and Italy. Sixteen indicators (38%) signalled stable waiting times and 8 (19%) a reduction in time to treatment. Twenty-one surveys [65, 77, 91–93, 95, 115, 116, 121, 124, 139–141, 148, 154–160], 2 studies using administrative data and surveys [128, 145] and 1 prospective study [124] reported on delays in cancer treatment. From those, eleven articles were international studies. All have reported delays or interruptions on different aspects of cancer treatment, namely in Canada, France, Germany, Italy, Netherlands, US, and UK.

Fifty articles reported on 'changes in treatment', resulting in 304 indicators collated. A total of 106 indicators with quantitative information (from 19 articles [57, 59, 72, 82, 84, 97, 103–105, 108, 109, 113, 125, 128, 142, 144, 145, 149, 161]) were collected from administrative data and 13 indicators from registry data [141, 145]. A total of 185 indicators were survey-base information [13, 53, 65, 77, 85, 92, 95, 120–123, 133, 137, 148, 152, 155–158, 162–166]. Changes in treatment including all the indicators are summarized in Fig. 3.

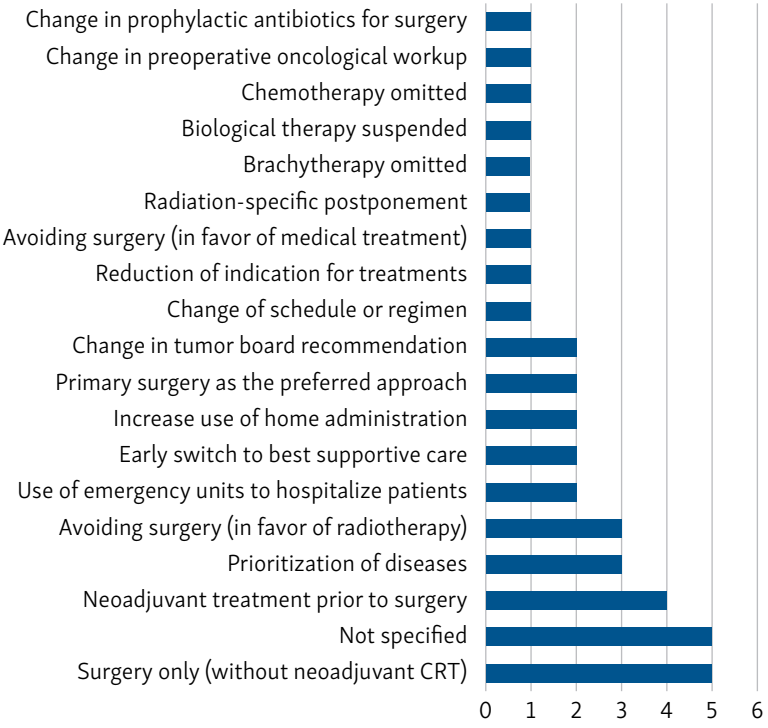
Figure 3 Treatment changes reported in the articles (n= 304 indicators from 50 articles).
IV: intravenous; CRT: chemotherapy.



Change in treatment performed (n=195 indicators)



Change in treatment 'protocol' (n=40)



Modifications in treatment were reported in 195 (64%) of indicators. The most frequent changes in treatment were in surgical procedures (n=56 indicators, 29%), radiation-specific changes (n=55 indicators, 28%) and change of original protocol of chemotherapy (n=45 indicators, 23%). Modifications documented in surgical procedures were a decrease in use of laparoscopic surgery together with an increase of open or radical surgery, an increase in stoma formation rate, and a decrease of immediate breast reconstruction rate in breast cancer patients. The radiation-specific care variations identified were radiotherapy hypofractionation, treatment disruptions, increase in short-course treatments, and physicians being less likely to prescribe adjuvant radiotherapy. Treatment 'protocol' changes were reported by 40 indicators. The most frequent change was performing surgery without neoadjuvant chemotherapy (Fig. 3).

A total of 12 indicators from 4 articles [49, 62, 100, 106] reported on the 'number of visits and admissions' of cancer patients to the hospital. Of these indicators, 10 (83%) signalled a decreasing trend. Two international surveys [62, 92] to health professionals have also disclosed a decrease in the number of oncology unit hospitalizations.

Regarding the 'utilization of telemedicine', 4 indicators were identified from 4 articles [75, 93, 110, 159]. Fourteen surveys [13, 65, 77, 116, 119–122, 141, 148, 152, 156, 159, 164] provided information on telemedicine use, from which ten were international studies. Three were patients' surveys. All the survey-based information and quantitative indicators reported an increase in the use of telehealth to provide cancer care. One article [167] assessed patient and providers' satisfaction regarding the use of telemedicine in rehabilitation of cancer patients. The proportion of patients that provided good feedback ranged from 63% to 84%, and the physicians' perspective was also satisfactory, ranging from 66% to 83% of physicians reporting positive feedback. Four international surveys [122, 148, 152, 157] addressed the implementation of virtual multidisciplinary tumor boards, showing a marked increase in the use of web-based platforms.

Two main outcomes were addressed in the included articles: 'procedures and surgical outcome measures' and 'mortality'. Fifteen indicators from 8 articles [100,

104–110] conveyed information regarding procedures' outcomes. From these indicators, 11 (73%) showed similar complication rates. One Italian survey [134] has also documented a stable number of complications after esophageal resections. With respect to mortality in cancer patients, 24 indicators were identified from 4 articles. Twenty of these indicators resulted from one Portuguese study [112], the other 3 indicators showed a stable postoperative death rate in patients with head and neck cancer (France) [109], and a stable in-hospital mortality rate for orthopedic tumors at the traumatology department (Germany) [130]. One Turkish study [107] documented increased mortality in occlusive colorectal cancers patients.

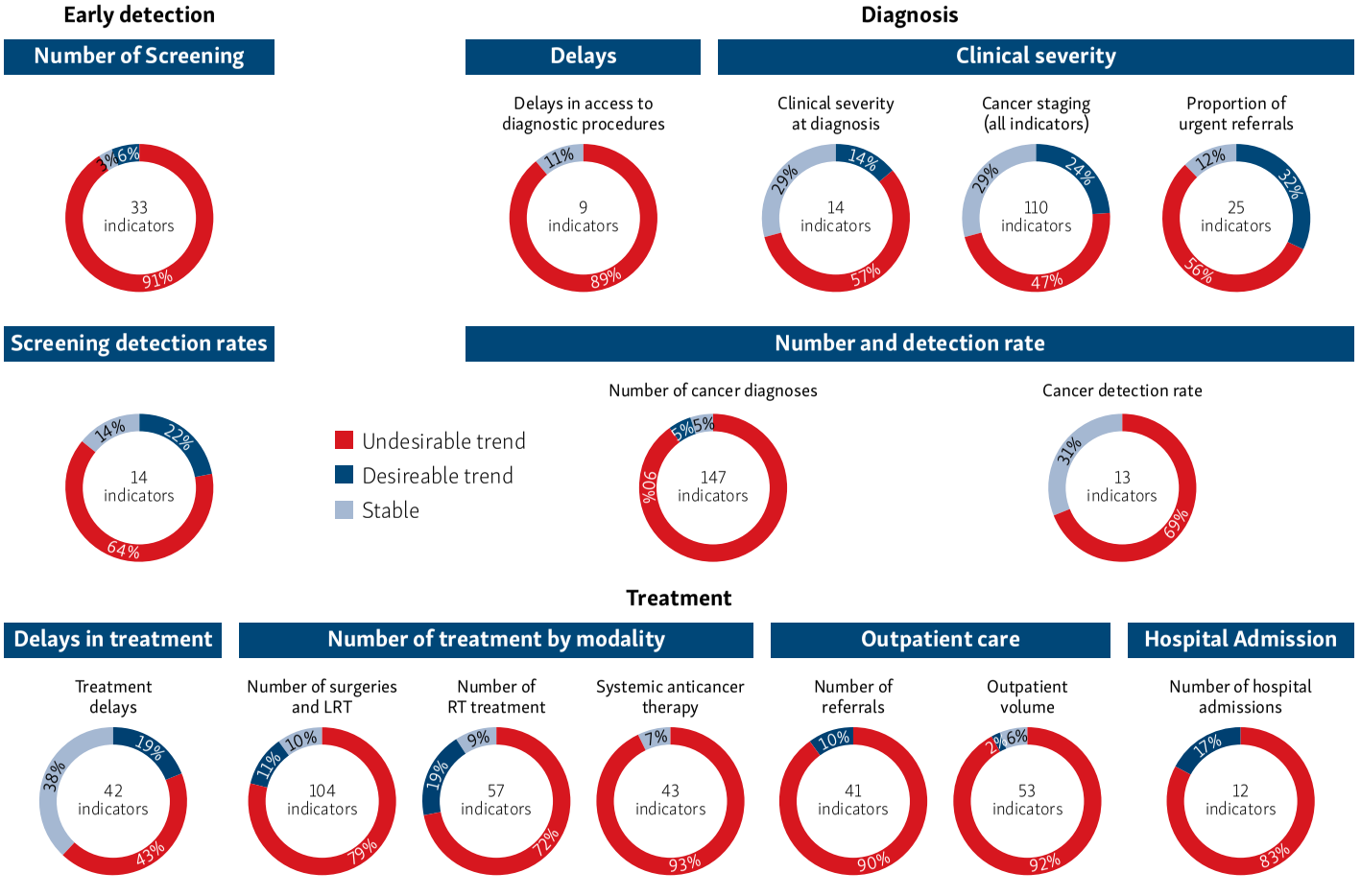
The trends of the indicators comparing the COVID-19 period with a previous time period are summarized in Fig. 4.

Discussion

In this study, we performed a scoping review to identify the indicators used in the literature to measure the impact of the COVID-19 pandemic on the cancer care pathway from January to June 2020, and the changes in the quality of care signalled by these indicators in OECD countries. We identified 135 articles, with a total of 1013 quantitative indicators collected, reporting on 94 countries. Changes in the quality of care are spread across the care pathway. This performance information suggests capacity constraints, it shows quick adaptations and innovations in cancer management. If collected in near-real-time and processed into actionable information, it would allow monitoring changes in care during the current pandemic and in future events more efficiently, supporting timely and adequate responses.

Our findings signal a major impact on the diagnosis of cancer: a decreasing trend in the number of screenings, diagnostic procedures, and, consequently, in the number of cancer diagnoses, resulting in increasing screening detection rates, and delays in diagnostic care. Indeed, in a recent OECD report, reductions in screening rates were reported by 15 out of 16 OECD countries that had data available and a decline in the number of new diagnoses was reported in the 12 countries with information

Figure 4 Cancer care indicators' trends (%) comparing the COVID-19 period (Jan-Jun 2020) with a previous one.



available [168]. The cancelation of elective procedures [22], and patients' avoidance of going to healthcare facilities [169, 170] were other contributing factors. Previous studies documented the decreasing number of primary care consultations for a wide range of clinical conditions [171, 172] and a relevant fall in new cancer diagnoses in primary care [83].

Trends regarding cancer staging at diagnosis portray a mixed picture. The reduction in the number of elective diagnostic procedures could explain stage-shifts in cancer presentation. We also found an increasing trend in the proportion of urgent/emergent cancer referrals and in the proportion of emergent procedures, as well as evidence of patients presenting with a more severe clinical condition to the hospital than before the pandemic. These trends suggest patients with advanced-stage cancers continued to seek care. It could also signal those patients waited longer before receiving care, with potential deleterious outcomes. These results highlight the need to closely monitor the impact of the COVID-19 pandemic on shifts in cancer staging at diagnosis and the relevance of collecting this data systematically, which is a reality only in a few OECD countries, such as the Netherlands and Slovenia [168].

With respect to treatment, about 40% of the indicators reporting on waiting times to treatment signalled an increasing trend, we observe a decreasing trend in the volume of the three modalities of cancer treatment, and a large number and diversity of information reporting on treatment changes. These results reveal the remarkable influence of the pandemic on patterns of cancer care in the first half of 2020. These changes result from postponements of care decided by physicians to decrease patients' exposure to hospitals [120], switch to audio- or video-consultations, and deferrals and treatment modifications guided by updated recommendations by many medical societies [11, 12], which were used by some OECD countries at a national level [168]. Almost two-thirds of the indicators reported changes in treatment, which shows that providers have quickly adapted their care practices, which strengthens the argument for the need for monitoring closely these changes. The relevant number of indicators collected from surveys, mostly conducted by international societies and networks of providers, highlight how medical societies and countries were unable to obtain these data using current health information

systems and data structures. While some of these care modifications could be learning opportunities for the future, this information should be standardised, transparent, and timely, allowing to appraise the modifications in care provided during crises regarding access, quality, and outcomes.

The increase in telemedicine utilization we report is a generalized trend across a range of medical specialties [3] and it constitutes a hallmark of the innovation triggered by this pandemic. Albeit the positive feedback by physicians and patients we report, telehealth risks to increase inequalities in access to care [173, 174].

Short-term oncological outcomes were addressed by a few indicators and are reported as being stable, which is in line with a recent international cohort study including 61 countries and 15 tumor types [22]. However, deferred care will most likely lead to worse long-term outcomes, which needs to be monitored. Attempts to quantify this impact were developed, for instance, by a British nation-wide modelling study where the authors estimated a total of 59 204–63 229 additional years of life lost attributed to four major cancers [175], compared with pre-pandemic data.

Previous works addressed the impact of the COVID-19 pandemic on regional or national settings [4, 57], on specific cancers [4, 5, 176], specific stages of the care pathway [61], or treatment modalities [22]. This scoping review provides a summary of cancer care performance indicators, concerning various diseases, from early detection to the treatment phase of the care pathway, within OECD countries. Additionally, we report changes in the quality of cancer care based on indicators' trends, from January to June 2020, which constitutes an innovative approach to assess changes in healthcare performance.

Our study has some limitations. The heterogeneity of study designs, populations, diseases, indicators, indicators' definitions and distribution of studies per country do not allow the application of a meta-analysis approach to quantify the real impact of the pandemic on cancer care and the generalization of these trends to all included countries. Furthermore, the time needed to collect, organize, and synthesize a relevant number of indicators in a meaningful way to inform decision-making explains why this study reports on the first semester of 2020. Nevertheless, this study presents a comprehensive overview of the cancer care pathway and the modifications and

adaptations that occurred during this period in a broad range of countries. The indicators we collated could already comprise useful tools to assess the health systems' response and changes in the quality of care after this period.

The COVID-19 pandemic keeps evolving until the present time and postponing of care was reported in some countries by the end of 2021 and the beginning of 2022 [177, 178], which means that this impact is adding up. Figures concerning new COVID-19 cases, mortality, and vaccination coverage, are presented daily to the public since the beginning of 2020. Additional and considerable efforts are needed to expose the effects caused by this pandemic in non-COVID-19 care, and some of the indicators we present could be useful to convey that message. Care inequalities could have been exacerbated during this pandemic, which also needs to be further studied regarding cancer care.

As new waves keep evolving, it is crucial to monitor performance indicators, such as shifts in cancer staging or worsening of outcomes. Also, the link between structure, process, and (short- and long-term) outcome indicators should be undertaken to allow an accurate and timely evaluation of the changes in the care provided during crises and in regular times. Tools like the 'Time to Act Data Navigator' [179] developed by the European Cancer Organization and the 'Global Cancer Observatory' [180] signal the ambition to address this lack of standardised and regular collection of data and indicators. Within the scope of Europe's Beating Cancer Plan, the European Cancer Inequalities Registry [20] aims to monitor inequalities across Europe, by providing reliable data on cancer prevention and care.

Conclusion

This scoping review provides a structured summary of performance indicators used in the literature to assess the cancer care pathway from January 2020 to June 2020, and the changes in the quality of care signalled by these indicators in OECD countries. This study shows health systems have struggled to ensure the continuity of care to cancer patients. It also highlights adaptations and innovations in cancer management,

as well as the importance of monitoring these changes closely, notably during crises. These performance measures could inform on the bottlenecks of the cancer care pathway, as well as moments for intervention during the evolving pandemic and in future crises. Furthermore, it could contribute to identifying disparities between and within countries and to better address the backlog this pandemic has created. To ensure the continuity of regular care pathways and enhance health systems' resilience and adaptability, further research and investment are necessary. It is critical to develop system-wide oriented intelligence and strengthen data infrastructures worldwide to constantly monitor changes in care provision. This would support timely and adequate health policy responses and improve the preparedness for future crises.

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Supplementary Material

Additional file 1—Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

Available at *https://tinyurl.com/Chapter3SM01*

Additional file 2—Search strategy

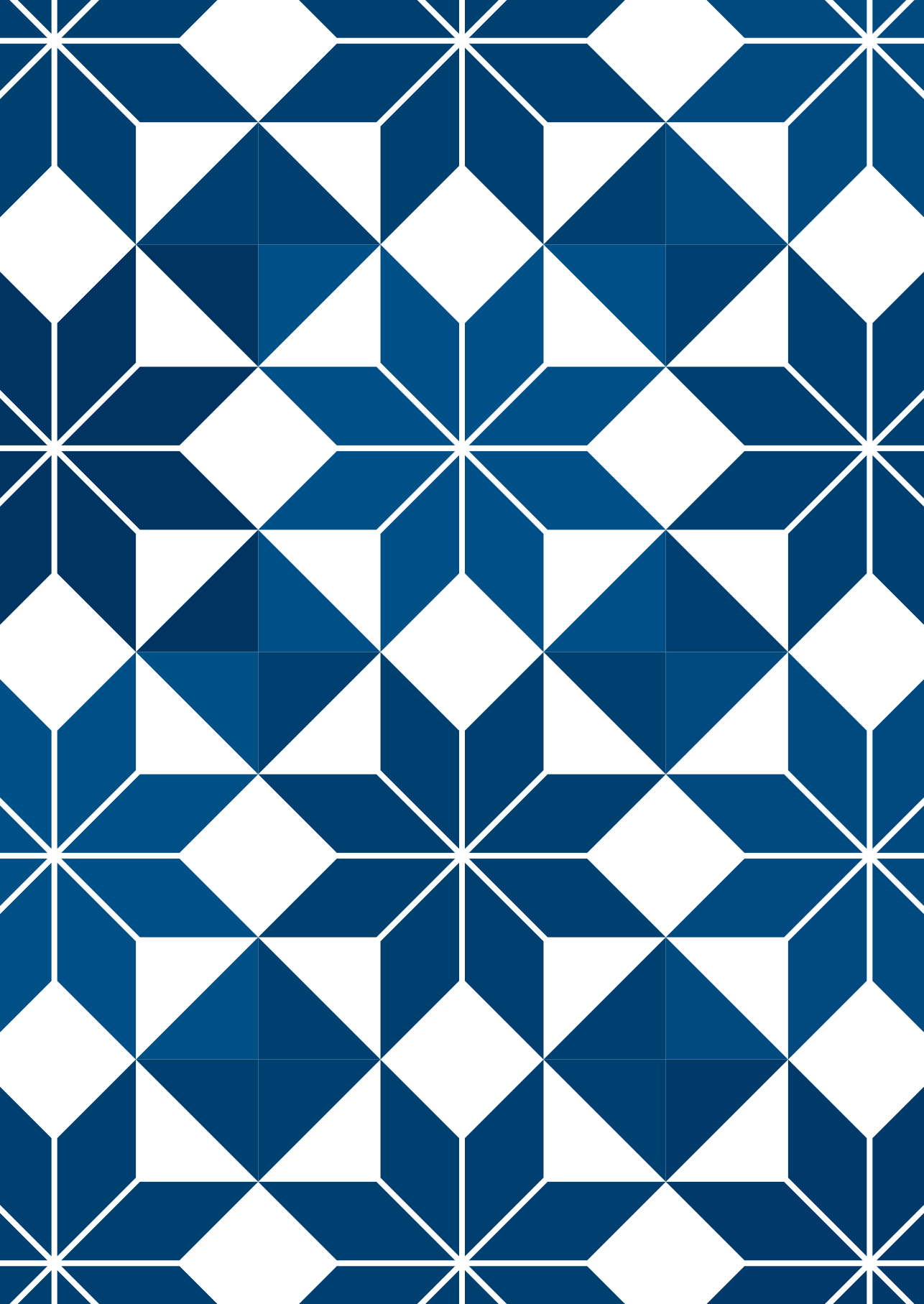
Available at *https://tinyurl.com/Chapter3SM02*

Additional file 3—Data Extraction Form

Available at *https://tinyurl.com/Chapter3SM03*

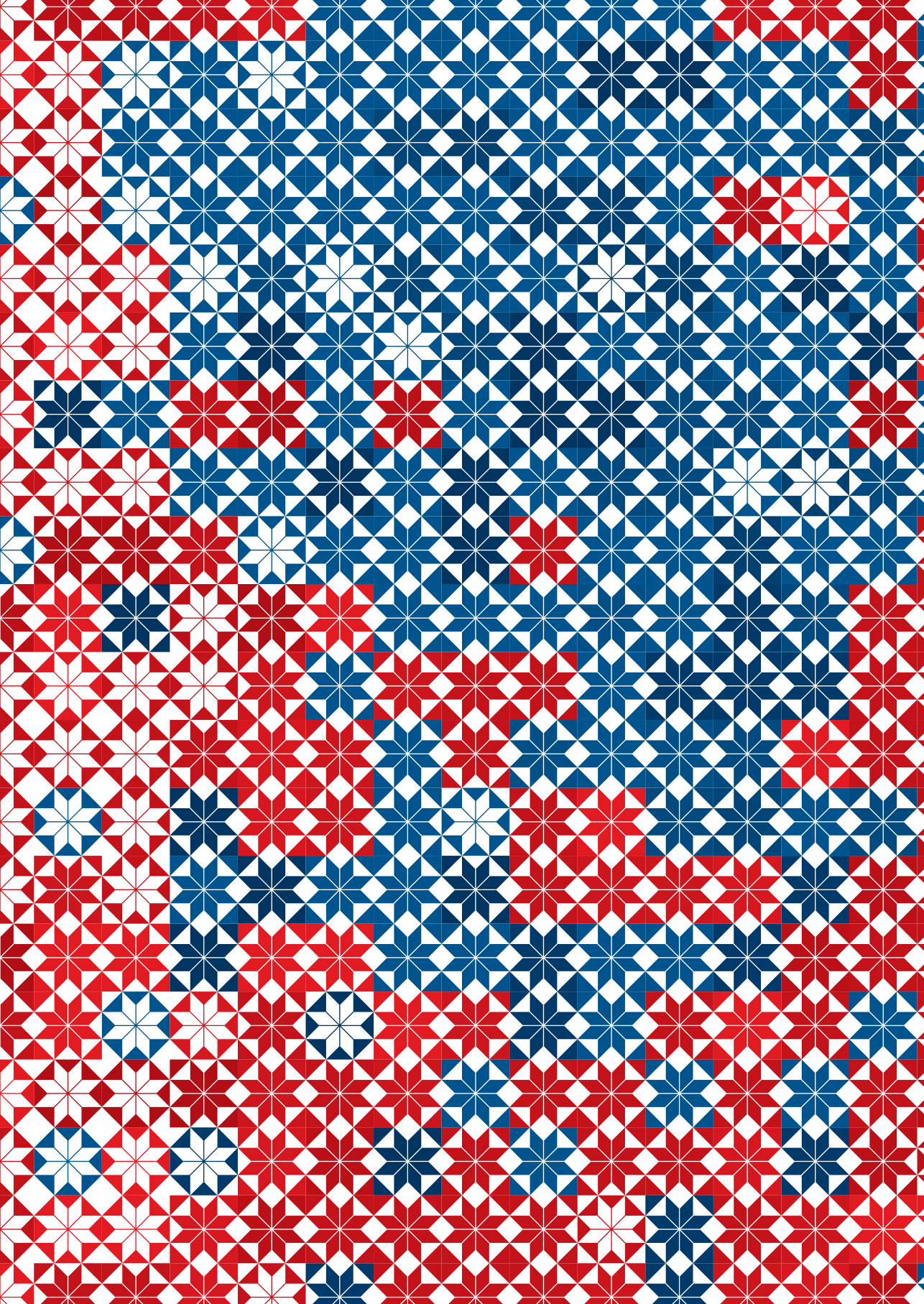
Additional file 4—Characteristics of the studies included in the review, and from which indicators were extracted and collated

Available at *https://tinyurl.com/Chapter3SM04*



Part II

Co-creation of tools to strengthen resilience and person-centredness in cardiovascular and cancer care pathways



Chapter 4

Development of a resilience assessment tool for cardiac care pathways in Europe: a mixed-methods study

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Abstract

Objectives: To develop a resilience assessment tool for cardiac care pathways in Europe, informed by stakeholder insights on the impact of COVID-19, emerging innovations, and recommendations to enhance resilience.

Design: Mixed-methods study comprising three phases: 1) survey among European cardiac care providers; 2) five multi-stakeholder focus groups; 3) participatory tool development. Quantitative data were analysed using descriptive statistics, and qualitative data were analysed thematically. Setting: The survey targeted cardiology professionals from the 27 EU Member States and Ukraine who worked during the COVID-19 pandemic. Focus group participants were purposefully sampled to represent clinical, organisational, and policy perspectives.

Participants: A total of 177 survey respondents and 40 informants in focus groups.

Results : Six key resilience dimensions of cardiac care pathways were identified: workforce, organisation of care delivery, governance and trust, communication and cooperation, medical devices and products, and data collection and use. Staff shortages and infrastructure capacity were key challenges during the pandemic. The most frequent measures were the reallocation of health staff (75%; n=133) and repurposing infrastructures (38%; n=32). Participants discussed the six resilience dimensions around a total of 17 sub-dimensions and 39 recommended actions to enhance resilience were identified. The resulting resilience assessment tool included four components: 1) mapping a context-specific cardiac care pathway; 2) stakeholder identification critical to participate in collective self-assessment; 3) a preparedness checklist generating a visual heat map; and 4) a resource toolkit.

Conclusions: The resilience assessment tool offers step-by-step guidance to strengthening cardiac care pathways across six key resilience dimensions, supported

by actionable recommendations. The tool enables the identification of context-specific vulnerabilities and improvement priorities, thereby supporting healthcare professionals and policymakers in enhancing preparedness and ensuring care continuity before, during, and after crises. Its implementation is currently being piloted in European hospitals to evaluate and refine its practical applicability.

Introduction

The COVID-19 pandemic caused major disruptions in cardiac healthcare delivery worldwide, notably reductions in the number of diagnoses of acute and chronic conditions, delays in seeking care and in access to treatment [1, 2, 3], resulting in higher mortality rates from heart diseases [3, 4, 5]. These consequences add to the large burden that cardiovascular diseases pose to health systems across Europe, as the leading cause of mortality [6] and a relevant cause of disability [7]. Furthermore, the pandemic had a significant impact on healthcare workers' mental health and aggravated workforce shortages [8].

The impact of the COVID-19 pandemic on cardiac care delivery and outcomes underscores the pressing need to improve care pathways' resilience to future systemic shocks, such as extreme climatic events, war conditions, cyberattacks, or financial crises, considering the constantly evolving political, economic, and climatic context worldwide. Health systems inputs generally include components such as the health workforce, physical infrastructure, and financial resources [9], while service delivery can be defined as 'the combination of inputs into a production process that takes place in a particular organizational setting and that leads to the delivery of a series of interventions' [10]. While the COVID-19 crisis has triggered swift adaptations and innovations in care delivery, there is a growing recognition that resilience should be embedded in systematic health system performance assessment and not only in crisis response [11, 12, 13].

Resilience can be defined as the 'institutions' and health actors' capacities to prepare for, recover from and absorb shocks, while maintaining core functions

and serving the ongoing and acute care needs of their communities' [14]. International reports have provided recommendations on how to improve health systems resilience [15, 16], notably focusing on establishing frameworks for coordination and decision-making prior to crises and anticipating the required capabilities and resources [15]. Nonetheless, there is a lack of systematic tools tailored to the cardiac care pathway, particularly taking stock of the lessons learned from the COVID-19 crisis.

The RESIL-Card Consortium was formed to address this critical gap (link to the project: *https://www.wecareabouthearts.org/resil-card/the-project/)*, consisting of four partners: We CARE Alliance (France), the Amsterdam UMC Health Care Systems and Services Research Group (Netherlands); the Catalan Health Service—CatSalut (Spain); and the Italian Society of Interventional Cardiology (GISE, Italy). It draws on the experiences of health system actors in the cardiology ecosystem, across clinical, organisational and policy levels, to learn how to strengthen cardiac care pathways' resilience and to foster cross-learning within and across organisations and countries.

This study aimed at developing a resilience assessment tool for European cardiac care pathways. The tool intends to provide a structured and adaptable approach for stakeholders in the cardiology ecosystem to assess their preparedness and enhance resilience within their contexts. The development of the tool was guided by three research questions, from the perspective of stakeholders in the cardiology ecosystem:

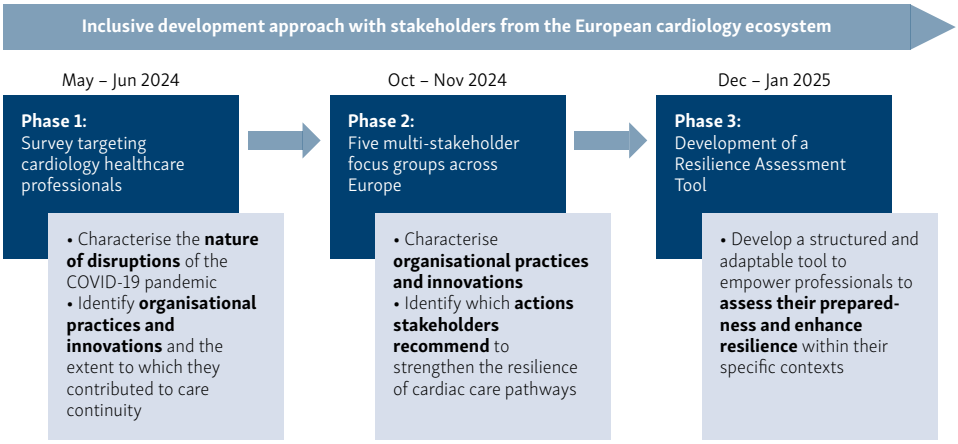
1. How did the COVID-19 pandemic disrupt cardiac care inputs and care delivery process?
2. What organisational practices and innovations emerged during the COVID-19 pandemic, and to what extent did they contribute to the continuity and quality of cardiac care?
3. What actions do stakeholders recommend to strengthen the resilience of cardiac care pathways for future health system shocks?

Methods

Study design and setting

We conducted an explanatory sequential mixed-methods study [17] comprising three phases: a survey followed by multi-stakeholder focus groups, which culminated in the co-development of a resilience assessment tool (Figure 1). This approach was conducted to obtain a comprehensive understanding of the COVID-19 pandemic experiences from a diversity of stakeholders and to develop a tool based on these experiences. This study adheres to the requirements of mixed-methods studies by Lee et al [18] (See Supplementary File 1).

Figure 1 Overview of the research phases to develop a resilience assessment tool for cardiac care pathways



First, a survey (Phase 1) was distributed to European cardiology healthcare professionals, aiming to identify and characterise the nature of the cardiac care disruptions caused by the COVID-19 pandemic, organisational practices and innovations. Second, informed by the survey's results, five focus groups (Phase 2) involving cardiac care stakeholders across European countries were conducted, to discuss the survey's results and complement where needed. Quantitative data guided the qualitative data

collection and was later integrated during the data analysis. The qualitative findings helped to interpret the quantitative results and provided additional insights. For example, survey findings identifying workforce shortages as a key disruption were used to shape focus group discussions on strategies for staff mobilisation, which in turn helped interpret and contextualise the survey results. Third, informed by Phases 1 and 2, a Resilience Assessment Tool for cardiac care pathways (Phase 3) was developed involving a broader team—the RESIL-Card Consortium—supported by a multi-stakeholder Advisory Board, including patient representatives.

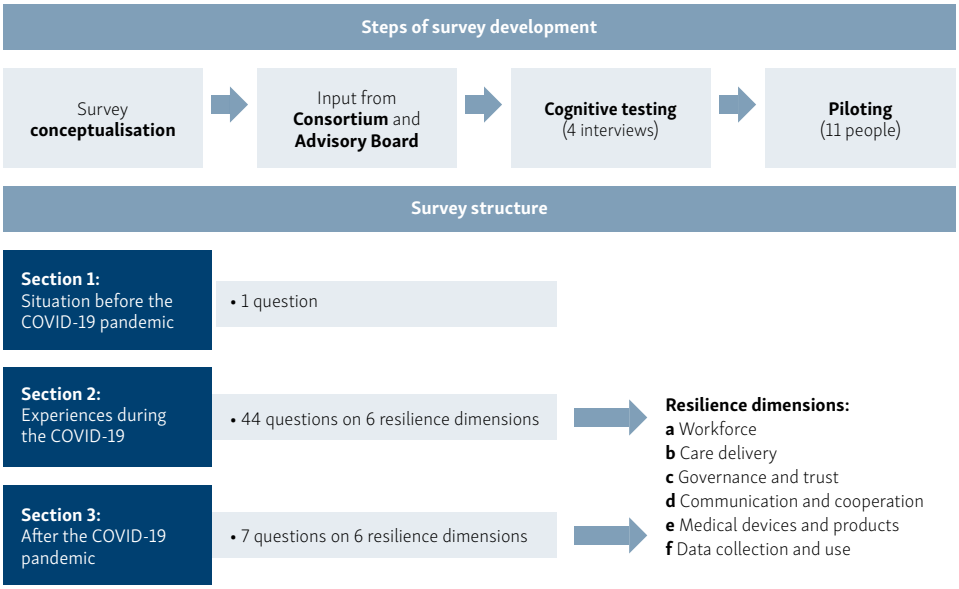
Data collection

Phase 1: Survey targeting cardiac care providers

A survey was developed, targeting healthcare professionals from the cardiology field from the 27 European Union (EU) Member States and Ukraine who had worked during the COVID-19 pandemic. It was informed by a scoping review published by some of the authors on the impact of the COVID-19 pandemic on cardiac care pathways [2] and on work from the We CARE Alliance on the impact and adaptations in care delivery during the pandemic [19] (Figure 2). In addition, relevant scientific literature and international reports on health systems resilience were consulted [15, 20] . The first iteration of the survey received input from four cardiologists from the RESIL-Card Consortium and from Advisory Board members. Following adjustments to cardiology-related terms and additional questions on gender, the questions were discussed in four face-to-face cognitive testing interviews (Supplementary File 2). The survey was piloted on the intended online platform (Microsoft Forms) with 11 people from the RESIL-Card Consortium, providing an estimation of the average time required to complete the survey (24 minutes).

The survey was structured in three sections: 1) situation before the COVID-19 pandemic, 2) experiences during the pandemic, and 3) lessons learned after the pandemic. The first section included one question to rate the most relevant challenges before the pandemic. The sections two and three were organised in six sub-sections,

Figure 2 Steps of the survey development and survey structure



which were identified from the literature as relevant dimensions to strengthen resilience: (a) workforce, (b) organisation of care delivery to cope with surge in demand, (c) governance and trust, (d) communication and cooperation, (e) medical devices and products, and (f) data collection and use. Supplementary File 3 presents the final version of the survey, which included 52 open- and closed-ended questions. The data collection comprised a period of six weeks, between 5th May and 16th June 2024. A link to the questionnaire was sent via email to 4338 European members of the 'PCR companions' community, an international network of interventional cardiologists and allied professionals. One reminder and reference to the survey were sent in two additional communications. Various partner organisations contributed to the dissemination of the questionnaire, including Societies of Cardiology from the targeted countries. Several initiatives were developed to raise awareness of the survey in national congresses and in social media (Supplementary File 4).

Phase 2: Multi-stakeholder focus groups

A total of five focus groups were organised, comprising between four and eleven participants. A purposeful sample of stakeholders was selected for the focus groups, representing three levels of health systems decision-making: micro (clinical), meso (organisational), and macro (policy). First, four focus groups convened, with participants from the countries most represented in the survey responses: two Italian focus groups with a regional focus—Campania and Lombardy regions—and two focus groups with a national focus—Spain and Netherlands. To discuss the transferability of these findings to other European countries, an international focus group was organised, with participants from Belgium, Greece, Poland, Portugal, Romania, and Sweden.

Each RESIL-Card Consortium partner was responsible for selecting and inviting participants by email in their native language (Supplementary File 5). The invitations for the international focus group aimed for a balanced geographical distribution across EU countries with participants proficient in English. Pre-reading materials in English were sent to all focus groups participants, including information about the project, the discussion questions, and presentation of the moderators.

The focus groups were conducted online and lasted on average 110 minutes. National and regional focus groups were held in the participants' native languages — Italian, Spanish, and Dutch — and moderated by each Consortium partner in their respective native languages. This allowed participants to express themselves without a language barrier. The international focus group was conducted in English. The meetings were recorded and transcribed verbatim with the participants' consent.

The focus group was structured in three parts. First, ASVC (first author) presented the project's aims and key findings from the survey. Second, the moderator guided the discussion around each of the six resilience dimensions addressed in the survey, focusing on two questions: 1) During the COVID-19 pandemic, what was your experience with practices and innovations implemented to ensure continuity of cardiac care? 2) What could be done differently in a future crisis to be more prepared and effective? Third, the conceptualisation of the resilience assessment tool

was discussed, focusing on two aspects: users and format. Finally, participants were asked about their interest to be involved in the piloting phase of the resilience tool.

Phase 3: Co-development of the resilience assessment tool

To conceptualise the tool, the authors considered the insights from the focus groups participants, as well as examples of resilience tools from the literature (such as [21, 22]). A participatory, multi-stakeholder approach was conducted, with ongoing contributions of the RESIL-Card Consortium and Advisory Board during various moments of consultation.

Data analysis

Survey data

Quantitative data [23] were analysed using descriptive statistics, conducted with Microsoft Excel. These data informed our research questions, namely: 1) the nature of the disruptions during the COVID-19 pandemic, 2) practices implemented, and 3) the prioritisation of actions to strengthen the resilience of cardiac care pathways. The qualitative data from the survey's open-ended questions was analysed using thematic analysis [24], through inductive coding.

These data informed the third research question, namely by identifying themes to strengthen resilience, which were considered as preliminary themes for discussion in the focus groups.

Focus groups data

The raw data comprised video recordings and transcriptions of focus group discussions with experts, and meeting notes prepared by each focus group moderator. The moderators of the focus groups reviewed the transcripts in their native language and translated them into English. A thematic analysis approach following the Template

Analysis procedure [25, 26] was used to analyse the data [23], using an inductive approach, considering a priori themes identified in the survey.

A stepwise process was conducted, as follows: 1) familiarisation with the data, conducting preliminary coding, supported by the summaries of the focus groups and the themes derived from the survey across the six resilience dimensions; 2) development of a code book to systematically categorise the data; 3) coding of focus groups transcripts according to the code book. The coding process was conducted by ASVC, adhering to the code book, and reviewed by the other authors. The code book was continuously refined throughout the coding process. In step 4, themes and sub-themes were identified from the data.

The preliminary results from the first three focus groups (Spain and Italy) were discussed with the Consortium during the project's General Assembly in October 2024. These discussions helped to refine themes and informed the topics to be explored in the subsequent focus groups. After the coding of all focus groups transcripts, team discussions were convened to refine the themes and sub-themes, including three one-hour meetings between ASVC, OBF, NK, and DK, as well as a one-hour Consortium meeting.

Synthesis of data to develop the resilience assessment tool

The themes identified in the survey and focus groups were complemented and refined to develop the tool: each theme was considered a 'sub-dimension of resilience', representing key aspects to be addressed within each dimension. For each resilience sub-dimension, sub-themes were proposed as specific 'actions' to be undertaken by stakeholders. Based on the key actions identified, questions for the preparedness checklist and specific recommendations were developed. The checklist questions and recommendations were reviewed and refined in discussions within the AUMC research team and the Consortium.

Patient and public involvement

Patient representatives participated in all RESIL-Card Consortium meetings, being closely involved in all research phases of this study. As members of the RESIL-Card Advisory Board, patient representatives participated in the survey conceptualisation and dissemination. Patients and/or patient representatives were also involved as informants in four of the five focus groups conducted. The tool was reviewed by patient representatives.

Results

Study population

A total of 177 healthcare professionals from 23 countries responded to the survey (response rate of 3,8%) (Supplementary File 6). Most of the respondents were physicians (92%, n=163), specifically interventional cardiologists (70% of the respondents; n=124), followed by general cardiologists (15%, n=27). Seven percent of the respondents were nurses (n=13). Professionals worked mostly in Italy (27%, n=47) and Spain (24%, n=43), in public hospitals (86%, n=153) and in hospitals with cardiac catheterisation laboratory available on a 24/7 basis (47%, n=83).

A total of 40 informants participated in the five focus groups, with a range between 4 and 11 participants per focus group, from nine European countries. Informants represented the three health system levels and a broad range of stakeholder type (Table 1) (see Supplementary File 7 for a detailed breakdown of participants).

Nature of disruptions to service delivery inputs and care delivery processes, from the perspective of European cardiac care providers

Infrastructure capacity and staff shortages were perceived as the most relevant challenges to provide cardiac care during the COVID-19 pandemic: shortage of

Table 1 Summary of the characteristics of the focus groups' informants (n=40)

Characteristics	Total of focus groups informants, n=40	
	n	%
Healthcare system level*		
Micro (clinical)	29	73%
Meso (organisational)	4	10%
Macro (policy)	3	8%
Cross-cutting (scientific society)	15	38%
Type of stakeholder*		
Patient / patient association	5	13%
Cardiologist	1	3%
Head nurse (ward; cardiac care unit, cardiac catheterisation laboratory)	5	13%
Allied professional	4	10%
Head of hospital department (cardiology, emergency department or cardiac care unit)	10	25%
General practitioner	4	10%
Hospital manager	4	10%
Scientific society	15	38%
Policy-maker/governmental organisations	3	8%
Country		
Italy	18	45%
Spain	11	28%
Netherlands	4	10%
Sweden	2	5%
Romania	1	3%
Greece	1	3%
Belgium	1	3%
Portugal	1	3%
Poland	1	3%
Gender		
Male	25	63%
Female	15	38%

* Eleven informants held two affiliations.

infrastructure capacity was perceived as very important or extremely important by 38% of respondents (n=68) and staff shortages due to SARS-CoV-2 infections by 35% (n=62) (Figure 3 (a)). Infrastructures and workforce shortages were also perceived as the most relevant challenges before the pandemic (see Supplementary File 8 for a detailed breakdown).

During the COVID-19 pandemic, the most frequent shortage in infrastructure capacity reported was related to ICU beds (n=152; 73%) (see Supplementary File 9 for a detailed analysis). Delays in accessing diagnostic procedures were frequently reported (n=116; 66%). The therapeutic procedure with waiting times most frequently reported, from a clinical perspective, was elective diagnostic cardiac catheterization (n=120; 68%). Regarding communication and cooperation aspects, changes in referral policies were frequently mentioned (n=95; 54%). The professionals most frequently involved and responsible for decision-making were hospital managers and the heart team, with varying percentages depending on the decisions. Concerning data aspects, 45% of the respondents (n=81) reported that data was available to monitor the volume of patients with cardiac diseases by each hospital. Shortages in essential medical devices were reported by 49% of the respondents (n=86), being more frequently related to mechanical ventilators (n=77; 47%).

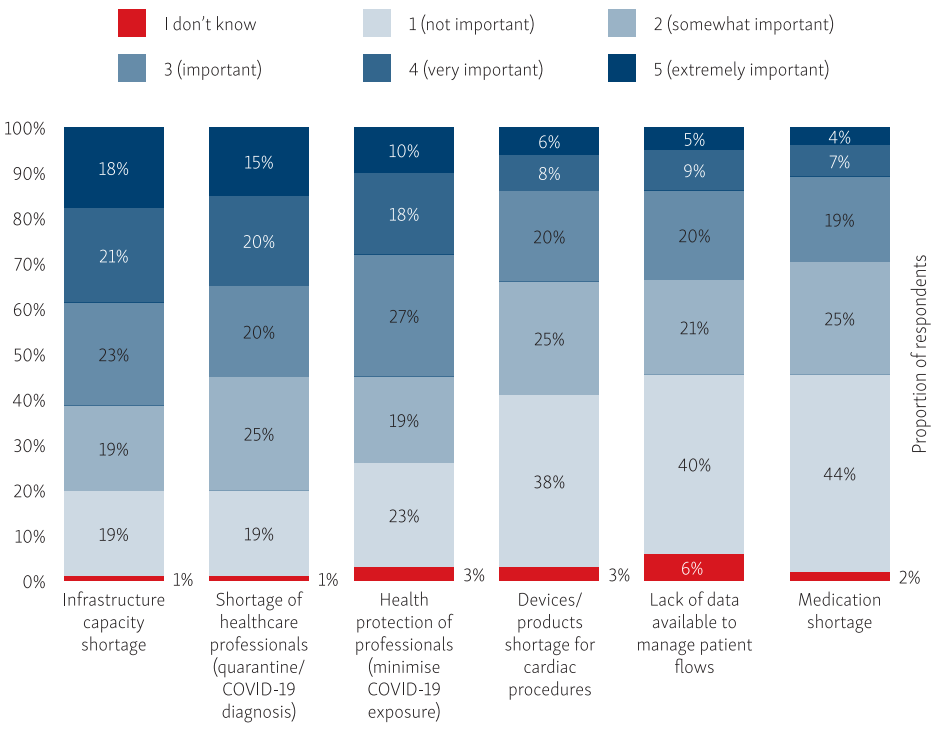
Practices and innovations during the COVID-19 pandemic and its perceived usefulness

The measure most frequently reported to address staff shortages during the COVID-19 pandemic was the reallocation of health staff to key clinical areas, mentioned by 75% of respondents (n=133) (Supplementary File 9 presents the complete list and frequency of measures implemented). Furthermore, reallocation of health staff was considered the most useful practice to minimise cardiac care disruptions, reported as very or extremely helpful by 45% of respondents (n=77), followed by the reorganisation of clinical teams to spread expertise (41%, n=70), the availability of flexible nurse teams (35%, n=60) and providing rapid training in key clinical areas (33%, n=56) (Figure 3 (b)).

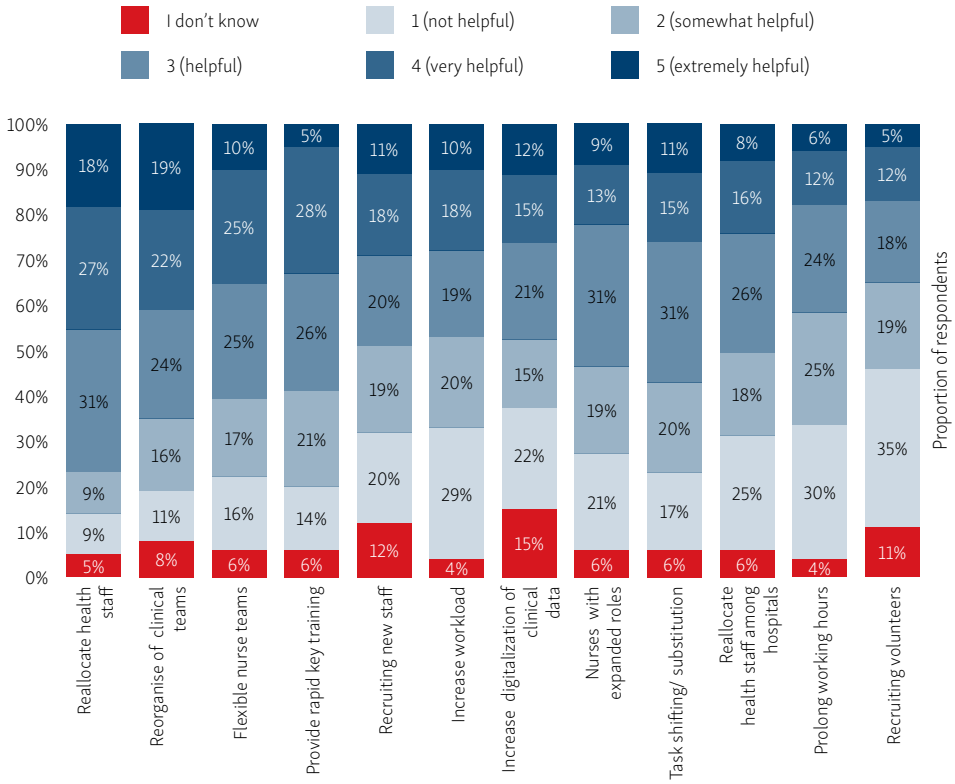
To address infrastructure capacity shortages at the hospital level, the most frequent practices were repurposing infrastructures (38%, n=32) and reducing regular activity (26%, n=22). New care delivery models were reported by 37% of the respondents (n=66), while 54% respondents (n=96) reported that no innovation in care delivery models was observed. Public awareness campaigns to citizens were reported by 57% of respondents (n=101) and new communication channels to inform patients were implemented 43% of the cases (n=76). A total of 55% of the respondents (n=98) reported decision-making processes through meetings, with inclusion of physicians. We observed no difference in trends between Italian and Spanish respondents, regarding the most frequent practices implemented during the COVID-19 pandemic.

Figure 3 Factors restricting access to cardiac treatment and the perceived usefulness of measures to minimise acute cardiac care disruptions caused by workforce shortages

a) Factors restricting access to cardiac treatment: relative importance by frequency and distribution (n=177)



b) Perceived usefulness of measures to minimise care disruptions related to workforce shortages (n=170)



Actions recommended to strengthen the resilience of cardiac care pathways

Workforce's health protection and enhanced communication with patients were considered as very or extremely important factors for ensuring access to cardiac care in future crises by 69% of survey respondents (n=122). The proportion of respondents who considered other factors as very or extremely important, across the six resilience dimensions, ranged between 62% (n=110) concerning improving coordination with primary care providers and 41% (n=73) in relation to improving international cooperation. Supplementary File 10 provides a detailed breakdown of all factors assessed.

A total of 17 resilience sub-dimensions and 39 related actions were identified

across the six dimensions of resilience. Supplementary File 11 provides the themes (resilience sub-dimensions) identified in the survey, which were complemented and refined through focus groups discussions to develop the resilience tool. The list of resilience sub-dimensions and related actions are listed in Table 2 and presented briefly below.

Table 2 Summary of sub-dimensions of resilience and related actions to strengthen resilience

Resilience sub-dimensions	Actions to strengthen resilience of cardiac care pathways
Resilience dimension: Workforce	
Workforce health protection and well being	Ensuring workforce health protection
	Monitoring and promoting workforce well-being
	Providing workforce training
Workforce shortages	Addressing shortages and increasing staff retention
	Regulating task shifting
	Preparing staff recruitment during crisis (care and technical support)
	Preparing mobilisation of personnel from outside the hospital
Reallocation of health staff	Preparing the redeployment of health professionals
	Organisation of new medical teams based on expertise
Resilience dimension: Care delivery—infrastructure and care models	
Infrastructure repurpose	Repurposing health departments
	Repurposing non-medical settings or setting up temporary infrastructures
Prioritisation of CV care and safety	Prioritising high standards of cardiovascular care and preventing care delays
	Ensuring patient safety (e.g. risk of infection)
Implementation of innovations	Leveraging digital health and telemedicine
	Piloting and applying early discharge protocols
	Developing home-based care
Reorganisation of services and pathways	Reorganisation of services and new protocols for care delivery
	Reorganisation of care pathways, ensuring 'clean' pathways
	Restructuration of circulation of professionals and supplies

Resilience sub-dimensions	Actions to strengthen resilience of cardiac care pathways
Resilience dimension: Communication and cooperation	
Patients, families and the public	Communication with patients and families/carers
	Communication with the public
	Communication between patients and their families/carers
Professionals in cardiac care	Among hospital professionals; Within hospital departments; Other hospitals; With Primary care; With the Ambulance sector; With International hospitals
Other sectors	With other sectors of society
Resilience dimension: Governance and trust	
Roles and processes for decision-making	Preparing decision-making processes beforehand
	Developing pre-crisis protocols and conducting simulations to test and update
Tools for decision-making	Preparing and applying triage scales
	Leveraging modelling tools
Trust	Ensuring that professionals trust in the organisation/region preparedness
Resilience dimension: Data collection and use	
Agreed-upon data to enable decision-making	Collecting agreed-upon data
	Ensuring timely access to data
	Developing digital channels to communicate with patients
Interoperability	Investing in data infrastructure development to improve interoperability and linkages
Resilience dimension: Medical devices and products	
Supply chain	Identifying and developing strategies to address potential supply chain bottlenecks
Flexibility	Consider repurposing materials and ensuring flexibility to find innovative solutions

Workforce

Informants highlighted the critical importance of monitoring and promoting the health protection and well-being of healthcare professionals. Factors such as insufficient protective equipment, training, heightened risk of infection, long working hours, and frequent staff reallocation negatively affected staff well-being. While

the ability to quickly mobilise professionals within and outside the hospital was considered key to addressing surges in care demand, this strategy poses challenges. One informant acknowledged that *'[the willingness to be reallocated] was higher when we could keep the teams intact and move them together towards COVID care'* (Head Nurse, Netherlands).

Addressing workforce shortages was also identified as a key factor to be able to absorb a crisis. Mobilising retired doctors and nurses was an aspect highlighted as helpful to prepare beforehand. As one informant the importance of: *'(...) [being able to know] who does what and who doesn't, what additional training is needed to be able to deploy and then arrange that very quickly.'* (Representative of Emergency Medical Services).

Care delivery—infrastructure and care models

The ability to quickly repurpose and upgrade infrastructure and to establish temporary facilities in response to surges in care demand were recurrent themes. One informant mentioned: *'we realised that converting a conventional room into an ICU was complicated, because of the issue of not being able to simultaneously put BiPAP or high flow. [...].So, I think that for the future, any unit, [...] should be fully prepared to do this upgrade.'* (Head of cardiology department, Spain).

Prioritising the continuity and quality of cardiac care during crises was also emphasised. Informants proposed the reorganisation of services and care pathways, including pre-defined 'clean' and 'dirty' pathways to sustain urgent and some elective care during crisis, as well as restructuring the movement of healthcare professionals, supplies, and equipment. Infrastructure should be prepared to accommodate this reorganisation, as one informant recognised: *'For instance, we opened a brand-new hospital (...). However, despite being brand new, it did not account for the division between a dirty pathway and a clean pathway.'* (Nurse, Italy). Implementing or scaling up innovations was also mentioned as contributing to strengthen the resilience of cardiac care pathways, such as home-based care models.

Communication and cooperation

Patient representatives and professionals highlighted the challenges related to the lack of information during the pandemic. Establishing official communication channels and providing targeted communication training were proposed as important strategies. As one informant underscored: *'[...] communication with patients and the rest of the population is a protocol that fundamentally applies to any type of [crisis]'* (Radiology technician, Italy).

Improving communication and cooperation within and beyond the health system was identified as a key priority. Within the healthcare system, collaboration among hospital professionals, across departments, with other hospitals, primary care providers, ambulance services, and international institutions should be in place before crises.

Furthermore, involving other societal sectors to ensure effective communication and coordinated responses was also mentioned, such as scientific societies and private sector health companies. One informant mentioned that 'The other decision that was made from the point of view of the scientific society was not to stop scientific communications and scientific meetings. *[...] we learned a lot from each other [...] thanks to the fact that scientific communication and the exchange of information did not stop. I think that these are things that the scientific community can and should do*' (Cardiologist and representative of scientific society, Netherlands).

Governance and trust

Informants mentioned that governance structures should establish clear roles and decision-making processes in advance, supported by pre-crisis protocols and simulation exercises. As one informant highlighted: *'we didn't have pre-existing protocols on how to act in catastrophic or pandemic situations and I think this was something that we need to have for the future for a better response.'* (General practitioner, Portugal).

Decision-making tools such as triage scales and modelling systems were identified as useful to support decision-making during crises. One participant underscored: *'If*

you have a system, where all you do in a hospital is numbered: what is #1? What is #3? and what is #10? Then, if you have a crisis, [...] if you have war, if you don't have any money, then you could just cut off 10, 9, 8, 7, 6, 5, 4 and just do number 1, 2 and 3 or number 1 to 6. [...] that is resilience. But that's very difficult. [...]' (Scientific organisation, Sweden). In Spain, a severity assessment scale was developed and validated to prioritise in-

terhospital transfers.

Consistent public and patient involvement were also highlighted as a priority. Furthermore, building and maintaining trust among professionals in each organisations or region's preparedness was emphasised to ensure a coordinated response during a crisis. As one informant acknowledged: *'Regarding the delay in renewing the pandemic plan, I was involved in an exercise in 2012, [...], at the Ministry of the Interior [where] we simulated a pandemic [...] The problem was, in fact, [...] translating those messages into everyday reality. When the COVID-19 pandemic began, none of what we had proposed was implemented. So that was the failure [...]: the lack of belief in preparedness and organizing for such situations.'* (Head of Intensive Care Cardiac Unit, Italy)

Data collection and use

Critical actions included improved digitalisation and health data infrastructure, particularly the collection of standardised data, timely access for decision-making, and the development of digital communication channels with patients. As one informant described: *'So it's always data. The big picture. What gives you control over it. [...] where is there still capacity and how are we going to distribute it? I can predict that if we get another crisis like that, then everyone will start acting the same again and then it is extremely important to have insight into your exact numbers. Otherwise it will simply become chaos, just like it was in that first wave'* (Representative of Emergency Medical Services).

Enhancing data infrastructure to support interoperability and system linkage was a recurrent theme to enable more coordinated responses. One informant highlighted: *'Where I think the biggest problem lies is in getting a good view of what is happening outside the hospital—that data was very difficult to get insight into.'* (Cardiologist, Netherlands)

Medical devices and products

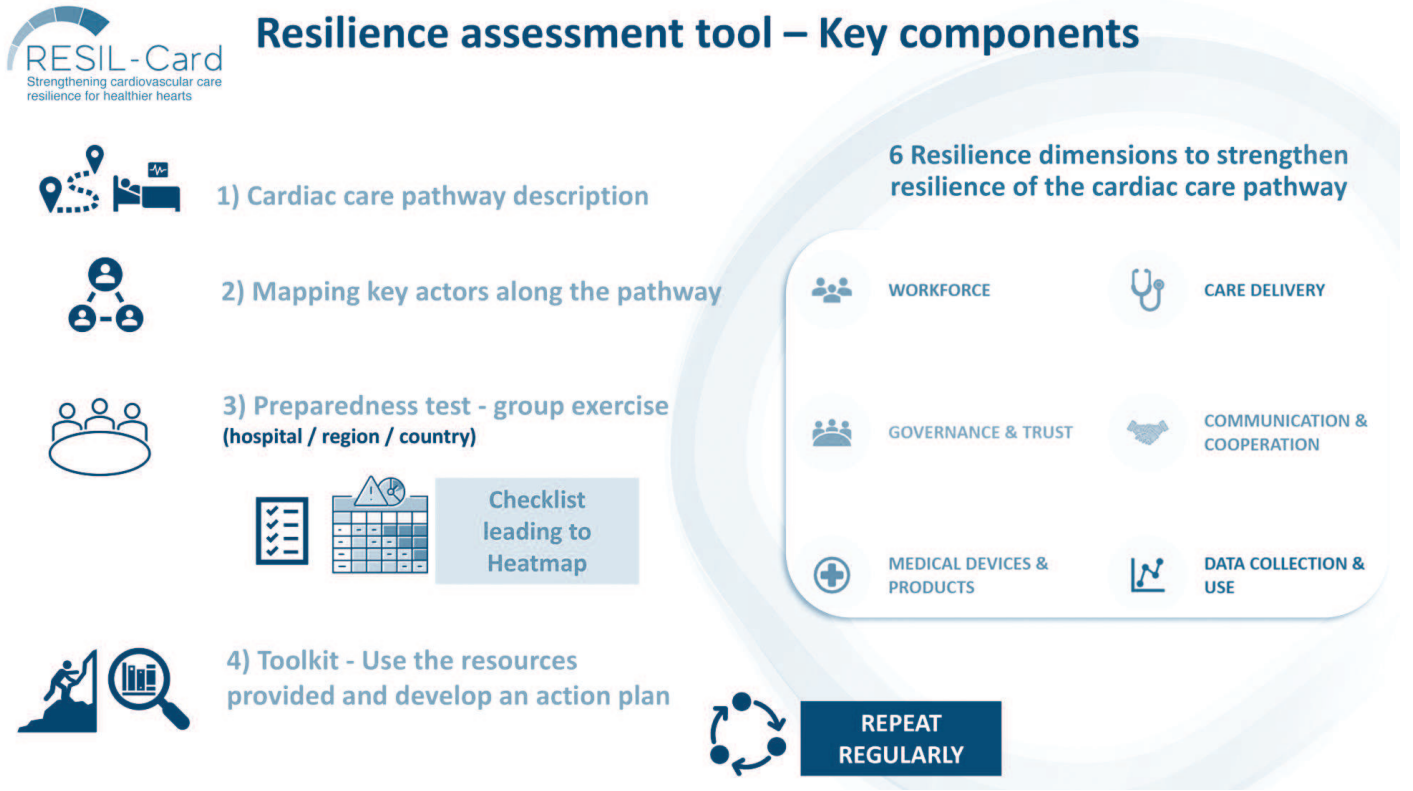
To avoid disruptions in supply of products and medical devices during crises, identified actions were to focus on identifying potential bottlenecks and developing strategies to address them. Additionally, ensuring flexibility by repurposing materials and adopting innovative solutions to overcome equipment shortages was emphasised. As one informant explained: '*And then devices that we didn't have, not only ventilators, but positive pressure devices [...] We had to adapt a little that we had at our disposal, with the help of an engineer [...] to free up a resource in the ICU.*' (Emergency department physician, Spain).

Structure of the Resilience Assessment Tool

Considering these data collected and based on discussion among the RESIL-Card Consortium, it was agreed that the tool would be designed to enhance the resilience to face various types of crises, targeting healthcare professionals in the hospital setting, while ensuring involvement of all professionals working with them and interaction with patients and the general population. Furthermore, it was agreed that the tool would include: a) an introductory component to highlight the importance of prioritising emergent cardiac care, b) the definition of resilience explicitly and repetitively in the tool, c) clear guidance for target users on how to use the tool, d) a component of social interaction to ensure that professionals from the same context would meet to assess their preparedness level and discuss actions to improve it, through a preparedness checklist, which would generate a preparedness visual heat map.

The tool comprises four key components (Figure 4) and is available at *https://doi.org/10.5281/zenodo.16994435*. First, users are guided to thoroughly describe the cardiac care pathway within their specific context. Second, users are prompted to identify the key actors who should collaboratively use the tool to conduct the preparedness exercise. Third, a group exercise involving a self-assessment checklist is provided. Upon completion, the checklist generates a visual heat map that highlights potential

Figure 4 Structure of the Resilience Assessment Tool



areas for improvement in each context. The fourth component is a toolkit with links to additional resources, including a list of good practices and literature compiled by the RESIL-Card Consortium, alongside a set of recommendations to support users in designing their actions.

Discussion

This study aimed to develop a structured and context-sensitive tool to assess and strengthen the resilience of cardiac care pathways. Using a sequential mixed-methods design, employing an inclusive, multi-stakeholder development approach, we first identified key challenges experienced during the COVID-19 pandemic and then translated these into a tailored self-assessment tool. The study identified six dimensions of health system resilience from the literature as relevant to cardiac care pathways: (a) workforce, (b) organisation of care delivery, (c) governance and trust, (d) communication and cooperation, (e) medical devices and products, and (f) data collection and use. A survey among cardiology healthcare professionals revealed that the most significant challenges to ensure cardiac care continuity during the COVID-19 pandemic were related to the first two dimensions, notably shortages of staff and infrastructure capacity. The factors considered most crucial to maintain access to cardiac care during crises were investing in the workforce's health protection and strengthening communication with patients. A total of 17 resilience sub-dimensions were identified, and 39 concrete actions were recommended to strengthen the resilience of cardiac care pathways, which culminated in the development of the resilience assessment tool.

Our study showed that addressing workforce shortages, investing in their health protection, and ensuring the ability to mobilise health workers should be prioritised to prepare for future crises, which is in line with previous studies. A survey to around 600 interventional cardiologists conducted in April 2020 reported that the availability of personnel in cardiac catheterisation laboratories was affected by

COVID-19 infections, quarantine, or staff reallocation [27]. Suboptimal availability of personal protective equipment was also reported [27]. The World Health Organization (WHO)/Europe framework for 'resilient and sustainable health systems' adopted in 2024 includes workforce training and support one of its four pillars, alongside models of care delivery, universal health coverage, and person-centred care [28]. The WHO study on 'Health systems resilience during COVID-19' likewise emphasised the mobilisation and support, scaling up capacity, and investing in training, flexibility and workforce's health [16].

Given the substantial burden of cardiac diseases and the importance of timely access to care on patient outcomes, maintaining quality standards is particularly critical in this clinical area. With respect to infrastructure shortages during crises, our results identified crucial aspects to ensure resilient cardiac care pathways: the ability to swiftly repurpose and upgrade medical infrastructure, to uphold high standards of cardiovascular care, notably leveraging innovative care models and flexible care pathways. A study in Dutch hospitals showed that flexibility measures related to building design were the most practical solutions to implement during COVID-19, namely creating triage areas and separate clean and dirty routes [29]. However, this study also highlights that flexibility in facility design is limited by the staff's adaptability and availability [29], underscoring that a combination of factors needs to be addressed to improve crisis resilience.

In Organisation for Economic Co-operation and Development (OECD) member countries, 13 out of 19 countries reported expanding their hospital networks, underscoring that collaboration was an important factor to foster resilience [15], which is in line with the present results. Governance aspects were reported in previous studies to be an important, nonetheless frequently overlooked, area of resilience [30]. In our study, establishing clear roles and decision-making processes in advance, supported by pre-crisis protocols and simulation exercises were also considered key elements of preparedness.

In agreement with our results regarding the need to invest in health data infrastructure to support decision-making, an OECD survey conducted in 2019-2020 showed that only 14 OECD countries had the ability to link data across different health

system settings [15]. After the COVID-19 pandemic, data linkage and data coverage have improved across OECD countries, although data quality and data interoperability still need improvement [31].

Supply chain problems were reported by 16 out of 24 OECD countries at the early stages of the pandemic [15]. Proposed strategies are regulatory changes, internal production and supply chain diversification [15]. This corroborates our findings, underscoring the importance of identifying and addressing potential supply chains bottlenecks to enhance preparedness.

In November 2024, the Council of the EU has approved a set of conclusions related to cardiovascular health in the EU [32], where this clinical area was considered a key priority. This has culminated in the launch of the EU cardiovascular health plan—the 'Safe Hearts Plan' in December 2025 [33]. Furthermore, in May 2025, the WHO Pandemic Agreement was formally adopted by the 78th World Health Assembly. The European commitment on improving the prevention and management of cardiovascular diseases, alongside the global focus on enhancing pandemic preparedness focusing in strengthening international coordination underscores the pressing need to empower professionals and policymakers on this topic.

At the policy level, the findings from this study may inform the development and implementation of the European Cardiovascular health plan. Specifically, the six resilience dimensions, their corresponding sub-dimensions and the outlined actions could contribute to define policy priorities aimed at enhancing the resilience of cardiac care pathways. At organisational level, these findings may support healthcare professionals in identifying key priorities in their context, such as developing decision-making processes, pre-crisis protocols, conducting simulations, and strengthening cooperation with other hospitals and with primary care providers. Healthcare professionals should play a key role in implementing the actions outlined in the resilience tool, ensuring the inclusion of patient representatives and scientific societies. The RESIL-Card Consortium is actively engaged, through dedicated work streams, in disseminating the RESIL-Card tool to promote its broader adoption across Europe, and encouraging patient involvement during its use. Ongoing activities include dialogue with national and European policy-makers, scientific societies and care providers.

Strengths and limitations

While a growing body of literature provides guidance on enhancing health system resilience [12, 15, 16], this study has the strength of focusing specifically on cardiac care delivery, building on lessons from the COVID-19 crisis and addressing the lack of standardised tools tailored to cardiac care pathways. Following a sequential mixed-methods approach, key challenges and strategies were identified in this study, from the perspective of stakeholders across health system levels across various European countries, facilitating cross-learning among organisations and countries. The regular involvement of the RESIL-Card Consortium and its Advisory Board allowed to integrate various perspectives in the tool development, enhancing the applicability of our findings and the fitness-for-use of the tool. Cross-learning across countries was previously acknowledged as a lever to enhance resilience [30].

This study has some limitations. We obtained a low survey response rate, with an overrepresentation of Italian and Spanish cardiologists, which limits the ability to inform how each resilience dimension should be prioritised to enhance the resilience of cardiac care pathways. Nonetheless, Italy was the first European country severely impacted by the COVID-19 crisis in Europe [33], making it a highly relevant context from which to gather insights. Furthermore, the sequential mixed-method design allowed to discuss and complement the quantitative survey's findings in the three focus groups with stakeholders from other European countries.

Despite the inclusive development approach conducted in this study, it was not possible to include participants from all European countries. As a result, certain challenges and lessons related to resilience may not be fully captured. Regardless, this study integrated perspectives from a broad range of stakeholders across a total of 23 European countries. We provide a comprehensive overview of resilience dimensions, sub-dimensions and targeted actions to strengthen the resilience of cardiac care pathways. Informed by the survey and focus groups' findings, the resilience assessment tool was designed to support users in identifying the weaknesses and strengths in their own context through a preparedness checklist leading to a heat map. These findings can support countries in enhancing their ability to withstand

shocks, by supporting end-users in the development of an action plan applicable to their own context.

Conclusion

Leveraging the COVID-19 experiences to develop actionable insights is essential for building more resilient healthcare systems across Europe. This study aimed to develop a structured and context-sensitive tool to assess and strengthen preparedness and response to a future crisis affecting cardiac care delivery in Europe. The resulting resilience assessment tool provides a step-by-step guidance to resilience building across six resilience dimensions, 17 resilience sub-dimensions, providing concrete actionable recommendations, while fostering collaboration among stakeholders in the cardiology ecosystem.

The survey's low response rate limited the ability to inform on the prioritisation of each resilience dimension. Nonetheless, the sequential mixed-method design allowed to discuss and complement the findings through five multi-stakeholder focus groups, followed by a collaborative multi-stakeholder development process. The pilot phase, which has started in early-2025, will ensure that the tool meets the needs of end-users, paving the way for wider implementation.

The tool may support policymakers and healthcare professionals in identifying and prioritising context-specific vulnerabilities and improvement priorities to strengthen the cardiac care pathway. Ultimately, the tool may advance the ability of health systems to cope with shocks and ensure high-quality cardiac care delivery before, during and after crises. These results are tailored to European countries. They are expected to be transferable to other medium- and high- income contexts, with similar health systems challenges and priorities. Future research could test and adapt these findings to other clinical areas and geographies, contributing to develop more efficient, equitable and patient-centred health systems across Europe and globally.

Ethics Approval

This study involves human participants, but an Ethics Committee exempted this study: Non-WMO Committee of the Medical Ethics Review Committee of Amsterdam University Medical Centers; Committee's reference number 2024.0020, on the 14th Feb 2024. The Medical Ethics Review Committee of Amsterdam University Medical Centers is registered with the US Office for Human Research Protections (OHRP) as IRB00013752. FWA number assigned to Amsterdam UMC: FWA00032965.

Participants in the study provided written informed consent during the recruitment phase and expressed their consent verbally at the start of the focus groups. Survey and focus group data has been anonymised and confidentiality was assured by referring to informants by country name.

Acknowledgments

We sincerely thank all professionals who generously contributed with their time and expertise through the cognitive testing of the survey, completing survey responses, and participating in the focus groups. We are grateful for the support of 'Global Heart Hub', whose collaboration was essential in ensuring the inclusion of the patient perspective throughout all the phases of this work. We would like to express our sincere gratitude to Caius Merșa, Giorgio Arca, Lorenzo Latella, and Marcin Ruciński for their valuable contribution as patient participants in the focus groups, which were instrumental to incorporate the patient perspective in this work.

We are also grateful to the RESIL-Card Consortium for their valuable input throughout the project, including their collaboration in the organisation and conduction of some focus groups. In particular, the colleagues from the Italian Society of Interventional Cardiology (GISE, Italy) and the We CARE Alliance. We extend our appreciation to the RESIL-Card's Partnering organisations and Advisory Board for their close involvement and contributions.

Preliminary results of this work have been presented in a scientific conference

for Interventional Cardiologists, EuroPCR, in May 2025. Results of this work have also been presented in a Poster presentation at the International Hospital Federation's World Hospital Congress, in November 2025.

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Supplementary Material

Supplemental Material 1—Completed checklist for mixed methods research manuscript preparation and review (Lee et al, 2022)

Available at *https://tinyurl.com/Chapter4SM1*

Supplemental Material 2—Cognitive testing interviews for survey development: interview date, participants, questions addressed, and changes to the survey

Available at *https://tinyurl.com/Chapter4SM2*

Supplemental Material 3—RESIL-Card survey

Available at *https://tinyurl.com/Chapter4SM3*

Supplemental Material 4—Organisations and initiatives to raise awareness to the RESIL-Card questionnaire (May and June 2024)

Available at *https://tinyurl.com/Chapter4SM4*

Supplemental Material 5—Focus groups—Breakdown of total number of invitations and participation in each focus group

Available at *https://tinyurl.com/Chapter4SM5*

Supplemental Material 6—Survey results—Study population

Available at *https://tinyurl.com/Chapter4SM6*

Supplemental Material 7—Focus groups: Detailed breakdown of informants

Available at *https://tinyurl.com/Chapter4SM7*

Supplemental Material 8—Survey results, Section1: Challenges before the COVID-19 pandemic

Available at *https://tinyurl.com/Chapter4SM8*

Supplemental Material 9—Survey results, Section2: Nature of disruptions during the COVID-19 pandemic and the practices and innovations implemented

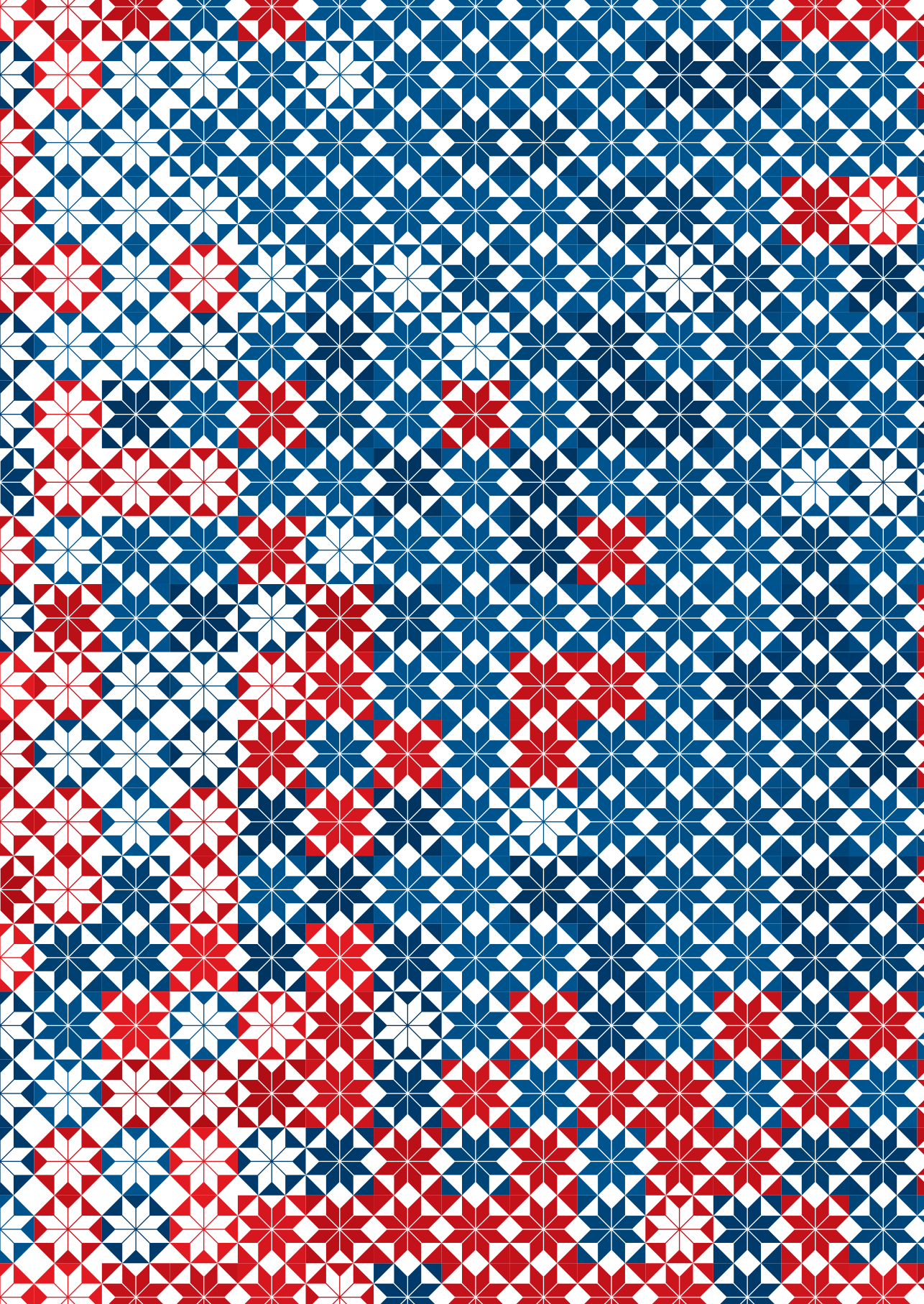
Available at *https://tinyurl.com/Chapter4SM9*

Supplemental Material 10—Survey results, Section3: Lessons learned after the COVID-19 pandemic

Available at *https://tinyurl.com/Chapter4SM10*

Supplemental Material 11—Themes identified to develop the resilience tool, per resilience dimension

Available at *https://tinyurl.com/Chapter4SM11*



Chapter 5

International multi-stakeholder collaboration to support implementation of cancer care efficiency metrics: a qualitative study to develop the All.Can Action Guide

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Abstract

Background: Cancer care efficiency contributes to overall healthcare systems performance. However, many healthcare systems experience challenges in measuring it effectively. All.Can, a multi-stakeholder organisation working to improve cancer care efficiency, has identified eight cancer metrics as a starting point for standardising efficiency measurement, focusing on timeliness of care, coordination of care, and patient-centeredness. This study aims to identify barriers and enablers to implementing these metrics globally and to describe the co-development of a guide to support stakeholders in embedding these metrics into healthcare workflows.

Methods: This qualitative study used a co-development approach in collaboration with the All.Can community. Semi-structured interviews were conducted to identify barriers, enablers and good practices in implementing cancer care efficiency metrics. Data were analysed using a combination of deductive and inductive coding, guided in part by the Implementation in Context (ICON) framework. A qualitative content analysis was conducted to explore the perceived actionability of contextual factors, which informed the development of an Action Guide grounded in health systems research principles. The guide was reviewed by potential end-users and launched in September 2024.

Results: Forty informants from 21 countries have participated in semi-structured interviews. Regulatory influences were most frequently cited as relevant factors for implementing timeliness-of-care metrics. Barriers included fragmented or missing regulations on cancer data collection and limited database interoperability, while enablers involved national strategies and standardised care pathways. For coordination-of-care metrics, regulatory issues were again central, notably the lack of regulation defining roles such as oncology nurses and care coordinators. Political

influences emerged prominently for patient-reported metrics, including lack of funding and absence of systematic data collection strategies. Advocacy was often seen as a key enabler. These informed the development of an Action Guide, intended to support the implementation of cancer care metrics.

Conclusions: This study identified contextual barriers and enablers for implementing cancer efficiency metrics and described the co-development of the All. Can Action Guide as a practical tool for policymakers, care providers and advocates. Through mapping priority areas for action, this study may strengthen data-driven decision-making, enhance timeliness and coordination of care, and ultimately improve patient outcomes and experiences worldwide.

Background

Cancer is a leading cause of mortality and morbidity globally [1], with far-reaching societal implications [2]. Cancer prevalence has been rising in the past years and is expected to continue increasing [2; 3], due to factors such as longer life expectancy [4] and more effective treatments. Thus, per capita health expenditure on cancer care is expected to increase by 67% across Organisation for Economic Co-operation and Development (OECD) countries between 2030 and 2050 [2]. Workforce shortages pose a key challenge to the delivery of timely, effective and equitable care [3]. Furthermore, cancer is an extremely heterogenous disease, with a wide range of treatment options and care pathways [5], emphasizing the importance of multidisciplinary care. These factors highlight the need for an efficient use of resources to ensure the sustained quality of cancer care, ultimately improving care experiences and outcomes for people with a history of cancer.

Efficiency is considered a cross-cutting dimension of health system performance, being key to health systems' adaptation to the growing healthcare demands within limited resources [6]. While some efforts to measure efficiency in cancer care internationally have been made previously [7], the lack of systematic and standardised measurement across countries hinders international benchmarking and efforts to

improve efficiency [3]. International collaboration is essential for developing solutions to address this issue. All.Can International (All.Can) is a not-for-profit, global multi-stakeholder organisation, working to improve the efficiency of cancer care. It operates through ten individual and 34 organisational members, as well as National All.Can teams, known as 'National Initiatives', across 21 countries. These include 12 countries in Europe, two in North America, two in South America, four in Asia and one in Oceania. All.Can is a unique example of an organisation dedicated to improving cancer care efficiency through multi-stakeholder cooperation.

In collaboration with the University of Southampton, All.Can has previously identified a set of eight cancer efficiency metrics as a foundational starting point for standardising measurement across global cancer care pathways [8]. These metrics focus on measurement of three core dimensions of efficiency: timeliness of care, coordination of care, and patient-centeredness. However, knowing 'what' to measure is only the first step; embedding these metrics across health systems to inform decision-making remains a significant challenge. A critical question is 'how' to effectively implement these metrics, particularly through a cascading approach from clinical setting to managerial and policy-level decisions. Actionable guidance is needed to support implementation, with a focus on understanding both the enabling and hindering conditions from a system perspective. Furthermore, the variety of actors and their roles in cancer care and policy across health system levels, alongside the variety of governance models across countries, demands an engaged, multi-profile, multi-level and collaborative international approach.

This study aims to identify barriers and enablers to implementing cancer efficiency metrics globally, at national and organisational levels, as perceived by multi-level stakeholders. To achieve this, the study describes the co-development of an actionable international implementation guide — the All.Can 'Action Guide for Efficient Cancer Care'. Designed for policy-makers, patient advocates, hospital managers, and healthcare professionals, the Guide is organised around three clusters of efficiency metrics (timeliness of care, coordination of care, and patient-centeredness) and aims to support these actors address real-world challenges and facilitators. With a focus on actionability, the Guide provides structured guidance and evidence-based

recommendations to support stakeholders in embedding these metrics into routine practice.

Methods

Study design

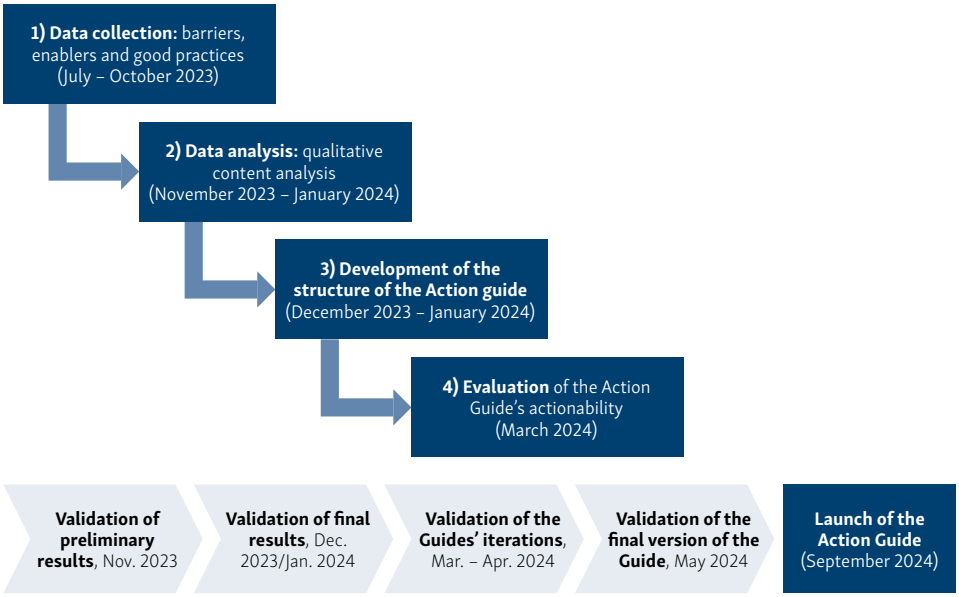
We conducted an exploratory qualitative design [9]. The study comprised two phases of data collection through semi-structured interviews: the first phase aimed to identify barriers, enablers and good practices for the use of cancer metrics at national and regional levels, while the second phase intended to characterise the implementation of good practices (Figure 1). Drawing on this data and applying a health systems research theory-based approach [10], we have outlined the structure of the Action Guide. The first iteration of the Action Guide was evaluated by potential end-users. During the design, development and validation phases, the research team engaged regularly with the All.Can community, employing a co-development approach to create an actionable implementation guide, aligned with the stakeholders' needs and expectations.

The research team included five experts in health systems performance measurement and management and a doctoral student in the same field. EP is CEO of All.Can International (Additional file 1 includes the detailed team composition). Reporting complies with the consolidated criteria for reporting qualitative studies (COREQ) [11] (Additional file 2).

Data collection

Target informants were national experts from All.Can from the three decision-making levels of healthcare systems—clinical, organisational and policy levels. All.Can comprises 34 organisational and ten individual members across the world, who promote its mission and work. Additionally, All.Can is active in 21 countries

Figure 1 Process for development of the All.Can 'Action Guide for Efficient Cancer Care'



through National Initiatives that tailor its goals to local contexts. Representatives of all National Initiatives and one individual member identified by the Secretariat of All.Can International were invited to participate in semi-structured interviews, by email. The background, aim and interview questions were sent in advance of each interview. The interview guide was structured in three sections, corresponding to the three metric clusters (Additional file 3). Based on their perception and knowledge, informants were also asked to provide examples of good practices from their country and identify potential informants.

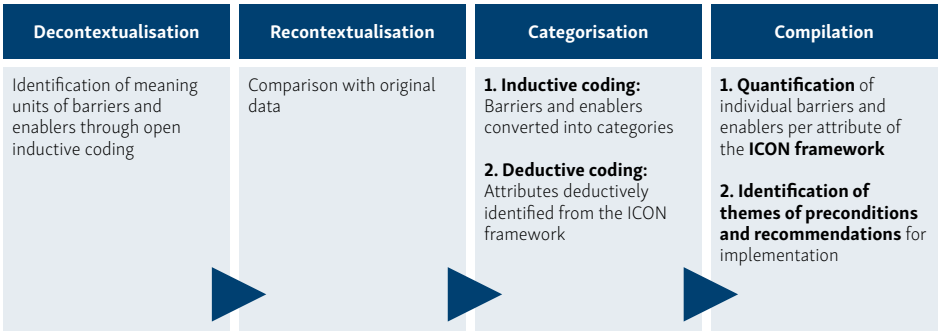
These interviews were conducted over a four-month period (July-October 2023) in pairs by the research team (DI, OBF, EB, ASVC, DK), for a duration of one hour, in English, via Microsoft Teams (version 25007.607.3371.8436). Requests to reply in writing were accommodated. Interviews were recorded and transcribed verbatim with the agreement of the informants. Transcripts were not returned to participants for comment. Field notes were prepared after the interviews by one interviewer and reviewed by the second. Five case studies were selected for in-depth characterisation, considering their potential for implementation in different contexts, scalability, and

how evenly they were distributed across the metric clusters. The language, platform, duration, research team, recording and transcription processes were the same as in the first phase. No repeat interviews were carried out. Data saturation was deemed to have been reached, considering that the last interviews yielded minimal novel insights and largely confirmed previously identified patterns.

Data analysis

A qualitative content analysis [12] was conducted to characterise the magnitude of importance of specific attributes of context, as perceived by participants (Figure 2). This method was chosen to allow for some interpretation regarding the actionability of stakeholders' implementation efforts. The ICON framework [13] informed the deductive coding to identify and structure the full spectrum of perceived contextual barriers and enablers. This framework outlines domains of determinants that are

Figure 2 Data analysis stages, adapted from Bengtsson et al [12].



considered to influence implementation outcomes, acting as barriers and enablers, focusing particularly on the identification of features of context. Data analysis was conducted with Microsoft Excel.

The data analysis followed a structured approach combining inductive and deductive coding, guided by the ICON framework. The combination of deductive and inductive coding intended to link context-specific barriers and enablers to determinants of this implementation framework, thus allowing to organize the findings in a

systematic and actionable way. First, open inductive coding was conducted to extract barriers and enablers from the transcripts. These were added into pre-structured spreadsheets — one for each metric cluster (Additional file 4) — representing the de-contextualisation phase. Next, the original transcripts were reviewed again by ASVC to ensure completeness and accuracy of the extracted content (recontextualisation).

In the following step, similar barriers and enablers were grouped into inductive categories (first step of categorisation). These categories were then deductively matched to the external-level attributes of the ICON framework (second step of categorisation), enabling a theory-informed structuring of the data. For example, a quote such as 'political momentum to focus on health data' was first coded inductively as 'political will' and subsequently linked deductively to the ICON attribute 'political influences'.

Finally, we quantified the number of barriers and enablers assigned to each ICON attribute to assess their relative prominence (first step of compilation). This quantification allowed to create three graphical representations, one per cluster of efficiency metrics (timeliness of care, coordination of care, and patient-centeredness), providing a transparent and reproducible way to visualise the relative prominence of different contextual factors across metric clusters, while remaining consistent with the qualitative nature of the study. Given that not all informants commented on every issue, we did not apply further ranking or weighting to the attributes [12]. To enhance the actionability of the findings for international stakeholders at different health system levels, themes and sub-themes of action were identified, considered as 'preconditions for implementation' (second step of compilation). These themes were identified by the lead researcher (ASVC) from the interview notes and team debriefs, and underwent slight changes after revision by the research team, often related to clarity of wording. To each theme/sub-theme, actionable recommendations were developed. Coding was conducted by one researcher (ASVC, OBF, DI or EB) and reviewed by another, throughout.

Inclusive development and validation process of the Action Guide

The Action Guide was created anticipating the implementation of metrics per cluster in different countries, at national and organisational level. To increase the actionability of the Guide for various users and uses, it was agreed to provide step-by-step guidance in a non-linear document, which offers the possibility to navigate the Guide with no predetermined order, according to each user's needs and with links to additional resources. As such, different entry points to the Guide were considered, inter-linked with clickable links to allow users to navigate from one to another to find useful resources for their needs. To do so, we made an inventory of theoretical frameworks of implementation science and we considered a classical framework of health systems research, developed by John Øvretveit [10], as an actionable way of organising our data. This framework considers three questions to assess 'why', 'what' and 'how' to evaluate in the context of health systems research. In the 'why' and 'what' sections, each efficiency cluster was characterised in detail, based on the literature, to provide background information to the users.

To evaluate the Guide's actionability , five of the informants from the second phase of data collection were purposefully selected and invited for three semi-structured interviews. These experts were potential end-users not directly involved in the development of the Guide, and experienced in implementing an innovative practice in their context. Interviews explored the usefulness, clarity and completeness of the Guide. The preliminary version of the Guide, the aims and interview questions were sent in advance of each interview (Additional File 5).

The Action Guide was developed with various moments of consultation over time with the All.Can community (Figure 1). Participants in stakeholder consultation included potential end-users, such as patient representatives, oncology healthcare professionals, academics, national health agency officials and industry representatives. This development process allowed to finetune the data analysis, to validate the results, and to receive feedback on successive drafts of the Guide. The Action Guide was launched in September 2024, where plans for international use and potential pilot projects were discussed.

The results of this study are presented by addressing both aims of the study together, per cluster of efficiency metrics: timeliness of care, coordination of care and patient-centeredness. For each cluster, we first present an overview of the quantification of individual barriers and enablers to the implementation of metrics by visually showcasing their distribution across the ICON attributes. Categories of barriers and enablers are then detailed in-text. Subsequently, the themes and subthemes of preconditions for implementation are presented in one table per cluster, together with illustrative quotes from the interviews.

Results

Characteristics of informants

A total of 31 informants from 21 countries participated in the first phase of data collection. Informants were from 12 countries in Europe (n=12; 39%), four countries in Asia (13%), two countries in South America (6%), two in North America (6%), and one in Oceania (3%) (see Additional file 6 for a detailed breakdown). From the 22 invitations sent, 18 semi-structured interviews were conducted and three participants opted for written responses. Representatives from one country have declined to participate, due to insufficient knowledge on the subject. Several interviews included multiple informants, with six interviews involving two participants and two involving three. The informants represented diverse professional backgrounds, including oncology healthcare professionals, patient representatives, researchers, national health agency officials, and industry representatives. Given that some informants held multiple affiliations, they provided insights from different levels of the health system (Additional File 6 provides a detailed breakdown). In the second phase, nine informants contributed with insights on five selected good practice case studies. These discussions focused on implementation processes, encountered challenges, and strategies that facilitated success.

The following sub-sections present the findings organised per cluster of metrics.

Case studies were considered an essential component to enhance the Action Guide's actionability to support end-users, by providing in-depth descriptions of phenomena in real-life contexts [14]. Data from these case studies can be found in Additional file 7.

Barriers, enablers and guidance to implement timeliness-of-care metrics

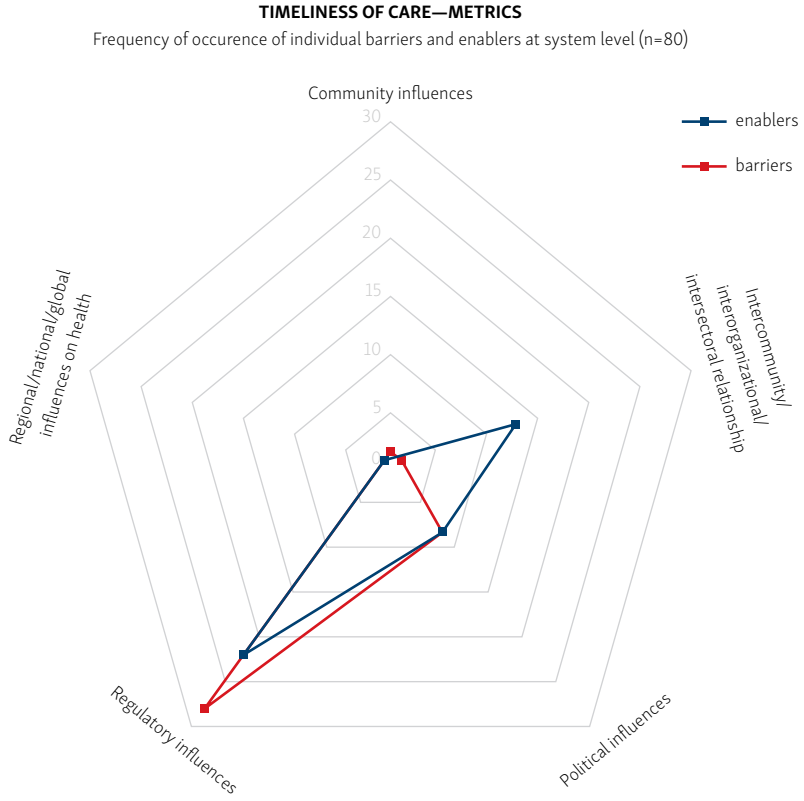
Regulatory influences were identified as being the most prominent attribute of barriers and enablers regarding timeliness-of-care metrics: a total of 50 (63%) barriers and enablers related to these metrics were mentioned as pertaining to regulatory aspects of implementation, followed by 16 (20%) concerning political influences, 13 (16%) related to intercommunity / interorganizational / intersectoral relationships and 1 (1%) related to community influences. (Figure 3) (Additional file 8 presents the breakdown of barriers and enablers mapped to the ICON framework).

With respect to regulatory influences, perceived barriers were related to the lack of a national approach regarding cancer data and different regulations supporting data collection between regions, provinces or territories. Various aspects related to the maturity of data ecosystems were perceived as barriers, such as the absence or underdevelopment of electronic health records, the lack of interoperability of databases, and lack of a nation-wide unique patient identifier. Data collection not being available for monitoring purposes at National level was another perceived barrier. Enablers included the implementation and update of national strategic planning documents, the regulation of standardised care pathways, and legislation supporting cancer data collection, namely the centralization of data collection.

Regarding political influences, the lack of political will and the time investment required to develop cancer registries were perceived as barriers, while collaboration at decision- making and external political pressure were considered enablers.

The themes of preconditions for implementation of timeliness-of-care metrics identified were: 'legal frameworks and strategy, policy context and funding', 'data governance', and 'data use and performance monitoring' (Table 1) (Additional file 9 presents the table of recommendations published in the Action Guide in relation to each theme/sub-theme).

Figure 3 Barriers and enablers of timeliness-of-care metrics at system level, mapped into the ICON framework (n=80)



Note: the unit of analysis are individual enablers and barriers identified in the total number of interviews and written replies recieved (n=21 responses from 21 countries). Each barrier and enabler identified was deductively coded using the attributes from 'external level of context' of the ICON framework.

Table 1 Themes and sub-themes of preconditions for implementation of timeliness-of-care metrics

Timeliness-of-care metrics

Themes of preconditions for implementation	Sub-themes	Illustrative quotes
Legal frameworks and strategy, policy context, funding	National cancer control plan, its development and regular update	'[this organization is mandated by the federal government] So they're the ones who hold the national cancers but create and encourage the implementation of the National Cancer strategy, for example. And they've also just released a National Cancer data strategy. So [they] work a lot with the cancer agencies directly to encourage alignment with that national strategy.' (Canada)
	National health data ecosystem, including a national approach to cancer data collection and funding to develop the health data infrastructure	'By legislation, pathology services have to give that information to the cancer registries and any patient receiving radiation oncology that again is legislated. That information has to be given to the cancer registry data. It's fairly good. And as I say, it's being enhanced at the moment by a number of federally funded projects to increase the information on recurrence and metastasis as well, which will be excellent' (Australia)
Data governance	Interoperability among databases, considering promoting the maturity of electronic health records and the implementation of patient unique identifiers	'There is the 'pension number', but healthcare is not allowed to use it for data linkages.'; 'Each hospital has a different system, but it is almost impossible to link them' (Australia)

Data use and performance monitoring	Mechanisms of feedback and learning, including investing in the availability of near real-time performance data, notably focusing on inequalities in access and quality of cancer care	'Treatment data is collected only at hospital-level (related to diagnosis and treatment) and is only available and used for reimbursement purposes, then only available to the health insurers and is not accessible for measurement efforts' (Sweden)

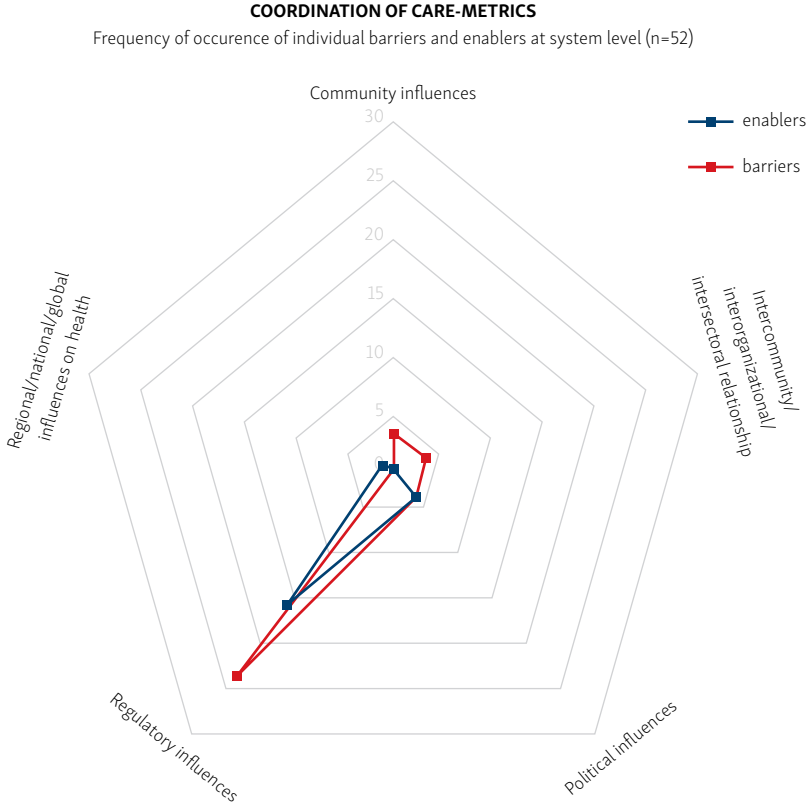
Barriers, enablers and guidance to implement coordination-of-care metrics

Regulatory influences were identified as being the most prominent attribute of barriers and enablers for implementation of coordination-of-care metrics: a total of 39 (75%) barriers and enablers mentioned were in relation to these aspects of implementation, followed by less than ten barriers and enablers in relation to each of the others attributes of context (Figure 4). (Additional file 8 presents the breakdown of barriers and enablers mapped to the ICON framework).

Concerning regulatory influences, the absence of regulations defining the roles of multidisciplinary teams, oncology nurses and care coordinators, and defining the centralisation of cancer care in specialised centres were referred as challenges to implementation, together with the lack of regulation pertaining to task shifting and task sharing. With respect to political influences, workforce shortages and the lack of national of prioritisation of cancer nurses regulation were mentioned as barriers, while political will was perceived as enabler. In relation to community influences, the existence of active National Associations of Oncology Nurses and the providence of care coordinators by Non-Governmental Organisations and patient advocacy groups were perceived as enablers.

The following preconditions themes for implementation of coordination-of-care metrics were identified in relation to the perceived barriers and enablers: 'workforce capacity', 'oncology nurses and cancer patient navigators', 'task sharing and substitution', 'multidisciplinary tumour boards', and 'comprehensive cancer centres'. (Table 2) (Additional file 9 presents the table of recommendations published in the Action Guide in relation to each theme/sub-theme).

Figure 4 Barriers and enablers of coordination-of-care metrics at system level, mapped into the ICON framework (n=52)



Note: the unit of analysis are individual enablers and barriers identified in the total number of interviews and written replies recieved (n=21 responses from 21 countries). Each barrier and enabler identified was deductively coded using the attributes from 'external level of context' of the ICON framework.

Table 2 Themes and sub-themes of preconditions for implementation of coordination-of-care metrics

Coordination-of-care metrics

Themes of preconditions for implementation	Sub-themes	Illustrative quotes
Workforce capacity	Monitoring and addressing workforce shortages in the cancer care ecosystem, ensuring it remains a national priority	'But in there is health and human resources, right? I mean, I think us like everybody else's experiencing a lot of crises and people leaving because of burnout from the pandemic and from the fact that working is already difficult because of the fragmentation, lack of information [...] There's more focus [and investment] is being put through [...] the human resource piece. [...] So there are priorities that have been named, that are being shared federally, provincially and territorially that relate to Health Human resources' (Canada)
Oncology nurses and cancer patient navigators	Regulation of the professional role of oncology nurses and cancer care navigators across the care pathway, ensuring similar mandates at subnational levels	'both the General Nursing Council and Patient Organisations urge the institutionalization of the role of nurse case managers at all levels of care to address the cancer patient process in a comprehensive manner, with the aim of increasing the quality of care (...) and minimising the time between procedures. (...) This figure of case manager in the oncology field is being included (...) in pioneering hospitals' (Spain)
Task sharing and substitution	Regulation concerning task sharing and substitution, ensuring harmonisation at subnational levels	'[task shifting] It does [happen], yes. again it's very variable. you know, [our country] has probably got a stronger doctor input into most areas of care than many countries.' (Australia)

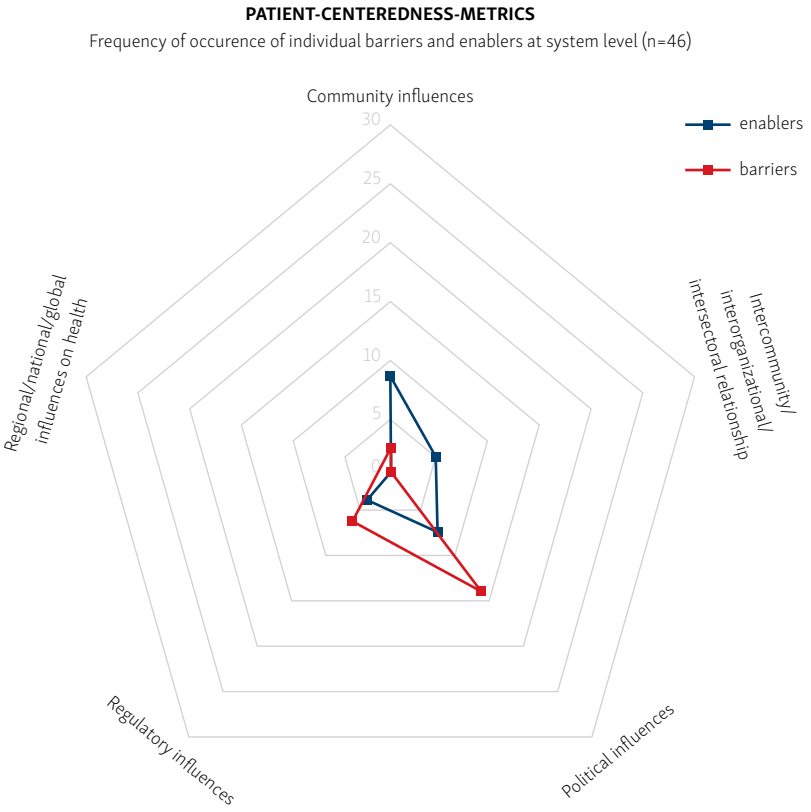
Multidisciplinary tumour boards	Regulation of multidisciplinary tumour boards to ensure meeting quality standards, ensuring harmonisation at subnational levels	'Multidisciplinary teams are not legally mandated nor regulated. [they] exist in most of the private sector, however this is not the case in the public sector. The patients have to move between hospitals to do different treatments [...]. Hospitals are connected in a way, to send patients for specific treatments from one hospital to another. But there is no 'team'. Also, teams have no psychologists or dieticians, for instance.' (Greece)
Comprehensive cancer centres	Centralisation of cancer care in specialised centres and monitoring patient access to ensure equal access to specialised care	'In fact, tumour boards are in the legislation for more 20 years but is it not obliged. Some private oncology hospitals organise their own tumour boards. [...] [Our country has] around 400 sites where patients are treated. You can imagine how difficult it is: oncologists are in small hospitals and they have to decide [...]. We do not have a centralised approach [...]' (Australia)

Barriers, enablers and guidance to implement patient-centeredness metrics

Political influences were predominantly reported as influencing the implementation of patient-reported-metrics: a total of 21 (46%) barriers and enablers were mentioned as being in relation to political aspects of implementation, followed by 10 (22%) barriers and enablers mentioned as related to community influences and the same number related to regulatory influences (Figure 5). (Additional file 8 presents the breakdown of individual barriers and enablers mapped to the ICON framework).

Regarding political influences, insufficient political will, funding and the absence of a national approach to systematic data collection were identified as a barriers.

Figure 5 Barriers and enablers of patient-centeredness metrics at system level, mapped into the ICON framework (n=46)



Note: the unit of analysis are individual enablers and barriers identified in the total number of interviews and written replies recieved (n=21 responses from 21 countries). Each barrier and enabler identified was deductively coded using the attributes from 'external level of context' of the ICON framework.

With respect to community influences, low levels of health literacy and societal advocacy groups with no connection to the health care system were perceived as barriers. Advocacy efforts by patient groups, NGOs and organizations' will to include patient perspectives were perceived as enablers.

With respect to regulatory influences, the lack of embedding of these metrics in existing cancer registries or databases and lack of enforcement and feedback

mechanisms were perceived as barriers. The use of standardised tools was perceived as an enabler.

Linking up the use of metrics to other functions and scaling up successfully run pilot projects were considered enablers for implementation related to interorganisational relationships.

Perceived barriers and enablers were identified in relation to the following preconditions: 'legal frameworks and strategy, policy context and funding' and 'data governance, use, and reporting'. (Table 3) (Additional file 9 presents the table of recommendations published in the Action Guide in relation to each theme/sub-theme).

Table 3 Themes and sub-themes of preconditions for implementation of patient-centeredness metrics

Patient-centeredness-metrics

Themes of preconditions for implementation	Sub-themes	Illustrative quotes
Legal frameworks and strategy, policy context, funding to patient-reported data collection	Political will and funding	'I think within the [health system] there is also the aim to try and put patient experience on an equal footing for clinical and quality outputs and safety, and so there's a real drive (...). So kind of developing national systematic ways of collecting data, allowing comparisons and driving improvement [...]' (Case study England's National Cancer Patient Experience Survey)
	National approach	'The cancer plan speaks very strongly about the need to collect patient reported outcomes and experience measures, but they're not collected systematically anywhere.' (Australia)
	Use of standardised tools	' [...] there was no instrument in [this country] for PREMs in cancer care. [...] This is why we looked into what was done in other countries. I think that the main thing here was there was a gap in the standardised instrument [...] to inform policies' (Case study Swiss Cancer Patient Experiences)
	Involvement of patient groups and non-governmental organisations	'I think [our team] really understands the importance of involving the patient in key decisions about the survey. [...] like the questions we should ask, how should we contact people, what the materials look like? [...] I think that's really important [...] that the patient should be involved at every step.' [...] 'I think another key enabler is the advisory group and the cancer charities that we have on the advisory group [...]. I think it adds to the

		legitimacy of the survey. If you've got large cancer charities that are clearly supportive of the survey [...], I think it gives patients more confidence in the survey and the importance of taking part. So when we come on to some of the challenges, the cancer charities have been really huge big advocates for the survey. [...] having the cancer charities there that have got a really strong voice and a really kind of political power in this space, it's been really, really helpful' (Case study England's National Cancer Patient Experience Survey)
Data governance, use, and reporting	Embedding of patient-reported metrics in cancer registries or databases	'As external researchers, we do not have access to patient data. [...] and there's no registry of all the patients that go through [...] care. [...]. So, really, access to patient information is the key barrier here. [...] Therefore, there are two main issues, identification of disease patients and identification of confirmed diagnosis. These are the two main challenges in these kind of [patient-reported measures] surveys.' (Case study Swiss Cancer Patient Experiences)
	Enforcement and feedback mechanisms	'the patient experience surveys [...] are developed [...] to provide that national monitoring of progress against policy regulation [...]. But also key is that we're able to give the [organisations] who participate in the survey information to allow them to carry out quality improvement.' [...] 'And you see data from these national surveys feature heavily in the Care Quality Commission, who are our regulator and inspector for Health and Social Care. And when they go and inspect organizations, they're looking at data from patient experience surveys [...], so that they can make judgments on how organizations are performing.' (Case study England's National Cancer Patient Experience Survey)

Structure of the Action Guide

The Action Guide was developed with three entry points: 'Why'—addressing the relevance of efficiency in cancer care, 'What'—characterising the three metrics clusters and related health system components, and 'How'—a roadmap to implementation (Figure 6). The 'How' section includes five steps: 1) it guides users to define context-specific priorities, drawing on the literature on cancer care efficiency; 2) it provides a preparedness checklist for metrics implementation, elaborated based on the categories of barriers and enablers identified; 3) it presents key contextual factors, based on the magnitude of relevance attributed to each ICON attribute at

system level and detailing specific categories of barriers and enablers; 4) the Guide lists potential key actors to be involved in implementation efforts, compiled from the stakeholders mentioned in the interviews; 5) it provides key recommendations for metrics implementation per cluster, which are action points derived from the themes of preconditions identified. The good practices case studies are characterised

Figure 6 Visual representation of the structure of the All.Can Action Guide



at the end of the Guide and referred in each related cluster with hyperlinks. Related literature resources are provided throughout the Guide.

Launch of the Action Guide and dissemination activities

214 The launch of the Action Guide took place at an in-person meeting with the All.Can community in September 2024, in Geneva. The general public could attend virtually and interact via the chat and live polls. A summary of the Guide's structure and guidance were presented in a plenary session, followed by a panel discussion. Live polls during this event showed the relevance, high level of interest and the intention to implement the Guide's recommendations by this community. The Guide is available at All.Can International's website (link: *https://www.all-can.org/what-we-do/policy-research/action-guide-for-efficient-cancer-care/)*. Following the launch event, various dissemination activities were carried out, enhancing the visibility of the Guide to a broader community (e.g. a conference abstract showcasing preliminary results was presented at the European Cancer Organisation's Summit in November 2024 [15]).

Discussion

Cancer poses a significant challenge to health systems and to society as a whole. At health system level, current efforts emphasize measuring inputs and outcomes of cancer care, while lacking a systematic approach to measure the efficiency of cancer care [3; 16]. However, international patient-reported data indicate that waiting times, poor care coordination and insufficient patient-centred care are critical concerns for individuals with chronic conditions [17]. Employing a qualitative content analysis, this study mapped barriers and enablers to implementing cancer care efficiency metrics across health systems from the perspective of international multi-level stakeholders from 21 countries. Barriers and enablers were mapped to the attributes of the context from the Implementation in Context (ICON) Framework, per cluster of cancer care efficiency metrics: timeliness of care, coordination of care, and pa-

tient-centeredness. Furthermore, this study described the development of an Action Guide to support implementation of cancer efficiency metrics globally through a participatory process, identifying actionable themes with recommendations for action for multi-level stakeholders, underscoring the strong role of political, regulatory and advocacy factors at system level. Addressing barriers related to the regulation of standardised care pathways measuring timeliness targets and maturity of data ecosystems, while leveraging enablers such as the regulation of oncology nurses specialists, care navigators, and a standardised approach to patient-reported data collection, can foster the efficiency of cancer care globally.

In relation to the timeliness-of-care metrics, regulatory aspects considered relevant to implementation were related to the development and regular update of national cancer control plans. Cancer plans contribute to prioritise cancer-specific actions at the health system level and are considered foundational to foster cancer control [18]. The 2019 WHO global survey [19] showed that, despite 92% of the 177 responding countries having cancer plans or strategies, 80% were operational, showing room for improvement. As our study showed, international collaboration may foster cross-country learning and exchange to define key priorities and advance cancer plans.

Furthermore, our findings underscore the importance of developing national health data ecosystems, notably fostering the maturity of electronic health records and interoperability of databases to support the implementation of time-related cancer metrics. These insights also align with global momentum around digital health transformation, highlighting the need to invest in interoperable health information systems that can support real-time monitoring and data-driven cancer care improvements. This is corroborated in a recent OECD report [16] showing that most EU countries struggle with effectively monitoring waiting times in the cancer care pathway. Our study further signals that the regulation of standardised care pathways, particularly including time targets, may prove a relevant enabler to foster timeliness of care. Previous studies have showed the potential for standardised cancer care pathways in improving cancer outcomes [20; 21].

Regarding the coordination-of-care metrics, a strong emphasis on regulatory

influences was also noticeable to strengthen the measurement and improve care coordination. Specifically, the regulation of advanced roles for nurses, care navigators, multidisciplinary teams, alongside concentrating cancer care. Previous research has underscored the potential to oncology nurses to deliver more integrated care [22; 23] and European countries have recently been implementing additional roles for nurses to tackle increased health needs and oncologists shortages [24]. A previous OECD report also underscored the role of legislation and regulation to remove barriers hindering the implementation of new advance practice nurses' roles [24]. Furthermore, cancer care often requires two or more professionals to perform a task at any stage of the pathway [25], therefore professionals' cooperation is paramount. In line with our findings, worldwide cancer associations have been pushing for standardised formats for MDT meetings to foster coordination and shared-decision making [26]. Additionally, concentrating cancer care is currently a priority in many countries and various initiatives have been leveraging national efforts to foster their implementation across Europe [16].

With respect to the implementation of patient-reported metrics, political will, funding and a national approach to systematic data collection were perceived as having a stronger role to implementation. While most countries lack the implementation of national and standardised methods to collect patient-reported data [16], political momentum is growing internationally to increase efforts for collecting patient-reported-data to monitor and improve care [17]. A systematic review addressing determinants to implement PROMs/PREMs has also identified the need to integrate them into existing workflow routines to ensure their use, to engage with health system's leaders, and to involve all relevant stakeholders [27]. Furthermore, our results signal the key role of advocacy efforts and the involvement of patient groups in the implementation of standardised approaches to patient-reported data collection.

In addition, the absence of systematic data collection and uneven implementation of standardised metrics may exacerbate health disparities, particularly for underserved populations. Equity considerations should therefore underpin efforts to implement cancer care efficiency metrics, ensuring that improvements in timeli-

ness, coordination, and patient-centeredness benefit all population groups equitably.

Strengths and limitations

The international and participatory nature of this project, including multi-level stakeholders, allowed to account for various perspectives, notably from patient representatives and other potential end-users of the All.Can Action Guide at organizational and health system levels. This inclusive process included various moments of consultation with the All.Can community throughout the entire project, since its inception until the launch of the Guide. This participatory approach not only enriched and validated the findings, but also enhanced their legitimacy and potential for uptake, by ensuring alignment with the perspectives of intended end-users.The implementation theory-based approach ensured a systematic and comprehensive mapping of factors influencing implementation of cancer efficiency metrics, while the quantification of the attributes of the ICON framework allowed to signal key areas to prioritise. Balancing the framework-informed method with an open-inductive coding to identify themes of preconditions enabled us to capture actionable points to which stakeholders may relate to drive change.

This Guide was developed with input from a single international cancer community– All.Can International –, and the barriers and enablers reported are based on the perception and knowledge of the participants. While many informants were engaged at national or policy level, their insights may reflect partial perspectives within complex and, in some cases, decentralised health systems. Therefore, the findings should be interpreted as exploratory and indicative rather than exhaustive representations of country-level performance. Given the relatively small sample of informants per country, these findings provide thematic insights rather than comprehensive system assessments. Nonetheless, the analysis informed by an implementation framework may offer practical guidance for stakeholders seeking to adapt and test these findings within their own contexts. Further empirical testing is needed to assess applicability in low-income countries. While the research team maintained a facilitative role in the co-development process, we recognise that our

background in health systems research and our collaboration with All.Can may have influenced how certain issues were framed.

Implications for practice and policy

By employing an inclusive development approach and applying a theoretical implementation science approach, this study offers practical insights into how global exchange and collaboration can promote cross-country learning for the effective uptake of cancer efficiency metrics. The interaction between academic and practical approaches led to the refinement of both the content and format of our findings. For instance, during discussions on the first iteration of the Guide, the All.Can community requested to modify the name initially proposed by All.Can—'playbook' -, considering the sensitive nature of the issue. Thus, 'Action Guide' was considered a more neutral and suitable title. This process emphasises the importance of striking a balance between theory and practice to effectively incorporate end-users' perspectives and needs into a widely accepted final product.

The inclusive development process conducted in close collaboration with an international community has also showed that there is a relevant added value in having an international multi-stakeholder organisation engaging with an academic institution to develop a guiding framework for implementation. This co-development process has proven effective and has already yielded tangible results, namely the organisation of pilot projects in various All.Can member countries, showing the interest of the cancer community in the guidance and resources the Action Guide offers. The involvement of All.Can as co-authors of this work underscores the rationale behind this approach and further highlights the benefits of collaboration in ensuring the actionability and applicability of this work.

As health systems face increasing pressures from rising cancer incidence and constrained resources, embedding efficiency metrics can also contribute to broader sustainability goals—ensuring that care improvements are delivered in a way that is both economically and operationally viable over time. The flexible, modular structure of the Action Guide also supports its scalability and adaptability to different health

system contexts, including varying resource settings.

Future research could evaluate the uptake and use of the Action Guide, exploring the extent to which the final product reached its potential. Additionally, while this research intends to provide evidence to cancer-related policy-making, some of the findings may potentially be extrapolated to other clinical areas. Notably, the challenges of monitoring timeliness of care and patient-centredness are transversal to health care delivery.

Conclusion

This study identifies the perceived contextual barriers and enablers for implementing cancer efficiency metrics from the perspective of informants from an international multi-stakeholder cancer community, focusing on timeliness of care, coordination of care, and patient-centeredness. Moreover, this study describes the participatory development of an Action Guide designed to enhance the actionability of these metrics globally. This research contributes to the field by identifying actionable themes that multi-level stakeholders in the cancer field can prioritise to advance the implementation of these metrics within their specific contexts.

The co-development of this Action Guide, owned and disseminated by an international multi-stakeholder cancer organisation, is a step forward to foster cross-country learning and ensure that research knowledge is effectively used to inform future cancer policies globally, ultimately aiming to enhance system performance, patient experiences and outcomes.

Ethics approval and consent to participate

This study was approved by the non-WMO Committee of the Medical Ethics Review Committee of Amsterdam University Medical Centers: committee's reference number 2023.0939. This committee is authorised by the board of directors of Amsterdam UMC

and supervised by the Medical Ethics Review committee. Participants in the study provided written informed consent during the recruitment phase and expressed their consent verbally at the start of the interviews. Interview data has been anonymised and confidentiality was assured by referring to informants by country name.

Acknowledgments

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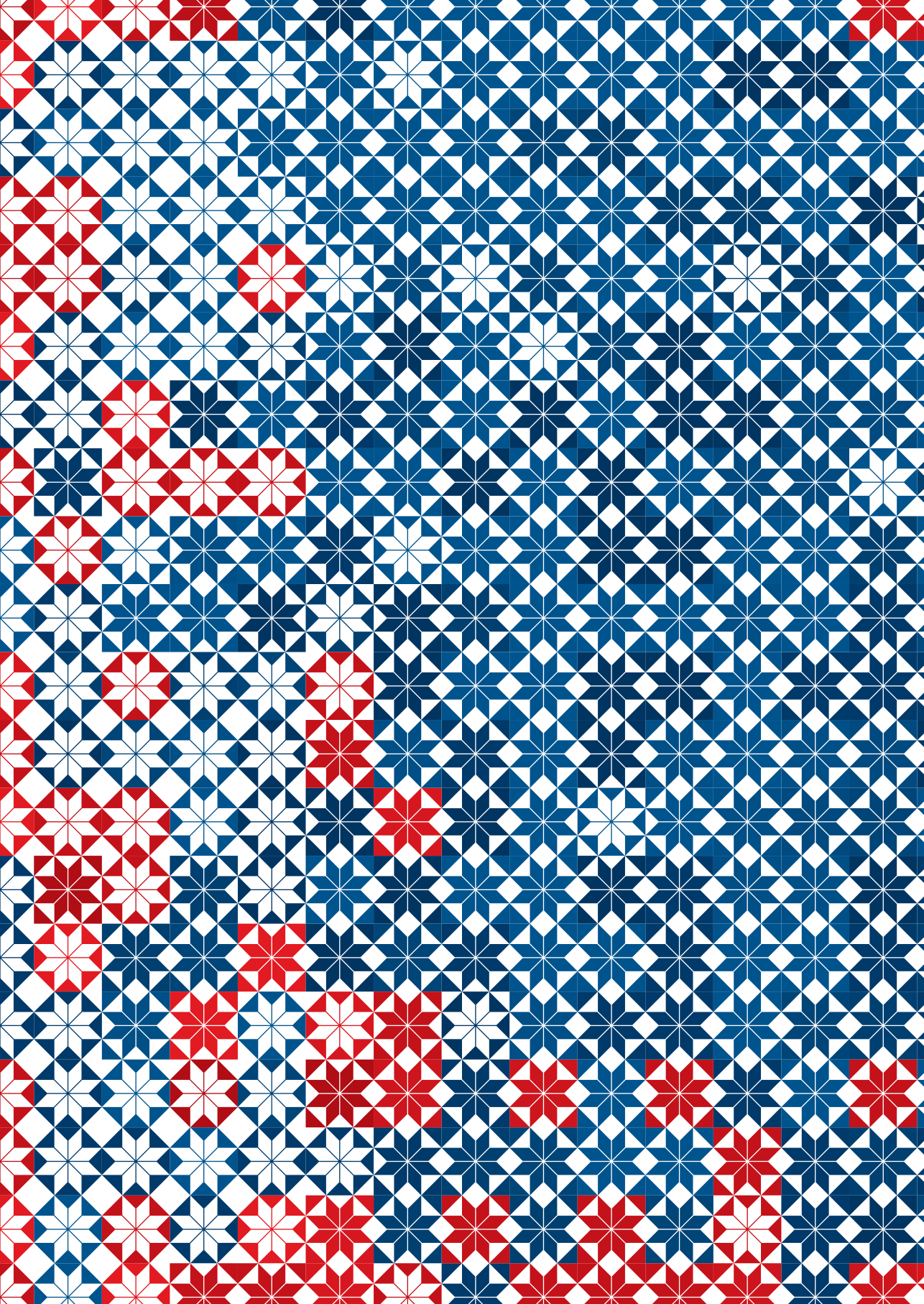
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Supplementary Material

Additional file 1—Research team characteristics and reflexivity statement following the consolidated criteria for reporting qualitative studies (COREQ)
Available at *https://tinyurl.com/Chapter5SM1*
Additional file 2—Completed consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist
Available at *https://tinyurl.com/Chapter5SM2*
Additional file 3—Interview guide for the data collection
Available at *https://tinyurl.com/Chapter5SM3*
Additional file 4—Spreadsheet for data collection of barriers and enablers
Available at *https://tinyurl.com/Chapter5SM4*
Additional file 5—Invitation letter to review the guide
Available at *https://tinyurl.com/Chapter5SM5*
Additional file 6—Overview of the informants by study phase
Available at *https://tinyurl.com/Chapter5SM6*
Additional file 7—Case studies' results of the All.Can Action Guide for Efficient cancer Care
Available at *https://tinyurl.com/Chapter5SM7*
Additional file 8—List of barriers and enablers per cluster mapped to the attributes of the ICON Framework and grouped in sub-categories
Available at *https://tinyurl.com/Chapter5SM8*
Additional file 9—Recommendations published in the Action Guide per cluster of metrics
Available at *https://tinyurl.com/Chapter5SM9*



Chapter 6

System-wide use of Patient Reported Outcome Measures (PROMs) in OECD countries: insights from a health policy survey and key informant workshops

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Abstract

Objectives: Patient reported outcome measures (PROMs) can systematically integrate the patient perspective to enhance value-based, people-centred healthcare. This study aims to assess the current systematic use of PROMs data across OECD countries and identify barriers and enablers for system-wide implementation from decision-makers' perspectives.

Methods: A cross-sectional country-level survey was conducted among country officials from 38 OECD member and accession countries, and key partners. Two researchers independently coded survey responses. Analysis of barriers and enablers to implementation was guided by the integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework and survey results were validated through two online workshops, with 72 and 81 key informants, respectively.

Results: Among 38 countries surveyed, 44 PROMs programmes were identified in 21 countries. Main purposes of data collection were quality improvement (95% of the programmes) and quality assurance (55%). The primary users of PROMs data were healthcare professionals (68%), policymakers (59%), and healthcare professional organisations (59%). Programmes more frequently engaged healthcare professionals (93%) than patients (79%). In most programmes (73%), patients could complete PROMs via online platforms, whereas in less than half (39%) PROMs data were embedded into electronic health records. The most reported barriers to implementation included limited staffing capacity, technological challenges and insufficient training for both patients and healthcare professionals.

Conclusion: Improved resource allocation, meaningful stakeholder engagement and embedding PROMs into data infrastructures can contribute to system-wide PROMs implementation.

Introduction

In recent decades, health authorities and policymakers have increasingly showed interest transitioning to a value-based, people-centred healthcare model, emphasising the integration of patient perspectives into care delivery and performance management [1]. In 2017, and reaffirmed in 2024, health ministers of the Organisation for Economic Co-operation and Development (OECD) countries committed to systematically measure patient-reported measures to gain insights into healthcare systems' performance [2, 3]. Patient-reported outcome measures (PROMs), health outcomes collected through standardised questionnaires directly from patients [4, 5], have emerged as essential tools to advance the value-based healthcare agenda by supporting decision-making at individual patient point of care (micro), organisational (meso) and system policy/regulatory (macro) levels (Box 1) [6, 7].

Box 1 Definition of clinical, organizational, and system levels

Clinical level (micro): Refers to the direct interaction between patients and individual healthcare providers, where PROMs are used to inform and tailor care for the individual patient.
Examples: A patient completing a PROM questionnaire during a follow-up visit with their general practitioner; PROMs used by a surgeon to assess recovery after knee replacement surgery.
Organizational level (meso): Refers to initiatives implemented within a single organization or a group of organizations, where PROMs data are collected and used to moniter and improve services at the organizational level.
Examples: A hospital department collecting PROMs to monitor outcomes across its patients; a hospital chain or network of primary care practices using PROMs to benchmark performance internally.
System level (macro): Refers to program coordinated at national or subnational level (e.g., province, state or region), where PROMs data are aggregated to inform system-wide policies, governance, accountability, and quality assurance.
Examples: A national PROMs program embedded in the health information system; a regional health authority collecting PROMs data across multiple hospitals to inform policy decisions.

Systematic PROMs data can offer unique insights into people's health and quality of life that are often not captured by traditional measures such as hospitalisations, prescriptions, or clinical results [6]. Aggregated PROMs data (routinely collected and analysed at the group level) can support quality improvement by nudging healthcare professionals to improve patient care when provided data are perceived credible, timely, and relevant to patient care goals [7, 8]. At system level, aggregated PROMs data can be used for quality improvement (through internal assessment to promote continuous improvement) and for quality assurance (through external assessment mechanisms such as accountability, public reporting and outcome-based payments) [9]. When integrated into performance measures, PROMs can enhance people-centredness, care quality, and potentially reduce low-value care and costs [6, 10, 11]. Yet, achieving substantial improvements requires sustainable system-wide approaches, where implemented PROMs programmes are maintained and institutionalised with stable operations such as integration into data infrastructures and stakeholder engagements [8, 9, 12].

Despite their potential, the system-wide implementation of PROMs faces multiple challenges. Previous studies identified barriers related to human factors (e.g., lack of motivation and limited time for learning or training among patients and healthcare professionals), organisational factors (e.g., health information infrastructure compatibility, resources) and system-level factors (e.g., lack of political and leadership support, lack of standardisation of PROMs tools and their use) [13]. Conceptual, methodological, and practical challenges have also been reported [14]. Political leadership has been particularly recognised as a key enabler for enhancing the implementation of PROMs [9, 11].

A 2019 OECD survey found 12 of 23 countries collecting PROMs at national level, while 15 planned expansion within five year [15]. Between 2018 and 2024, 19 pioneering countries joined up to design, develop and implement the OECD's Patient-Reported Indicator Surveys (PaRIS) initiative which collects PROMs alongside patient-reported experience measures (PREMs) from more than 100 000 patients and 1 800 primary care practices across these countries [16].

Given the rapidly evolving landscape and growing interest in PROMs programmes

[17-20], a comprehensive study on their systematic use at the national level, and barriers to implementation is needed. Although several studies have examined barriers and enablers, the application of implementation science frameworks to organise these factors contextually is missing. While the use of PROMs in clinical patient care, specific disease areas and hospital settings are well-documented [21-26], few studies address system-level initiatives [21, 23]. Some studies assessed the use of PROMs within the concept of value-based people-centred healthcare using desk reviews and expert interviews, though limited to selected countries [9, 27-30]. This study provides insights from 38 OECD member and accession countries, and key partner countries committed to advancing the people-centred healthcare agenda through PROMs while examining the barriers and enablers encountered from decision-makers' perspectives.

This study aims to assess the current systematic use of PROMs data across OECD countries and identify barriers and enablers for system-wide implementation from decision-makers' perspectives. The objectives of this study are to identify the main purposes of PROMs data use, examine the key stakeholders utilising PROMs data, assess the extent to which PROMs are embedded within data systems, and explore the engagement of patients and healthcare professionals in the collection and use of PROMs data.

Methods

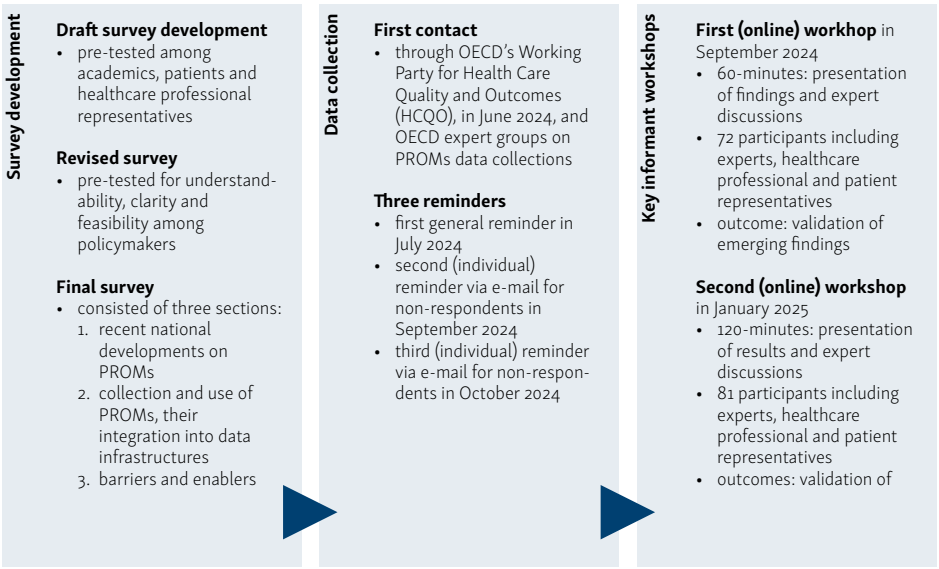
Study design

A cross-sectional country-level self-reported survey was conducted among official delegates of 48 OECD member and accession countries, and key partner countries between June and October 2024. Delegates are appointed by their respective Ministries of Health and represent their countries in official OECD bodies, therefore involved in decision-making processes. Results were validated through two online workshops with 72 and 81 key informants. Figure 1 details the key steps in the survey

development, data collection and key informant workshops.

The research design was submitted to the Amsterdam UMC ethical committee [METC number 2025.0662], which determined it was not subject to the Medical Research Involving Human Subjects Act (Wet Medisch-Wetenschappelijk onderzoek met mensen (WMO)) approval. The CROSS checklist was used to report this study
230 (supplementary material 1) [31].

Figure 1 Key steps in survey development, data collection, and validation of results



Development of the survey

The survey was developed iteratively with input from patients, healthcare professionals, academics and policymakers. The researchers (CK, ASVC) developed the first draft of the survey between March and April 2024. The integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework informed the development of the first draft [32]. Determinant frameworks are theoretical approaches developed in implementation science to better understand the factors that influence implementation [33]. For this study, conducted with key

informants at system level, we considered a framework that specifically addresses the relevance of context to implementation. This framework, which highlights the central role of context, has undergone extensive development and widespread use [19]. Supplementary material 2 shows how each of the core constructs of the i-PARIHS framework was applied in the survey domains. Members of the research team who have expertise in PROMs in practice, research and policy (KdB, MvdB, OBF, DK, NK, JVM) reviewed and provided feedback.

The final survey included 38 questions—a mix of open-ended, binary and multiple-choice questions (supplementary material 3). The barriers section combined multiple-choice categories with open-text fields to reflect well-established barriers from the literature, while allowing elaboration. The enablers question was open-ended to capture a wider range of perspectives from decision-makers. The survey was designed to capture initiatives mainly at national and subnational levels, as well as at organisation level when no system level initiatives existed. Initiatives at the clinical level were out of the scope of the survey. Respondents were asked to suggest up to five key informants from their respective countries who are known (inter) nationally for their expertise and involvement in the collection and use of PROMs. These key informants were then invited to attend two online workshops to discuss and validate the results.

Data collection

The survey was shared with country officials via the official communication channel of the OECD in June 2024, reaching officials of 48 countries, including all 38 member countries, six candidate (Argentina, Brazil, Bulgaria, Croatia, Peru and Romania) and four partner countries (Malta, Singapore, South Africa, and Ukraine), represented by 385 country officials. To gather comprehensive and accurate information, country officials were encouraged to share the survey with relevant national and subnational stakeholders involved in PROMs data collection and use. To increase response rate, the survey was also shared with the members of two OECD expert groups on condition-specific PROMs through e-mail. No new country was invited through expert

groups. Three reminders were sent between July and October 2024: the first to all country officials, and subsequent ones to non-respondents until the deadline.

The survey was available online in Microsoft Forms©, with a Word version provided upon request. Respondents could submit their responses through the online platform or via email to the contact researcher (CK). Multiple responses from the same country were allowed through country officials and relevant stakeholders who received the survey through their country officials or OECD expert groups on PROMs.

Validation of results through key informant workshops

In total, 101 key informants were invited; two online workshops in Sep 2024 and Jan 2025 validated the collected data, assessed their accuracy, and reviewed results and emerging policy and practice recommendations (figure 1). Before the meetings, informants received the agenda including discussion points and expected outcomes. Before the second meeting, informants also received the draft report including the results, list of PROMs programmes and informants, and draft policy and practice recommendations. In both meetings, one researcher (CK) presented the findings and participants were invited to comment on their validity and accuracy, in a session moderated by other researchers (MvdB, KdB). A final report was shared with all country officials and key informants for accuracy check.

Data analysis

A data extraction template in Excel was created by one researcher (CK) where all responses were compiled, and it was reviewed by another researcher (ST) (Supplementary material 4).

First, descriptive quantitative analysis was conducted in Excel to analyse the multiple-choice (close-ended) questions, referring to purposes of PROMs data use, quality assurance mechanism used, users of PROMs data, integration into data infrastructures, engagement of patients and healthcare professionals and barriers.

Second, a qualitative thematic analysis [34] was conducted on the open-ended

text regarding the barriers and enablers. Two researchers (CK, ST) independently conducted inductive and deductive coding of the data, making it reflexive and dynamic, allowing for continuous refinement throughout the analysis, as recommended by Braun and Clarke [35, 36]. The inductive component involved generating themes from the responses without pre-defined categories, followed by a deductive component applying the i-PARIHS framework to categorise barriers and enablers [32]. First, to map survey responses to the i-PARIHS framework, three researchers (CK, ASVC, ST) held a 90-minutes online meeting to discuss the initial data coding and map responses to the core constructs of the framework through deductive coding. After agreement on the mapping, one researcher (ST) coded all responses by aligning with the agreed framework mapping exercise and another researcher (CK) reviewed all codes mapped on the framework. Both researchers reviewed each other's coding and discussed any conflict to reach consensus.

Insights from two online workshops with key informants were used to refine the findings from the survey. Although no formal qualitative analysis was conducted on the workshop discussions, the participants' comments were used to reinforce the survey results and provide additional contextual validation, contributing to the triangulation of findings.

All authors reviewed and approved the final results. The presence and number of PROMs programmes were presented at country level. The characteristics of the programmes, such as their purpose, users, integration into data infrastructures, and engagement with patients and healthcare professionals, were presented at programme level. Barriers and enablers were presented at respondent level.

Results

Survey respondents

The study received responses from 38 countries out of 48 invited countries, resulting in a response rate of 79%. A total of 59 responses were received across 38 partici-

pating countries, with a median of one response per country (range: 1-6) (table 1). Among respondents, 64% (38 out of 59 respondents) completed all sections of the survey. About 31% of responses (18 out of 59) had missing data primarily in reporting of PROMs programmes. Most of responses were from countries where there was no reported PROMs data collection and use, explaining the lack of responses to the PROMs programme details section. Only 8% (5 out of 59) of respondents reported PROMs data collection in the recent developments section but did not respond to the questions on details of PROMs programmes.

Table 1 Survey respondents

Country	Number of responses per country	Median response completeness (%)	Number of reported PROMs data collection	Median response completeness related to the characteristics of the PROMs programmes (%)
Australia	3	100	2	100
Austria	2	90	3	100
Belgium	2	90	2	100
Bulgaria	1	40	0	NA
Canada	1	100	7	100
Colombia	1	40	0	NA
Costa Rica	1	20	0	NA
Croatia	1	20	0	NA
Czechia	1	40	0	NA
Denmark	1	100	1	100
England (UK)	3	100	3	100
Estonia	1	100	2	100
Finland	1	100	2	100
France	2	70	1	10
Germany	3	100	3	100
Greece	1	100	2	100
Iceland	1	20	0	NA
Ireland	1	100	2	100

Israel	1	100	1	100
Italy	2	100	2	100
Japan	1	20	0	NA
Latvia	1	20	0	NA
Lithuania	1	20	0	NA
Luxembourg	1	100	2	100
Mexico	1	20	0	NA
Netherlands	6	90	5	100
New Zealand	1	100	1	100
Norway	2	100	2	100
Portugal	1	100	1	100
Romania	1	40	0	NA
Slovakia	1	20	0	NA
Slovenia	1	100	2	100
South Korea	1	40	0	NA
Sweden	1	100	1	100
Switzerland	4	100	4	100
Türkiye	1	40	0	NA
United States	2	100	2	100
Wales (UK)	1	100	1	100

PROMs programmes at system level across OECD countries

Survey responses identified 55 PROMs programmes in 24 out of 38 countries (63%), with a median of one programme per responding country (range=0-7). Each PROMs programme was reported only once. Among these programmes, more than two thirds (44 out of 55 programmes, 80%) reported that the scale of PROMs data collection was at the national or subnational level. Eleven out of 55 (20%) programmes reported data collection only at the organisational level. While these programmes concerning only the organisational level fell outside the predefined scope of this study, these were provided by respondents and therefore these data were analysed separately (supplementary material 6).

Purposes of PROMs data use

Quality improvement was the primary purpose for PROMs implementation in 38 out of the 40 programmes (95%) that reported on the purpose of PROMs data use (table 2). Quality assurance followed, reported in 22 programmes (55%), while quality assurance combined with accountability mechanisms was reported in 21 programmes (53%). The most frequently used quality assurance mechanisms were public reporting (22 out of 40 programmes, 55%), audit and feedback (19 out of 40, 48%), and clinical pathways (17 out of 40, 43%). Less often mentioned were regulations of inputs (n=11; 28%), clinical guidelines (n=8; 20%), and supervision (n=6; 15%). Other quality assurance mechanisms were reported in fewer than 10 programmes, namely accountability reporting (n=5; 13%), pay for quality (n=4; 10%), certification (n=3; 8%), and accreditation (n=3; 8%).

Table 2 Key characteristics of PROMs data collections and use

Characteristic (number of respondents)	Number of responses (%)
Purposes of PROMs data use (n=40)	
Quality improvement	38 (95)
Quality assurance	22 (55)
Quality assurance and accountability	21 (53)
Quality assurance mechanisms (n=40)	
Public reporting	22 (55)
Audit and feedback	19 (48)
Clinical pathways	17 (43)
Clinical guidelines	8 (20)
Regulations of inputs	11 (28)
User of PROMs data (n=41)	
Healthcare professionals	28 (68)
Healthcare professional organisations	24 (59)
Policymakers	24 (59)

Managers	19 (46)
Patients or patient organisations	13 (25)
Integration of PROMs into data infrastructures (n=41)	
Online platforms accessible via mobile phones, tablets and computers	30 (73)
PROMs embedded into electronic health records	16 (39)
Engagement of patients in the PROMs programmes (n=42)	
Patients as partners with decision-making roles	14 (33)
Patients involved in advisory groups without decision-making role	16 (38)
Patients consulted or informed of the PROMs programmes	15 (42)
Patients not engaged at all	9 (21)
Engagement of healthcare professionals in the PROMs programmes (n=42)	
Healthcare professionals as partners with decision-making roles	29 (69)
Healthcare professionals involved in advisory groups without decision-making role	16 (38)
Healthcare professionals consulted or informed of the PROMs programmes	10 (24)
Healthcare professionals not engaged at all	3 (7)

Users of PROMs data

Healthcare professionals were identified as the primary users of PROMs data (28 out of 41 programmes, 68%), followed by healthcare professional organisations (24 out of 41, 59%) and policy makers (24 out of 41, 59%) and managers (19 out of 41, 46%). Patients and patient organizations were reported as PROMs data users in 14 (34%) and 12 (29%) out of 41 programmes, respectively.

Integration of PROMs into data infrastructures

Out of 40 programmes, 16 (40%) reported that the PROMs data were embedded into electronic health records. In 30 programmes (73%), online platforms were made available to collect PROMs data, which were accessible via mobile phones, tablets and/or computers. Once collected, 26 out of 41 (63%) programmes reported that the PROMs data were stored in central data repositories, where data from one or more sources are stored and managed in one location, facilitating data management.

In 11 out of 41 programmes (27%), patients were able to see their own results, without being able to interact further. In 35 out of 40 programmes (88%), healthcare professionals could interact with PROMs data either by viewing individual patient results, comparing aggregated results or seeing summaries. In 26 programmes (65%), healthcare professionals had access to real-time individual data and in 16 programmes (40%) to real-time aggregated PROMs data. In 24 programmes (60%), healthcare professionals could see the summary of PROMs results.

Engagement of patients and healthcare professionals in the PROMs programmes

Out of 42 programmes responding to patient engagement, patients were engaged in 34 (81%) programmes at some level. In 14 programmes (33%), patients were partners in the PROMs programme such as in steering committees with decision-making roles. In 16 out of 42 (38%) programmes they were involved in advisory groups but did not have any decision-making role. In 15 out of 42 programmes (36%), patients were consulted on or informed of the PROMs programmes.

In 39 out of 42 programmes (93%), healthcare professionals were engaged at some level. In 30 out of them (71%), they were partners with decision-making role, while 16 programmes (38%) reported involvement of healthcare professionals without decision-making role. In 10 out of 42 (24) programmes, they were consulted on or informed of PROMs programmes.

Barriers and enablers to system-wide implementation of PROMs

The major barriers from the perspective of decision makers were resource constraints, technological limitations and lack of learning and training for patients and healthcare professionals. Out of 28 respondents, 22 (79%) reported staffing shortages for data collection and analysis, 21 (75%) reported financial limitations for acquiring and implementing PROMs, 21 respondents (75%) reported compatibility issues with existing health information systems, 15 respondents (54%) lack of learning and training for patients, 14 respondents (50%) lack of knowledge and training for healthcare

professionals, and 14 (50%) and 15 (54%) respondents low response rates due to lack of motivation or interest among patients and healthcare professionals, respectively. While low response rates due to time commitment of healthcare professionals was an important challenge (18 respondents, 64%), patients were perceived less concerned about it (10 respondents, 36%). Concerns about data privacy regarding patient and healthcare professional engagement were reported by nine (32%) and three (11%) respondents, respectively. In addition, 11 (39%) respondents encountered language and literacy barriers affecting comprehension of questions by patients a challenge in PROMs collection and use.

When applied to the i-PARIHS framework, many challenges were identified in the 'Recipient' (providers and patients) construct, namely regarding lack of time, resources and support, skills, motivation, and values and beliefs (Supplementary material 5). Nonetheless, factors at the health system level were also reported as having a role, such as resource constraints, both financial and in staff, and technological limitations.

Perceived levers to advance PROMs data collection and use at the system (macro) or organisational (meso) level, were distributed across different constructs within the framework: 'Innovation' through underlying knowledge and sources, 'Recipient' through time, resources and support, skills and knowledge and motivation, and 'Context' through policy drivers, priorities, incentives and mandates, inter-organisational networks and relationships, senior leadership and support at organisational level, structure and systems and learning networks (Supplementary material 5). Common themes were identified as perceived enablers, including effective governance and policy implementation through political commitment and national approach, integration in health information systems (e.g. electronic health records, national registries) and development of data infrastructures, communication, awareness raising and learning and training (both for healthcare professionals and patients). Some respondents also mentioned developing non-financial (e.g., feedback reports, public reporting) and financial incentives for healthcare professionals and other stakeholders, developing further evidence on the importance of collecting and using PROMs by linking it to spending and other databases (e.g., administrative)

and developing standardised methods and guidelines for collection and reporting of PROMs data.

Insights from key informant discussions

240 Participants highlighted the growing momentum in PROMs adoption across countries, the need for stronger data integration, standardised tools, and increased patient and healthcare professional engagement. Case studies from multiple countries demonstrated strategies, including embedding PROMs into electronic health records, leveraging digital tools for real-time feedback, and using PROMs data to drive quality improvement initiatives. Experts shared the identified barriers, providing contextual information on key challenges, such as resource constraints and variation in implementation across healthcare settings.

Discussion

Summary of main findings

This study assessed key characteristics of PROMs use across 38 OECD member and accession countries and identified both barriers and enablers to their system-wide implementation. While most OECD countries have implemented PROMs programmes at system level, their integration remains uneven. Quality improvement emerged as the primary purpose of PROMs data use. While healthcare professionals are the primary users of PROMs data, their use by policymakers is not systematic. Online platforms are used widely to collect data, and nearly one third embedded PROMs data intro electronic health records. In nearly all programmes, healthcare professionals can interact with PROMs data by seeing results from individuals or comparing groups. In a much lesser extent, patients can see their own results, without further interaction. While most PROMs programmes engage healthcare professionals, patient engagement remains limited.

These findings confirm that scaling up PROMs programmes to achieve system-wide implementation is frequently constrained by multiple factors. These factors are resource constraints and compatibility issues with existing health information systems as reported by decision-makers. Key enablers for advancing PROMs data collection and utilisation at the system level include strong governance, integrated data infrastructures and active engagement of patient and healthcare professional.

Comparison with existing literature

Since the introduction of the value-based healthcare concept in early 2000s [1], collection and use of PROMs have evolved rapidly, showing growing interest among decision-makers in implementing PROMs programmes at the system-wide level. Our findings confirm growing national interest in PROMs. Compared with a 2019 OECD survey [15], more countries have developed PROMs programmes, consistent with international trends. A study conducted in Australia in 2016 showed although many organisations in the healthcare sector were interested in PROMs, their development, collection and use were patchy and inconsistent [29]. An international study in 2021 identified nine out of 13 countries collecting PROMs data at national level and using for different quality assurance mechanisms [28]. Our study showed that the remaining four countries now also collect and use PROMs data at national level, indicating the progress made in these countries. This growing interest among countries for PROMs use at the system level highlights the need for further research on their role in decision-making and their impact on quality improvement.

Our study showed that PROMs are primarily used for quality improvement, followed by quality assurance. This usage was proportionally higher than reported in a 2021 review of 13 countries, which found that 10 used PROMs for comparing health establishments, four for public reporting, and five for pay-for-performance [28]. A systematic review found little to no effect of quality improvement methods based on aggregated PROMs data, though specific mechanisms remain understudied [14]. A review of national programs in England and Sweden found both successful in collecting PROMs data [37]. In Wales, introducing PROMs was associated with a 70%

reduction in low-value appointments [38]. Another analysis showed fewer patients than expected required follow-up at six months post-surgery [38]. The Australian Joint Registry found patients undergoing early revision had lower post-operative PROMs scores, highlighting PROMs' potential to identify patients needing timely intervention [39]. While promising, evidence of PROMs' impact on system-level care quality remains limited. Stronger evidence on PROMs impact on healthcare system performance is needed to support their role in policymaking. Without robust evidence, PROMs risk being 'nice-to-have' rather than essential for patient-centered decision-making.

Our study showed frequent use of digital tools for PROMs data collection and use, yet limited integration into electronic health records. A recent systematic review of literature assessing the benefits and disadvantages of electronic PROMs collection and use found that they costs less, improves data quality, results in similar or faster completion times, and requires less administration time compared to paper-based PROMs [40]. Reported disadvantages included substantial financial investment, technical issues and difficulties with access for certain patient groups [40]. When effectively integrated into information systems, PROMs can also contribute to quality improvement throughout the healthcare systems [37, 38]. Integrating PROMs into electronic health records and allowing interaction of patients and healthcare professionals with PROMs data can enhance PROMs data collection and use [38, 41, 42]. While minimising data collection burden, electronic PROMs data collections integrated into health information systems can also ensure timely access to patient-reported data. This integration, ensuring linkage with other databases (e.g., clinical records, administrative, registries), can inform decisions by policymakers and other stakeholders such as practitioners, health service managers and researchers [38, 43].

Our study found that most programmes engaged patients and healthcare professionals. While healthcare professionals often had decision-making role, patients were often engaged as advisors, consultants or informed as end-users. Engagement of patients and healthcare professionals in PROMs programmes and the level of their engagement were not systematically explored in previous international reviews on PROMs use [28-30] During the field testing of PaRIS in 17 countries, patients and

healthcare professionals often played a passive role, as opposed to an active role, according to the national implementation plans [44] A follow up study among same countries showed that approximately half of countries mentioned co-development with primary care professionals in their main survey implementation plans [45]. Engagement of healthcare professionals has been shown to improve the acceptability of routine collection and use of patient-reported measures in clinical practice and implementation of patient-reported measures [9, 46-48].

Through the use of an implementation science framework (i-PaRIHS), our results showed that most encountered barriers were reported as being related to the 'recipient' construct, namely by lack of time, resources and support, skills and knowledge and motivation. However, the perceived levers to develop PROMs programmes at system level were touching upon different constructs, namely, 'innovation' through underlying knowledge such as harmonisation and standardisation and 'context' through policy drivers and incentives. A qualitative analysis from a systematic review also reported barriers at different levels, namely conceptual (e.g., stakeholders involved, subjectivity of PROMs), methodological (e.g., choice of measurement, focus of measurement, representativeness of collected date) and practical (e.g., funding for implementation, support from government, technological support) barriers [14]. Another international implementation study focusing on cancer metrics signalled a relevant role of external health system level factors, namely the lack of a national strategy to systematic data collection of patient-reported metrics was perceived as a key barrier and political will and patient advocacy as relevant enablers [49]. As illustrated in the OECD's PaRIS initiative, international collaboration can support the overall goal of achieving more people-centred healthcare systems through use of shared resources on data collection, analysis, and training, fostering cross-country learning and strengthening healthcare systems globally [44].

Policy and practice recommendations from this study

In light of the results from previous studies, our findings stress that while significant progress has been made, achieving full system-wide implementation of PROMs

requires political leadership, sustained efforts and targeted strategies.

PROMs initiatives, often confined to specific diseases, standalone units, or research projects, must be scaled up to encompass entire healthcare systems. Historically, value-based healthcare initiatives have been initiated at organisational level, mostly at hospital settings. While today there are existing initiatives at system-level, many initiatives stay limited to specific diseases/conditions. Access to high-quality people-centred care across the healthcare system should be universal, requiring upscaling and broadening of existing initiatives and fostering a culture of improvement across the healthcare system. Policies should equip key stakeholders- policymakers, healthcare professionals, patients and citizens to learn from and act on PROMs.

Integrating PROMs within national healthcare plans and priorities is critical for advancing value-based, people-centred healthcare systems. Countries with national plans have progressed significantly over the past years. Investing in data infrastructures to make PROMs data integral part of systematic data collections and engaging patients and healthcare professionals to increase their appropriateness and acceptance are essential to develop sustainable programmes.

Strengths and limitations

To our knowledge, this is the broadest capture of the international landscape on the systematic use of PROMs at system level. Responses were provided from policymakers, registries representatives and academics. While the list of PROMs programmes included in this study is not exhaustive, nevertheless, our study reported information from 38 countries reporting 55 different PROMs programmes. As survey responses rely on policymakers' and experts' perspectives, the results may not fully capture on-the-ground realities of PROMs implementation. We also lack information about how and to what extent the reported PROMs programmes were implemented in the countries, including their interactions with quality assurance mechanism or uses for decision making. Countries with limited PROMs activity may have provided incomplete responses and we did not receive any information from nine countries. In addition, the study does not assess the effectiveness of PROMs programmes in

achieving quality improvement or patient-centred outcomes. Nevertheless, results were discussed and validated by 81 key informants. This alignment across multiple data sources strengthens the robustness of the findings through methodological triangulation, enhancing confidence in the study's conclusions.

Conclusion

The findings support that several countries are taking initiative to advance value-based, people-centred healthcare. Most OECD countries implemented PROMs programmes; however, system-wide implementation remains fragmented, hindered by insufficient patients and healthcare professional engagement, resource constraints and technological limitations. Further attention should focus on resource allocation, meaningful stakeholder engagement and stronger link with data systems, to accelerate PROMs implementation and contribute to more people-centred healthcare systems.

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Supplementary Material

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Supplementary material 1—Checklist for Reporting Of Survey Studies (CROSS)

Available at *https://tinyurl.com/Chapter6SM01*

Supplementary material 2—Mapping of the core constructs of the i-PARIHS framework to the survey domains and questions

Available at *https://tinyurl.com/Chapter6SM02*

Supplementary material 3—Final survey

Available at *https://tinyurl.com/Chapter6SM03*

Supplementary material 4—Data extraction template

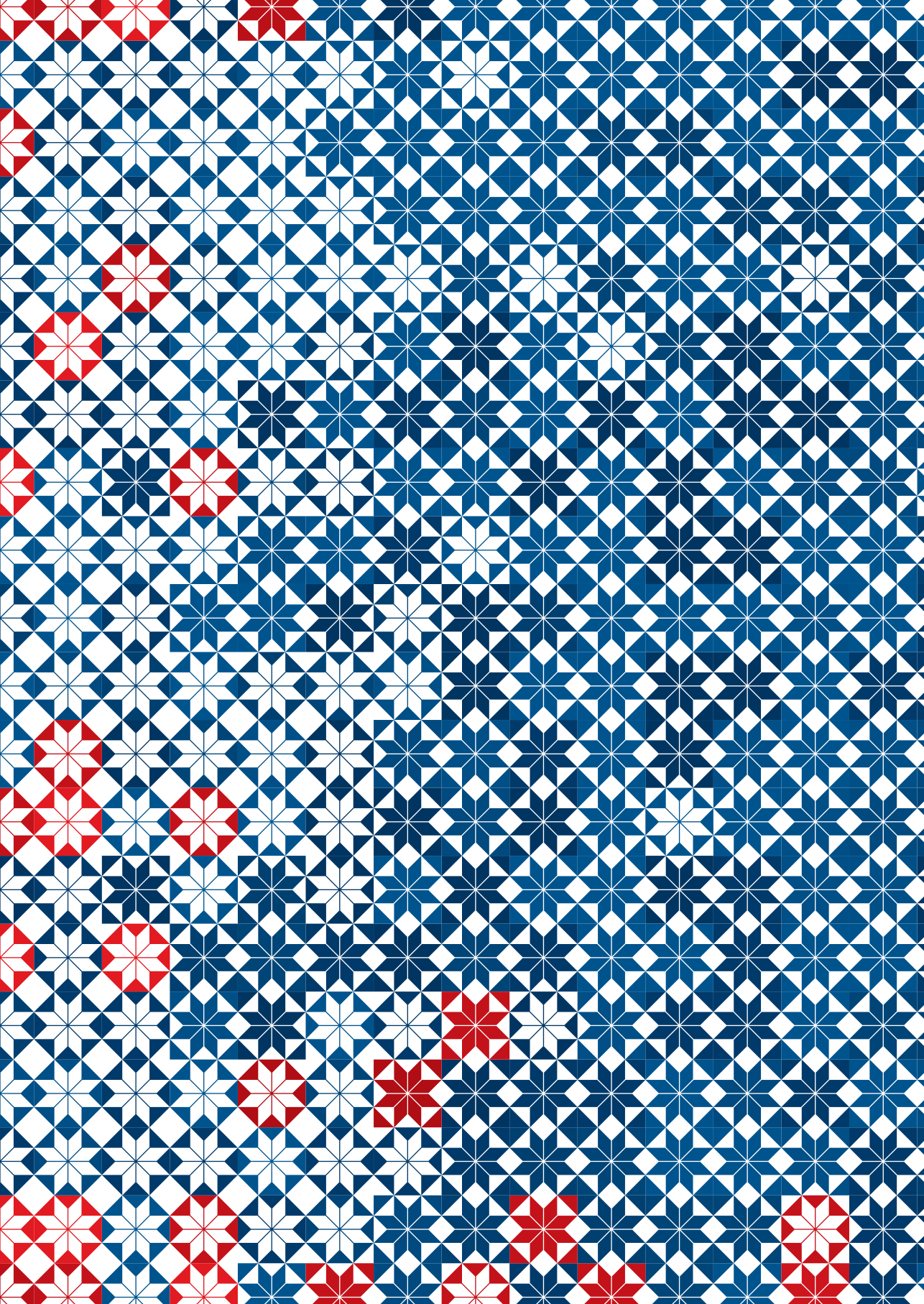
Available at *https://tinyurl.com/Chapter6SM04*

Supplementary material 5—Application of the perceived barriers and enablers to the i-PARIHS framework

Available at *https://tinyurl.com/Chapter6SM05*

Supplementary material 6—Characteristics of the programmes reporting only at the meso level

Available at *https://tinyurl.com/Chapter6SM06*



General discussion

The impact of the COVID-19 pandemic on cardiovascular diseases (CVD) and cancer services [1, 2], combined with their rising prevalence in an ageing population and a decrease in the share of the working-age population, places significant pressure on health systems [3]. Additionally, a wide range of social, economic and ecological mega-trends [4] are increasing the focus on the ability of health systems to respond to shocks [5] and on aligning healthcare with population expectations and needs [6, 7].

This thesis aimed to generate new insights into how the performance of cardiovascular and cancer care pathways can be assessed and strengthened, and to provide evidence to support decision-making at the clinical, managerial, and policy levels. Building on lessons learned from the COVID-19 pandemic, this thesis applies co-creation as a practical approach to develop tools that can inform stakeholders across these care pathways. To achieve this, the thesis addressed two main research questions, which form the basis of its two Parts (Table 1): 1) How can the impact of shocks on healthcare delivery for people living with cardiovascular diseases and cancer be monitored through performance measurement and a care pathway approach?, and 2) How can the performance of cardiovascular and cancer care pathways be strengthened to promote more resilient and person-centred healthcare delivery?

Summary of findings

In Part I, which includes the studies described in **Chapters 1-3**, three scoping reviews were conducted. These studies aimed to assess the changes in the quality of care during the COVID-19 pandemic in member countries of the Organisation for Economic Cooperation and Development (OECD), through the identification of per-

Table 1 Outline of chapters and their aims

Sections	Chapters	Aims
Part I: Assessing the performance of acute cardiovascular and cancer care pathways during the COVID-19 pandemic	Chapter 1	To assess the impact of the COVID-19 pandemic on hospital cardiac care pathways, as assessed by performance indicators
	Chapter 2	To assess changes in the quality of acute care during the COVID-19 pandemic through summarising available performance indicators and assessing their trends
	Chapter 3	To assess changes in the quality of cancer care through the summarisation of performance indicators and assessing their trends
Part II: Co-creation of tools to strengthen resilience and person-centredness in cardiovascular and cancer care pathways	Chapter 4	To develop a resilience assessment tool for cardiac care pathways, providing recommendations to enhance resilience
	Chapter 5	To identify barriers and enablers to implementing cancer metrics globally and to describe the co-development of an implementation guide to support their embedding of these metrics into cancer care pathways
	Chapter 6	To assess the systematic use of PROMs data and to identify barriers and enablers for system-wide implementation, from decision-makers' perspectives

formance indicators in the literature to assess this impact. In **Chapter 1**, indicators across the hospital cardiac care pathways were retrieved from 94 studies. In **Chapter 2**, a total of 152 acute care studies were included, with a substantial number of indicators focusing on cardiovascular emergencies. **Chapter 3** assessed the cancer care pathway from a total of 135 studies.

The indicators retrieved in **Chapters 1-3** allowed the mapping of the entire cardiovascular and cancer care pathways, including the stages of diagnosis, treatment, outpatient care/follow-up, and outcomes. Changes in the performance of these pathways were assessed through these indicators' trends. **Chapters 1-3** reported

decreasing trends in the number of admissions and in the volume of diagnostic and treatment procedures, alongside increased treatment times, and more clinically advanced conditions at presentation, when comparing these trends with periods before the COVID-19 pandemic. Concerning outcome indicators, a mixed picture was observed, namely stable outcomes in patients diagnosed with acute coronary syndromes, alongside an increasing trend in the short-term mortality rates of people with cardiac diseases (**Chapter 1**). Most of the indicators reported a stable trend regarding 'procedures and surgical outcome measures' in cancer care delivery (**Chapter 3**).

Part II included three empirical studies embedded in international multi-stakeholder projects, applying principles of Participatory Action Research (PAR) through co-creation, to strengthen more resilient and person-centred healthcare delivery. The study described in **Chapter 4** reports the development of a structured and context-sensitive tool to assess and strengthen preparedness and response to future crises affecting cardiac care delivery. Embedded in a Europe-focused project, the study identified six dimensions of health system resilience from the literature as relevant to cardiac care pathways: (a) workforce, (b) organisation of care delivery, (c) governance and trust, (d) communication and cooperation, (e) medical devices and products, and (f) data collection and use. The factors considered most crucial to maintain access to cardiac care during crises were investing in the workforce's health protection and strengthening communication with patients. The findings informed the development of a resilience assessment tool comprising four components: 1) the mapping of a context-specific cardiac care pathway, 2) a stakeholder mapping exercise, 3) a self-assessment preparedness checklist addressing the six resilience dimensions and 17 sub-dimensions, and 4) a resource toolkit to support the development of an action plan to strengthen resilience. The tool is being piloted in European hospitals to refine its practical applicability.

The study described in **Chapter 5** described the participatory development of an Action Guide designed to support the embedding of cancer care performance indicators across cancer care pathways globally, in collaboration with a non-profit, multi-stakeholder global organisation.

The study identified key barriers and enablers to advance the implementation of cancer metrics, focusing on three clusters of metrics: timeliness of care, coordination of care, and person-centeredness. Regulation of standardised cancer care pathways and legislation supporting data collection were identified as relevant enablers. Key barriers were underdeveloped electronic health records and lack of database interoperability and of nation-wide unique patient identifier.

The study described in **Chapter 6** assessed the current systematic use of PROMs across health systems, as part of OECD's PaRIS initiative [7]. A total of 44 PROMs programmes were identified spanning 21 countries. Most of the programmes reported data collection at national or subnational level. The primary purpose of PROMs implementation across countries was quality improvement. System-wide implementation of PROMs remains constrained by several factors, such as limited resources, insufficient engagement from patients and clinicians, and technological barriers.

Parts I and II provide complementary insights into understanding and strengthening of cardiovascular and cancer care pathways. Part I characterised the impact of the COVID-19 pandemic across all stages of these care pathways by systematically mapping performance indicators and their trends. Building on the indicators, challenges, and disruptions identified in Part I, Part II developed actionable tools to support improvements in measuring and strengthening resilience and person-centredness across health systems.

Reflection on the findings

Part I

Performance indicators in the literature spanned the entire cardiovascular and cancer care pathways, although with variable depth across stages

Across the care pathway stages, some were less well represented or lacked specific indicators. Both the diagnosis and treatment stages mainly included volume infor-

mation (e.g., number of patients or procedures) and clinical severity. Clinical severity was assessed through various measures, such as the level or urgency by triage system and clinical or analytical parameters. These data provide relevant information about access to care during a crisis. Some indicators assessed innovations employed during the COVID-19 pandemic, such as the use of telehealth in the fields of cardiology (**Chapter 1**) and cancer (**Chapter 3**). While changes in cancer treatment were reported by various quantitative indicators and through survey-based data (**Chapter 3**), indicators explicitly reporting changes in the treatment of cardiovascular conditions were not retrieved. Few indicators in the literature monitored outpatient care.

Most of the performance indicators provided process information, such as the volume of patients admitted and the number of diagnostic/treatment procedures performed. The volume and waiting times for elective care are two common indicators to assess health system resilience related to elective care [8]. Timeliness of care was assessed through various indicators, particularly related to pre-hospital care (**Chapter 2**), acute coronary syndrome treatment times (**Chapter 1**), and access to cancer care (**Chapter 3**). Some indicators monitored timeliness of care indirectly by assessing 'delayed presentation', for instance the time after symptom onset in patients with acute coronary syndromes arriving to the Emergency Department. A smaller share of indicators assessed the operational times in acute care related to other diseases, which is a key component to monitor access and care continuity during a crisis. Moreover, a lack of indicators assessing coordination of care, patient experiences, patient-reported outcomes, or patient safety culture is noteworthy. These are key aspects for international benchmarking and quality improvement.

These indicator gaps may result from various factors. Fragmented data infrastructures, with limited interoperability and data linkage between different databases hinder the monitoring of timeliness and coordination of care across healthcare settings and levels of care. Person-centred measures are most likely lacking as a result of the limited systematic collection of patient-reported metrics across health systems [9, 10]. Furthermore, the search strategy for the three scoping reviews in this thesis did not include the search terms 'patient-reported measures' neither 'patient safety', which may partially explain why these specific indicator themes

were not retrieved. Patient safety culture (PSC) measures are frequently assessed by surveying the health workforce on an ad-hoc basis [11]. A first pilot data collection focusing on PSC conducted by the OECD in 2020-21, based on survey data, showed many opportunities for improvement [12]. More recent data reported that only 44% of nurses and physicians perceive their work pace and staff levels as adequate for ensuring patient safety [3].

Moreover, a smaller proportion of indicators in the literature reported outcomes during the COVID-19 pandemic, with the exception of the short-term outcomes after an emergency department visit (**Chapter 2**). Since cancer often presents as a chronic disease that evolves over a medium-term period, its outcomes cannot be sufficiently assessed through short-term evaluations alone. Nonetheless, some indicators retrieved may signal initial changes in presentation and staging, which ultimately influence outcomes, such as 'clinical severity at diagnosis', 'changes in cancer staging', and 'proportion of urgent/emergent referrals and procedures'. Outcome indicators such as 30-day mortality rates following stroke or acute coronary syndrome and five-year cancer survival are well-established indicators to monitor the quality of care, and are regularly reported in flagship international reports [3, 13].

Performance trends during the COVID-19 pandemic signalled that health systems struggled to maintain care continuity

Overall, the three studies of Part I reported similar trends across the cardiovascular and cancer care pathways. The results signalled both patient- and health system-related delays, highlighting a compromise in access and timeliness of care during the pandemic. The reduction in the volume of admissions and procedures has resulted from the suspension of elective procedures and changes in treatment [1, 2, 5]. Nonetheless, the reduction of hospital visits and worsening clinical condition at presentation signal patient-related delays and are concerning trends. These findings suggest that the population delayed seeking care, either due to fear of COVID-19 infection or perceptions of overwhelming the health system. Insufficient population awareness, misinformation, lack of trust and insufficient communication channels

with healthcare professionals may have contributed to these delays [14-16].The reduction of visits by non-urgent patients may provide a window of opportunity to reduce unjustified use of the Emergency Department, however, this would need to be complemented by primary care strengthening and cooperation.

Similar performance trends have been reported across OECD countries. Notably, marked reductions in hospital inpatient activity, particularly elective care [5] and increased waiting times on the list for elective surgeries [8]. Health systems were not sufficiently prepared and the health workforce was overstretched [5]. High unmet needs were reported across 22 OECD countries: more than one in five people, on average, postponed a medical examination or treatment [5].

Innovations, such as telemedicine and changes in treatment, signalled quick adaptations and flexibility from healthcare professionals. Treatment plans and care pathways were swiftly adjusted in response to the need to reduce hospital visits and the risk of infection, as well as to cope with the shortage of professionals, intensive care unit beds, and ventilators [5]. These findings suggest that health systems gradually adapted during the crisis. However, the delays in access to diagnosis and treatment suggest that health systems were not able to cope with the surge in demand from patients with COVID-19, suggesting the need to foster preparedness and increase the ability to cope with future shocks.

The performance indicators retrieved signal meaningful changes in care delivery across the care pathways, nonetheless they lack standardisation and disaggregated information

The results from Part I show the ability of the performance indicators retrieved to inform on meaningful trends across the key stages of these care pathways, thus showing the potential to support decision-making. However, indicators frequently presented heterogeneous terminologies and methodologies. This lack of standardisation in performance monitoring between organisations, regions and countries hinders cross-organisation and cross-country comparison for benchmarking. It also undermines the ability of health data infrastructures to support real-time

decision-making across health system levels. Some international initiatives aim to support countries through the standardisation of performance indicators to facilitate cross-country exchange and benchmarking [3, 17]. The indicators provided in our results may support the standardisation of indicators and foster their embeddedness across health information systems.

Furthermore, in the three studies of Part I, most of the indicators were retrieved from studies using retrospective cohort design. Survey data were another important data source to assess the performance of cardiovascular and cancer care delivery, and were much less represented in the acute care context. This signals that most countries lacked timely access to this performance information to support decision-making during the pandemic. Most performance indicators are currently reported for year t-2 and only a minority for year t-1 [18]. A more regular and near-real-time measurement of these indicators could support monitoring of these pathways in future shocks. This may contribute to avoiding or minimising disruptions of care delivery during crises, building resilience and people-centeredness into health systems.

Additionally, the availability of performance indicators disaggregated by aspects of socio-economic status, gender or ethnicity is still lacking in most contexts. This information is key to monitor and improve equality in access and quality of care provided, thus contributing to enhance health system resilience. Populations living in vulnerable situations face worse health outcomes, with evidence of sustained socio-economic health gaps across OECD countries [3]. Furthermore, the impact of the COVID-19 pandemic was uneven across population groups [19], highlighting the importance of monitoring disaggregated performance information during crises.

Various international initiatives have been deployed to tackle these challenges. In 2024, the OECD Meeting of Health Ministers called on the OECD to support countries to tackle gender health disparities, namely through the improvement of data infrastructure and data analysis [20]. At European level, the European Cancer Inequalities Registry (ECIR) presents information disaggregated by sex, education, income, urbanisation, age, disability, and employment status, by country [21]. The recently launched EU Safe Hearts Plan also targets health inequalities across and within EU Member States, namely driven by gender, geography, and socioeconomic

factors [22]. These are essential efforts, which need to be broadened and replicated at national level, to foster the resilience of care pathways.

Part II

Co-creation served as a development approach to generate actionable tools to support decision-making across health system levels

In Part II, the co-creation approach employed allowed the development of actionable tools to support decision-making and implementation in policy and clinical contexts. A 'research derived actionable tool' has been previously described as a construct with three core components: a) 'knowledge object', which considers that it is possible to recognise the knowledge generated by the research within the tool, b) a 'medium for communication' of the tool, which considers its target population, and c) a 'prompt for action', which encourages an action or a decision not to act [23].

In this thesis, co-creation served as a key approach to operationalise resilience and person-centredness as measurable dimensions of performance. Practical insights were co-developed for and with end-users, across all the phases of the research. In doing so, the lead author assumed the role of an embedded researcher, thus ideally positioned to foster co-creation. Being an embedded researcher facilitates establishing a close relationship with the organisation and their stakeholders, contributing to achieve results relevant to stakeholder needs [24].

The international and participatory nature of the three studies of Part II accounted for diverse perspectives. This diversity enriched the research findings and fostered a sense of ownership, which contributes to a more successful adoption of the findings and tools developed. In **Chapter 4**, broad involvement of multi-stakeholders ensured that resilience measurement was captured through components that reflect the ability of the health system to sustain care under stress. This was translated into a tailored self-assessment tool for cardiac care pathways. The All.Can implementation guide further demonstrated how cross-country exchange and learning can contrib-

ute to embedding resilience and person-centredness into performance monitoring (**Chapter 5**). In **Chapter 6**, OECD's country officials were consulted to map barriers and enablers to the system-wide implementation of PROMs.

The three studies of Part II contributed to making person-centredness a more actionable dimension of health system performance. **Chapter 4** highlighted the importance of communication with patients as a key factor for resilient cardiac care pathways, **Chapter 5** provided practical insights for implementing cancer-related patient-reported metrics, and **Chapter 6** contributed to characterising PROMs programmes across OECD countries and identified barriers and enablers for their implementation.

The co-creation process presents some limitations, which may be evident in different stages of the co-creation process. Challenges include sampling stakeholders to include a broad range of opinions, the presence of power imbalances which may hinder free expression of opinions, limited engagement of end-users with the solutions developed, among others [25]. In Part II, these limitations were minimised through the embedding of each project within established networks or international organisations. By engaging in the active role of embedded researcher in each project, network and organisation, the co-creation process increased the probability of sustained engagement of the end-users and facilitated the expression of opinions in a familiar environment. **Chapter 4** was initiated by a global network of interventional cardiologists and nurses in the cardiology field. Besides our own role as academics with expertise in the field of health services research, the project also involved an Italian cardiology society, a regional public health institute in Spain and an Advisory Board including organisations representing patients, nurses, allied professionals, and women physicians. **Chapter 5** was developed in close collaboration with a non-profit, multi-stakeholder global organisation—All.Can. This organisation includes ten individual and 34 organisational members, and National teams across 21 countries. **Chapter 6** involved OECD's country officials, as part of OECD's PaRIS initiative [7]. The OECD includes 38 Member States, from which 19 have participated in the PaRIS initiative.

Embedding resilience in cardiac care pathway design requires an adaptable workforce, flexible infrastructure and care models, clear protocols, robust data systems, and strong cooperation and trust across healthcare settings

In the wake of the COVID-19 pandemic, prioritising health system resilience as an explicit aim of health systems and testing it regularly are necessary steps for resilience strengthening [5]. The development of the resilience assessment tool for cardiac care pathways (**Chapter 4**) signalled the current lack of operationalisation of resilience across most health systems and services. It has highlighted the crucial need to develop tools and indicators to assess resilience to inform decision-making, from the perspective of cardiac care stakeholders. The co-creation of a resilience assessment tool showed the high level of interest from stakeholders across health system levels in various European countries. This motivation could be leveraged to pursue strategic efforts to enhance the resilience of care pathways. An essential point should be a strong commitment to ensure workforce health protection, a pivotal aspect of resilience.

Other international initiatives have been conducted to support stakeholders in enhancing health system resilience. At European level, 'A Practical Handbook For Resilience Testing' was launched in March 2024 [26]. At global level, the World Health Organisation (WHO) has developed the 'Health Systems Resilience Toolkit' [27], including technical resources to support countries in resilience-building efforts. **Chapter 4** follows a similar approach to the 'Practical Handbook' [26], as both present a collaborative resilience testing methodology to empower stakeholders to strengthen resilience in their context. **Chapter 4** focuses particularly on the cardiac care pathway. However, many themes and actions go beyond the health service or organisation, requiring policy embedding at national or sub-national levels.

The resilience dimensions identified and characterised in **Chapter 4** have been informed, in particular, by the OECD's HSPA framework [18] and the report 'Ready for the next crises' [5]. The component of 'expenditure and financing', proposed by the OECD's HSPA framework, is not captured in **Chapter 4**, as it was not an immediate concern by the stakeholders involved in the study (e.g. care providers

and scientific societies). Total health expenditure was not significantly associated with COVID-19 infections or excess deaths in the first two years of the pandemic in OECD countries [5]. Nonetheless, at health system level, the financing function of health systems is a relevant aspect to ensure resilience in the long-term [5, 28]. Furthermore, the population health dimension, proposed by the report 'Ready for the next crises' [5] was also not specifically addressed in **Chapter 4**, since the tool was developed for the hospital context. However, a healthier population contributes to more resilient health systems, thus improving preventive care should also be a core component of resilience [5]. Furthermore, the key aim of the resilience tool developed in this study is to contribute to ensure care continuity during crises, thus improving population health.

Potential indicators to assess health system resilience across the shock cycle were previously proposed by the OECD [3, 18]. These indicators focus on 'health system capacity', 'performance under stress' [18], and 'vulnerability of populations' [3]. They span the six resilience dimensions and related sub-dimensions identified in **Chapter 4**. For instance, monitoring the workforce well-being and health protection, the use of innovations, such as telehealth, the impact on timeliness of care, among others. Some of these indicators are already being collected, but many are not systematically collected [3, 29], such as the existence of preparedness plans or workforce strategies to increase workforce capacity [18]. The indicators proposed by the WHO to assess health system resilience include the components of service delivery, workforce, data, medicines and technologies, health financing, and governance and leadership [30]. As mentioned, the resilience tool developed in **Chapter 4** does not address health financing, while all the other indicators' themes were characterised.

Common key elements for enhancing the performance of cardiovascular and cancer care pathways, focusing on resilience and person-centredness: Workforce, Data, and Patient engagement

Despite the focus on different clinical areas—cardiovascular diseases and cancer—, the results of Part II highlight key common themes to assess and strengthen the

performance of these pathways, which are: a) **workforce** capacity, training and health protection, b) development of **data** ecosystems with harmonised regulations, interoperability, and systematic use of data for performance monitoring; c) **citizen and patient engagement**, specifically through stronger communication and cooperation. On the latter aspect, **Chapter 6** has particularly highlighted barriers and enablers for fostering the systematic collection of patient-reported data. These results signal the potential of strategically prioritising these aspects in the pursuit of more resilient and person-centred systems in the wake of COVID-19. These three themes are elaborated below, in relation to the results of Part II.

Strengthening the workforce, with a focus on capacity, training and well-being

Population ageing leads to an increase in the share of older population, higher demand for healthcare workers and a reduction of the working-age population [3]. **Chapter 4** highlighted that addressing workforce shortages was essential for resilient cardiovascular care pathways.

In **Chapter 5**, workforce capacity was also highlighted as a key factor to ensure coordination of cancer care. These results are aligned with findings from OECD countries. Higher workforce capacity—health and social care workers—during the COVID-19 pandemic was significantly associated with lower excess mortality, as compared to the OECD average [5]. **Chapter 6** highlighted that staff shortages for data collection and analysis and lack of knowledge and training were relevant barriers to implement PROMs programmes. These factors hinder progress in monitoring person-centeredness at health system level.

Chapter 4 also highlighted that the reallocation of professionals was key to ensure quick adaptation to the surge in care demand during the COVID-19 pandemic. To do so, continuous training was essential, which, in some contexts, was organised through informal channels during the crisis. In **Chapter 5**, new professional roles and task sharing were also considered essential aspects to enhance coordination of cancer care. The workforce's flexibility, namely the ability to task shifting and to employ new models of care delivery, was considered valuable to respond to surges

in care demand during the COVID-19 pandemic in OECD countries [5, 28]. A flexible workforce is more able to quickly adjust to different care settings, new work environments, and new care pathways [5]. To do so, is it key to increase and tailor training during shocks [5].

Chapter 4 further signalled that sustained monitoring and support to ensure professionals' well-being and health protection were essential to ensure a healthy and flexible workforce. In the analysis of health systems resilience conducted by Thomas and colleagues, the workforce's well-being and capacity were considered essential elements in every plan for crisis response and adaptation [31]. As such, integrated and planned strategies related to the workforce are considered essential to ensure quality of care during shocks [31]. The European Cancer Inequalities Registry Analytical Report, recently published by the OECD and the European Commission, also underscores the importance of preventing burnout among professionals to enhance the resilience of cancer care pathways [32].

In 2024, the Health and Care Worker Policy Lab was launched to monitor and address the gap in existing legal and policy environment to support healthcare workers across WHO Member States [33]. This online global repository compiles documents about the status of laws and policies related to the health workforce from around 190 countries. The resources are aligned with the elements that constitute the 'Global Health and Care Worker Compact' adopted in 2022 by the World Health Assembly [34]. A recent study provided a global baseline overview of how countries' national laws are aligned with the content of the Global Compact [35], showing significant gaps in national legal environments to protect health workers.

At international level, various initiatives are being developed and implemented to tackle this challenge. In 2022, the 75th World Health Assembly has adopted the 'Working for Health 2022–2030 Action Plan', an implementation tool to drive investment in health and care workers. It invites stakeholders across the health sector and related sectors to deploy initiatives that aim to promote investment mainly addressing working conditions and training.

Ten actions were proposed in the WHO report 'Health and care workforce in Europe: time to act' (2022). These recommendations include: training and continuous

professional development; working conditions, improvements in work-life balance and protecting health and well-being; technology use to support professionals; health information systems to enable data collection and analysis, workforce planning and governance, and public investment and optimisation of the use funds [36].

The results of **Chapter 4** may support these efforts, by highlighting specific actions to enhance care pathways' resilience. For instance, preparing training materials in advance, conducting simulation exercises, planning the reallocation of health professionals through the timely identification of professionals' skills and of professionals to provide training during crises. **Chapter 5** may also inform these initiatives by signalling the importance of the regulation at national level of the professional role of oncology nurses and cancer care navigators to improve the coordination of cancer care and regulation concerning task sharing and substitution to promote professional's flexibility.

Developing data infrastructures, particularly to provide more timely performance information and across health settings

The three studies of Part II highlighted the central role of robust data ecosystems for performance monitoring and health system resilience. In **Chapter 4**, the importance of close to real-timely data to monitor the cardiac care pathway was underscored as a key factor for care pathway's resilience. Interoperability across datasets was considered essential to enable coordinated and swift responses during crises. Availability of home care and primary care data enable a better coverage of the care pathway. In **Chapter 5** the lack of interoperability of databases and unique patient identifier was considered to hinder the ability to monitor the timeliness of cancer care. **Chapter 6** highlighted that only 40% of PROMs programmes among OECD countries had PROMs data embedded into Electronic Health Records (EHR). The development of data infrastructures was identified as a relevant enabler and compatibility issues across databases were considered a barrier to system-wide implementation of PROM programmes.

This evidence emphasises that digitalised health systems require high-quality

and interoperable data to ensure resilience and person-centred care. Well-developed health data infrastructure is considered a key enabler to foster the development and use of HSPA in OECD countries [37]. Countries are investing in expanding their health information infrastructure to improve accessibility of data and interoperability across health system settings [3]. Access to EHR has increased across OECD countries, however only two countries ensure full access to EHRs capabilities [3]. The OECD has proposed three work streams to further advance health data infrastructure: interoperability, health data governance frameworks, and sharing of best practices focused on data security [38].

This thesis' results only account for the application of artificial intelligence (AI) in healthcare delivery to a small extent. Some stakeholders in **Chapter 4** have mentioned the added value of AI in helping with the planning of the reallocation of healthcare professionals or in developing new workflows. The data collection of the studies of this thesis have occurred in a period where AI development was at earlier stages. Nonetheless, the rapid development of AI technology has the potential to streamline decision-making processes and to enhance the efficiency of care delivery. In the US, the Joint Commission (the main US hospital accreditor), together with the Coalition for Health AI (a clinician-led group involving various stakeholders), have developed guidance on responsible use of AI in healthcare [39]. Specific requirements include AI training for medical staff, regular risk and bias assessments, and regular quality monitoring of AI performance.

Improving communication with patients and monitoring patient-reported data systematically, notably during crises

Improving communication and cooperation with citizens and patients was a central theme in the three studies of Part II. **Chapter 4** highlighted the importance of official communication channels to facilitate exchange with citizens, patients and their communities and to foster trust in health systems during crises. **Chapter 5** underscored the key role of the involvement of patient groups and non-governmental organisations to support implementation efforts to improve person-centredness in cancer care.

Active engagement of patients and healthcare professionals was also perceived as a relevant factor to enable system-wide PROMS data collection in **Chapter 6**.

Enhancing communication was not highlighted in many of the international work addressing health systems resilience. Nonetheless, previous studies have underscored the key role of engaging with local communities [28] and training healthcare professionals with communication tools to apply during exceptional times [40]. For instance, Hart and colleagues have developed a toolkit with strategies to support family-centred inpatient care during the COVID-19 pandemic [40], relying on innovations to ensure family involvement during hospitalisation.

Current data collection and use of PROMs and PREMs is still insufficient to monitor the performance of the entire care pathway from the patient perspective. In an analysis of five cardiology-related Swedish National Quality Registries and two standards from the International Consortium for Health Outcomes Measurement (ICHOM), most of the quality measures monitored focused on clinician-reported outcomes [41]. Patient-reported outcomes were rarely reported, including patients' activities and lived experience. In cancer care, standardised person-centred care indicators are also rarely collected at national level [17]. In 2025, the OECD has conducted a pilot data collection on six cancer care indicators. In line with **Chapter 5**, only one indicator directly accessed a person-centeredness component, namely the 'use of systemic anti-cancer therapies in the last 30 days of life' [17]. From the 18 countries participating in the OECD pilot data collection, only 11 were able to provide data for this indicator. The other five cancer indicators addressed timeliness and quality of care [17].

To further incorporate the patient perspective in health system performance assessment, various national and international initiatives have been developed in the last decade. At international level, the OECD has led the PaRIS initiative [7]. A total of 19 participating OECD countries jointly developed and implemented a new set of indicators to measure the outcomes and experiences of people with chronic disease in the primary care setting [7]. In the hospital context, the Health at a Glance 2025 edition reports on PROMs before and after hip replacement surgery [3]. Since 2012, the ICHOM, an US-based nonprofit organisation, develops standard sets of

patient-centered outcomes [42]. These sets are used in healthcare facilities across the world, contributing to the standardisation and cross-country comparison of outcome measures across various clinical conditions. Nine cardiovascular sets and five cancer sets were developed by ICHOM's [42].

Nonetheless, several challenges persist to ensure the implementation of internationally comparable sets of patient-centered indicators. In line with the findings from in **Chapter 6**, recognised barriers to implement globally standardised outcome indicators include the insufficient linkages between administrative data sources. In the hospital-wide context, one Dutch study identified that, despite a solid infrastructure and embedding in the hospital priorities, time, knowledge and skills were considered insufficient by most healthcare professionals [43]. In line with the findings of **Chapter 5**, the Dutch study suggested that having PROM data embedded in EHR could reduce the burden of healthcare professionals. The role of nurses as part of support teams was also highlighted as a relevant facilitator, enhancing person-centeredness. This is aligned with the important role of these professionals in various support tasks, as underlined in **Chapter 5**.

Complementarity of Parts I and II

Together, the findings from performance measurement (Part I) and co-creation (Part II) illustrate a learning health system perspective. Part I identifies performance gaps and bottlenecks exposed by the COVID-19 pandemic, while Part II provides co-created strategies and tools to address these gaps. By combining systematic performance measurement with participatory tool development, this thesis moves beyond documenting disruption towards demonstrating how evidence can be translated into system-level learning and action.

Methodological considerations

Overall methodological design

In Part I, a scoping review methodology was applied, following the framework de-

veloped by Arksey and O'Malley [44] and Levac et al [45]. This methodology provides a structured approach that allows the summarisation and mapping of large and diverse bodies of literature [44, 45]. Furthermore, it serves as a valuable approach for identifying knowledge gaps within a specific domain [46]. Thus, it is well suited for the purpose of mapping a broad range of indicators and showing key trends. It is particularly appropriate given the heterogeneity of measures and contexts in which the effects of the COVID-19 pandemic on care delivery were assessed.

A participatory empirical approach was employed in Part II, aiming to generate actionable insights for practice and policy within cardiovascular and cancer care pathways across different health systems. To do so, the three studies of Part II were embedded in international multi-stakeholder projects. As mentioned earlier, these empirical studies applied a co-creation approach, to ensure the integration of stakeholders perspectives and needs into the design of practical tools. This inclusive development process also aimed to foster ownership and improve their fitness-for-purpose and -use.

Through the integration of the scoping review and co-creation methodological approaches, this thesis addresses the dual objectives that were set out. Part I provides a systematic and comprehensive summary of performance indicators and performance trends across the cardiac and cancer care pathways. These indicators may be standardised and monitored to support decision-making across health system levels in future shocks. Part II builds on the challenges and impact documented in Part I, by actively engaging with health system stakeholders and providing context to the performance information retrieved. The incorporation of stakeholders perspectives and lessons learned in Part II bridges the gap between research and practice. Moreover, it cultivated ownership and supported the development of actionable and evidence-based tools. These tools may inform improvements in the assessment and

strengthening of resilience and person-centredness at service and system level, by informing decision-making at the clinical, organisation and policy levels.

Engaging with international stakeholders across health system levels allowed the characterisation of challenges, opportunities, and lessons learned through the integration of diverse perspectives. These diverse viewpoints enriched the findings and ensured that the tools developed were contextually rich and comprehensive in scope. Through the involvement in these projects as an embedded researcher, it was possible to actively participate in the entire development process of the tools developed. In particular, through the participation and presentation of the results in meetings and events related to the projects. This interaction between the academic and practical approaches allowed for the refinement of the content and format of the tools developed. This co-creation approach has demonstrated its effectiveness by producing concrete outcomes, such as the successful results of the pilot testing of the RESIL-Card tool in various countries (**Chapter 4**) [47] and the All.Can Action Guide (**Chapter 5**) [48, 49]. These reflect the actionability of the tools developed for the cardiovascular and cancer care communities, as well as their interest in the resources offered by the tools.

The co-creation development process presents some limitations, as highlighted before. In **Chapter 4**, the network that was established prior to the study consisted of mainly clinicians. Thus, significant efforts were made to engage with a broad range of stakeholders in the cardiac care ecosystem. Nonetheless, the study was dependent on the professionals' willingness and time to participate. For this reason, in some of the focus groups some stakeholder types were not represented. **Chapter 5** drew on All.Can International's network, established prior to the study. This enabled to gather insights from an active and highly engaged global community. However, this may have introduced selection bias. Although it is a multi-stakeholder network, the participants representation per stakeholder type was uneven: most stakeholders were healthcare professionals and patient representatives. A minority were from governmental agencies or healthcare management. Moreover, the types of stakeholders participating in the study varied across countries, which may have hindered the completeness of the information. **Chapter 6** leveraged the OECD

network of country officials, which ensured similar stakeholder types and a similar level of knowledge among participants. However, not all officials were aware of the full range of regional and local initiatives to collect PROMs data, which limited the completeness of the results.

Validity

The major challenges posed by the COVID-19 pandemic across health systems led to a significant amount of evidence published on its impact. This has provided a relevant opportunity to study new performance indicators that could be monitored in future shocks. In **Chapter 1-3**, the heterogeneity of indicators' definitions, study designs, periods compared, and sample sizes did not allow to conduct meta-analyses to quantify the impact of the pandemic. It was also not possible to assess inequalities related to gender or socio-economic aspects. The heterogeneous number of studies per country resulted in skewed samples. It also needs to be taken into consideration that care providers experiencing the most severe impact were probably the ones more willing to publish it. Despite these limitations, the scoping review methodology proved valuable to provide a comprehensive and systematic mapping of performance indicators in the cardiac and cancer fields. As stated earlier, it proved a suitable method to identify indicators across these care pathways, categorised according to their clinical meaning and relevance. The overview of indicators across the care pathways showed their potential to signal trends in quality of care during crises. As mentioned before, these trends are aligned with the literature on the impact of the pandemic, which signals that these indicators may prove useful to standardise and monitor across health systems.

In **Chapters 4-6**, capturing the perspectives of stakeholders across health system levels was prioritised, to ensure actionability and ownership of the findings and tools developed. **Chapters 4 and 5** captured data across the three health system levels by engaging with stakeholders at different levels. These studies included around 200 informants, including patients/patient representative, physician, head nurse, allied professional, head of hospital department, general practitioner, hospital manager,

professional association, scientific association, researcher, national health agency, and industry representative. **Chapter 6** specifically addressed the system/macro perspective of implementation, including around 100 informants at the policy-making level of health systems.

In Part II, the operationalisation of the principles of Participatory Action Research followed different approaches, adjusted to the contexts of the organisations/ projects in which the studies were embedded. Regardless, as previously described, the participatory development approach included various phases, allowing for an iterative and inclusive process. Therefore, the heterogeneous co-creation methodologies employed did not influence the participatory nature of the tools developed. However, the applicability of the tools is particularly dependent on the contexts in which each tool was developed.

Chapter 4 was embedded in an European-based project. It included partners representing a broad network of cardiologists and various stakeholders involved in cardiac care delivery. A bottom-up and inclusive approach was applied, through an explanatory sequential mixed-methods study, to ensure that the care providers' perspective was effectively captured. The first step was a survey to care providers. Building on the survey's results, multi-stakeholder focus groups were conducted. Focus groups are a relevant qualitative method that enables collaboration and interaction to collect insights from various stakeholders, particularly their experiences and knowledge [50]. The insights of stakeholders from different organisations and countries and their experiences were complemented and validated during these discussions. This enabled participants from different organisations, regions and countries to recall the pandemic experiences, to share insights, complement and discuss each other ideas. This approach allowed to effectively capture a rich diversity of perspectives and ensured that this richness was taken into consideration throughout all the development process. The resilience tool development was informed by the previous steps. Other resilience tools were considered for reference, such as tools related to health systems and from different disciplines. The discussions among the entire Consortium and input from the Advisory Board contributed to ensure the stakeholders engagement throughout the study and ownership of the insights

generated.

In **Chapter 5**, the project was embedded in the international global multi-stakeholder organisation All.Can International. In this case, an exploratory qualitative design was conducted. It included semi-structured interviews and various moments of interaction with the All.Can community. The multi-stakeholder and international nature of this cancer organisation, combined with the aim of developing structured implementation guidance for its members, justified the option to conduct individual interviews. This approach enabled contextual characterisation and facilitated an in-depth understanding of barriers and enablers for implementation in different countries. The data analysis and the preliminary versions of the Action Guide were discussed in several moments with the broader All.Can community. This methodology proved effective in ensuring close involvement and ownership across the entire community. This fostered its uptake and use across the organisation after its launch.

Chapter 6 was embedded in an OECD initiative to comprehensively study the systematic use of PROMs programmes at national level and barriers to implementation. The OECD has a vast network of official national delegates across 38 OECD countries, allowing to capture the decision-makers' perspectives at system level. Thus, a survey among official delegates was employed to characterise the systematic use of PROMs data and to identify enablers and barriers for their for system-wide implementation. Two workshops organised at the OECD level allowed discussion and validation of the survey's findings.

Generalisability

Cross-country generalisability

This thesis has an international focus throughout all the studies. Part I—including **Chapters 1 to 3**—and **Chapter 6** focus specifically on OECD countries. These share a common framework for health system performance measurement [18]. **Chapter 4** includes European countries and **Chapter 5** spans 21 countries across the world, mostly high- and middle-income countries: 12 in Europe, two in North America, two

in South America, four in Asia and one in Oceania.

Across these international settings, several commonalities exist between health systems organisation, shared challenges and priorities. The investment in developing and strengthening HSPA and the focus on fostering resilience and person-centeredness are on the policy agenda in various countries [51-53]. At European level, there has been a strong investment in initiatives aimed at improving the quality of cardiac and cancer care delivery [13, 32, 54, 55]. At the OECD level, many initiatives have been focusing on fostering health system resilience [18, 20, 26] and person-centeredness, such as the PaRIS initiative [7]. These commonalities contribute to ensure that the studies are applicable to these international contexts. Nonetheless, differences in governance structures, digital maturity and data infrastructures may influence the transferability of the tools.

In Part II—**Chapters 4-6**—the users are encouraged to adapt the resources and recommendations to the specific context of their organisation or health system. This enables the tools and guidance developed to be context-sensitive. This tailored adaptation contributes to ensure that the tools remain effective and relevant within various national contexts. In **Chapter 4**, it was not possible to include all European countries with equal representativity, which may limit the generalisability of the results and the tool's applicability. This was balanced with the representations of various countries in the international focus groups and the broad range of international stakeholders involved throughout the study. In particular, professional and patient representatives with broad international representation, such as Women as One and Global Heart Hub, were closely involved in all the study's phases. The fact that data saturation was reached in the focus groups, without new relevant themes emerging in the international focus group, suggests that the tool developed is most likely generalisable across Europe.

The findings of this thesis may not be applicable to low-income countries. These often have different health system challenges, such as underdeveloped health information infrastructures and more limited human and financial resources. Validation and adaptation of the tools developed in these settings are necessary to ensure its applicability in these contexts.

Generalisability to other clinical fields

Chapters 1 to 3 focused specifically on the cardiac and cancer clinical fields. Therefore, their applicability to different clinical areas needs further testing. Nonetheless, the care pathway approach applied and the type of indicators retrieved could inform the development of performance indicators to other clinical areas. For instance, indicators related to clinical severity at admission, timeliness of care, treatment changes, and surgical outcome measures need to be adapted and validated to the specific clinical conditions being assessed.

Several aspects of the resilience tool for cardiac care pathways described in **Chapter 4** are potentially transversal to many clinical fields, as signalled by the similarity of resilience themes identified at health system level [5, 26]. For instance, the need to ensure the adaptability and well-being of the health workforce, the relevance of infrastructure flexibility and the reorganisation of care pathways, strengthening communication and cooperation between clinical settings and with communities, fostering data interoperability and timely data collection of agree-upon and standardised performance measures, as well as effectively monitoring and developing strategies to address supply chain bottlenecks. These aspects make the tool a suitable starting point for testing and validation in various clinical areas. Similarly, the findings of **Chapter 5** may inform about barriers and enablers for implementation of indicators in other clinical fields, besides cancer. In particular, if related to timeliness and coordination of care or person-centredness. Regardless, this evidence needs to be tested with stakeholders from different clinical fields.

Theoretical and conceptual implications

This thesis advances the conceptual integration of resilience as a core dimension of performance. Existing resilience indicators need to be broadened and refined to ensure alignment with the dynamic nature of health systems [18]. While previous literature has addressed health systems resilience primarily at system level, this thesis extends this work by operationalising resilience at a care pathway level, from

diagnosis to follow-up care. By doing so, this thesis informs the development of additional indicators to support systematic resilience monitoring at international, national, regional and local levels. These findings help clarify which measures require standardisation and which data infrastructures need strengthening to enable regular data collection in support of decision-making. This information can guide indicator development efforts in specific contexts, as well as relevant implementation initiatives.

This thesis also contributes to advancing the conceptual integration of person-centredness as a core dimension of performance. It highlights the key role of citizen and patient involvement to resilience strengthening (**Chapter 4**), as well as the essential role of political will, funding and a national approach to systematic data collection, supported by improvements in the levels of health literacy and high engagement of societal advocacy groups connected to the health system (**Chapter 5**). The assessment of the systematic integration of the patient perspective in **Chapter 6** provides further evidence of the importance of promoting meaningful stakeholder engagement and leveraging data infrastructures to enable the systematic collection of patient-reported metrics at system level.

Furthermore, this thesis contributes to strengthening care pathway thinking in performance measurement. Conducting performance measurement through a care pathway lens fosters a reflection on performance that mirrors the patient trajectory, thereby increasing its relevance and interpretability for patients. Considering care pathways as units of performance analysis promotes the contextualisation of metrics along the patient journey within the health system. In doing so, patients may become more meaningfully involved, supporting shared decision-making across health system settings. Furthermore, performance measurement through a care pathway lens facilitates the measurement of care continuity across settings and levels of care. It enables improved coordination across care providers by identifying bottlenecks or inefficiencies in the patient journey. As such, the care pathway approach is closely aligned with health system goals of improving resilience and person-centredness across patient trajectories.

The findings suggest that person-centredness is not only a performance goal in its own right, but also a key mechanism through which resilience is realised along

care pathways. Embedding person-centredness into health system performance measurement strengthens health system resilience. Strengthening communication channels with citizens and their representatives, alongside improving the systematic collection and use of patient-reported data contributes to health systems that are more responsive to population health needs. Embedding person-centredness and resilience in care pathway design supports the operationalisation of learning health systems, in which performance information is continuously used to adapt care delivery to changing contexts and needs.

Co-creation served as both a methodological approach and a conceptual learning mechanism within complex health systems. By employing co-creation, key stakeholders were engaged in a systematic and iterative manner, enabling the development of tools grounded in real-world experiences and lessons learned. This process resulted in outputs that are highly actionable for end-users. By embedding continuous participatory feedback loops into knowledge generation, this thesis shows how co-creation can support ongoing learning and adaptation in health systems, allowing them to respond more effectively to contextual needs and population preferences over time.

Policy and practice implications

As previously noted, the resilience tool developed in **Chapter 4** targeted stakeholders at organisational level, while **Chapter 5** assessed the cancer care pathway from a system perspective, and **Chapter 6** was developed as an instrument to improve implementation of patient-reported measurement at the macro-level. Nonetheless, all key stakeholders were involved in the studies, including clinicians and patients/patient representatives. As such, this thesis has built on the advantages of linking decision-making at the three health system levels to foster improvements at system-level. Below, we outline the main implications of this thesis' findings by health system level.

For clinicians and managers

As mentioned earlier, embedding patient feedback mechanisms requires improved training and awareness among both patients and professionals at the local level. Clinicians and heads of unit can contribute to these efforts. Engaging with patient organisations and communities and developing communication channels at organisational level are essential to improve communication during crises and enhance person-centred care delivery.

From a managerial perspective, the findings of this thesis underline the relevance of embedding resilience in care pathway design, notably through the incorporation of the key aspects outlined in the previous sub-sections. The development of strategies to support the workforce at organisational level is key, particularly through regular training and monitoring of well-being measures. Moreover, the co-creation process applied in this thesis underscores its value to develop trust, ownership and context-sensitive tools. This approach could be leveraged at organisational level in the development of local protocols and regular simulation exercises. By doing so, organisations may foster a more flexible and resilient workforce and enhance trust in the protocols developed, which may improve the responses during crises.

For policymakers

As discussed previously, at regional and national levels, investing in the standardisation of performance indicators and their embedding in regional and national data infrastructures is an essential step to better monitor the performance of care pathways, particularly during crises. The indicators identified in the scoping reviews may inform these efforts. Moreover, monitoring the resilience and person-centredness of care pathways also depends on well-developed data infrastructures. As mentioned earlier, resilience should be embedded in care pathway design across health systems. In addition to investments in health data infrastructures, including interoperability, this requires improved measurement and sustained investment in key areas identified

in this thesis: workforce, flexible infrastructures and care models, pre-established and tested protocols, and strong cooperation and trust across healthcare settings.

For international organisations (EU, OECD, WHO)

This thesis findings may continue to inform international efforts to collect and standardise performance indicators in the cardiovascular and cancer field. In particular, informing international initiatives such as the OECD cancer pilot data collection [17] and the performance of cardiovascular healthcare [55]. Embedding resilience across legislation and policies should be prioritised to strengthen preparedness at health system level, including through cross-sectoral approaches.

Recommendations for future research

Further research could focus on the development, standardisation, and assessment of the fitness-for-use and -purpose of the performance indicators identified in this thesis for cardiovascular and cancer care pathways. Standardised indicators measuring timeliness of care and person-centeredness require particular attention. Ensuring such standardisation would strengthen performance monitoring and enable cross-country comparisons.

Furthermore, future research is necessary to develop and validate resilience indicators at the health system level. As discussed earlier, embedding these indicators within national health data infrastructures would enable longitudinal monitoring and support regular quality assurance cycles. This integration would support healthcare performance management by providing care providers and decision-makers with robust tools to identify vulnerabilities and promote quality improvement.

The co-created tools developed in this thesis have the potential to be tested in real-world clinical and policy contexts. While the tools developed in **Chapters 4** and 5 have been piloted in some countries, their applicability could be assessed in additional countries and across other clinical areas. As mentioned previously, testing

their validity in low-income countries would help ensure global relevance and could support advances in equity in healthcare delivery.

Finally, another important field for future research is to explore how artificial intelligence tools can be incorporated and leveraged to support healthcare performance measurement across care pathways and inform decision-making, notably during crises. To fulfil that, the far-reaching potential of artificial intelligence can be rooted in primary sources of care delivery, rather than built separately. Research on examining opportunities to strengthen patient involvement in decision-making and to ensure participatory approaches in governance and performance management is also key. By combining standardised performance measurement with participatory approaches and digital innovation, future research can further advance resilience and person-centredness across health systems.

Conclusion

Building from the experiences and lessons learned from COVID-19 pandemic, this thesis provides insights to advance both the assessment and the strengthening of cardiovascular and cancer care pathways. By applying performance measurement through a care pathway lens, the thesis demonstrates how the impact of system-wide shocks on care delivery can be systematically monitored across diagnosis, treatment, follow-up, and outcomes.

The performance indicators identified across these pathways revealed meaningful changes in care delivery during the pandemic, highlighting gaps in access, timeliness, coordination, and person-centredness. These findings underscore the importance of standardising performance indicators that reflect care continuity and patient experience, and of embedding them within robust and timely data infrastructures. Combining data-driven insights with collaborative development proved to be an effective approach to support continuous learning, resilience, and person-centred care delivery. Strengthening the workforce, developing interoperable data ecosystems, and enhancing citizen and patient engagement were identified as key elements

for fostering resilience and person-centredness. Embedding co-creation within international networks and organisations supported ownership, relevance, and implementation across diverse contexts.

Through the integration of perspectives from the macro-, meso- and micro-levels, this thesis' findings may inform policy-making, as well as decision-making at organisational and clinical levels. By linking the activities across levels, health systems ensure alignment in goals and actions, which fosters quality improvement. To this end, uniform standardised performance information should be used across health system levels to improve decision-making towards this goal. Building on a major global health crisis, this thesis shows a way forward towards more resilient and person-centred care pathways. Ultimately, it seeks to contribute to improving care experiences and outcomes for people living with cardiovascular conditions and cancer, both in future crises and in routine care delivery.

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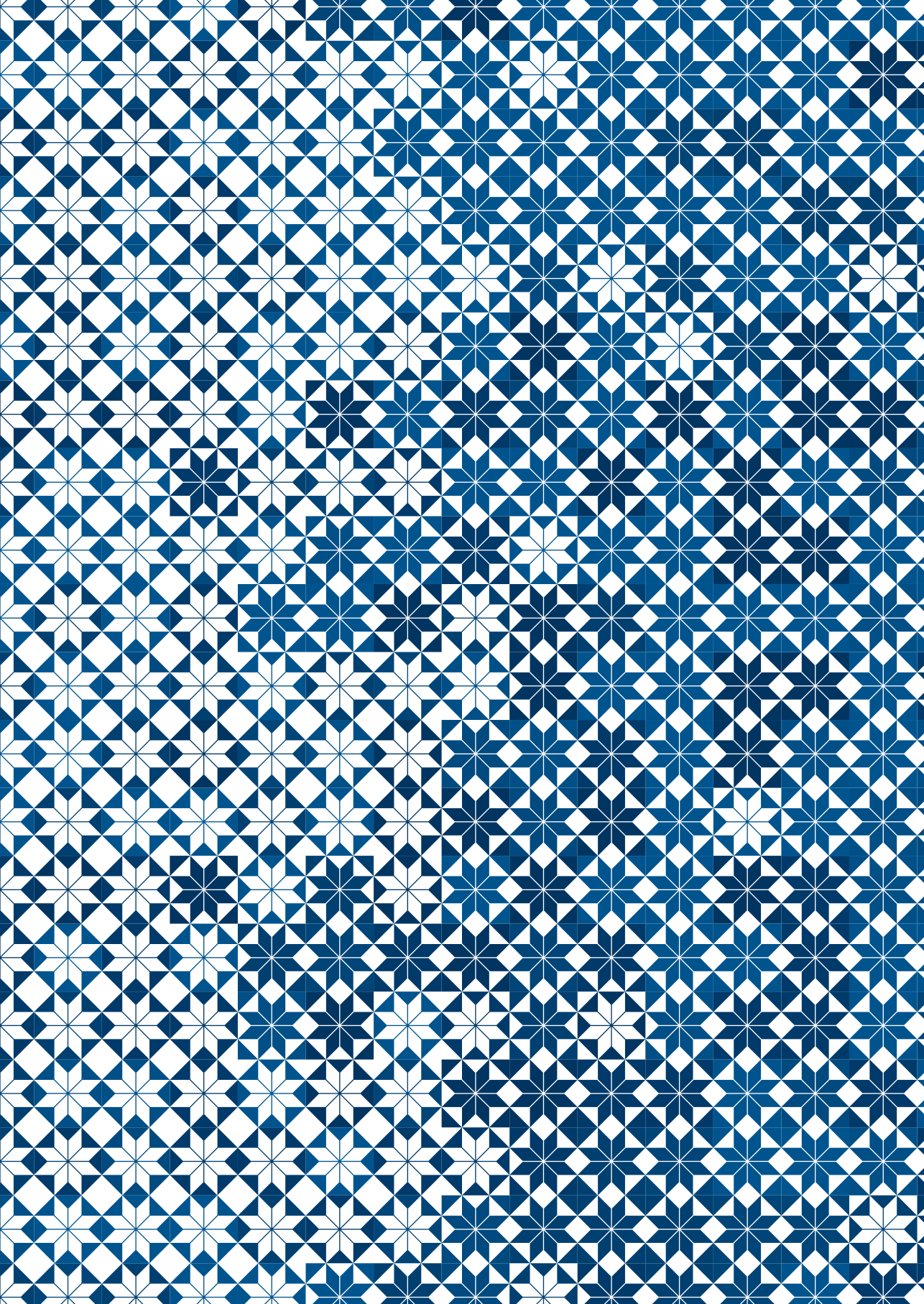
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Appendices

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Author contributions
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Acknowledgements
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Summary

The COVID-19 pandemic revealed vulnerabilities in health systems' ability to ensure access to and quality of care for people living with cardiovascular conditions and cancer during crises. Applying a whole-system approach, this thesis aims to support decision-makers across health system levels in strengthening the performance of cardiovascular and cancer care pathways, both during crises and in regular times. With a particular focus on resilience and person-centredness in healthcare delivery, this thesis addresses two main research questions, which guided Part I and Part II:

I) How can the impact of shocks on healthcare delivery for people living with cardiovascular diseases and cancer be monitored through performance measurement and a care pathway approach?

II) How can the performance of cardiovascular and cancer care pathways be strengthened to promote more resilient and person-centred healthcare delivery?

Part I includes the studies described in **Chapters 1-3**, focusing on OECD countries. These studies map performance indicators and synthesise trends in changes in the quality of care delivered during the COVID-19 pandemic across acute cardiovascular and cancer care pathways. The scoping review methodology is applied in these three studies. In **Chapter 1**, indicators across the hospital cardiac care pathway were identified. In **Chapter 2**, focused on acute care delivery during the COVID-19 pandemic, a substantial number of performance indicators assessing acute cardiovascular conditions were mapped. **Chapter 3** assessed the cancer care pathway. These three studies show similar trends across the acute cardiovascular and cancer care pathways. Notably, indicators show decreasing trends in the number of hospital admissions and of diagnostic and treatment procedures during the pandemic, compared with previous periods. Other indicators' trends suggest worse

clinical condition at presentation to the hospital and delays in treatment. These results underline the importance of monitoring the performance of these pathways systematically and regularly. These data may inform on which indicators should be prioritised for performance monitoring, promoting their standardisation and embedding in health information systems. This information may support clinical, managerial, and policy responses during crises.

The performance indicators identified in **Part I** show variable depth across stages of the care pathways, probably reflecting limitations in health information systems and related to the search strategy. Furthermore, this performance information lacks standardisation and disaggregated information, constraining the ability of decision-makers to respond effectively.

Part II describes three empirical studies in **Chapters 4–6**. These studies employ co-creation as a development approach to create actionable tools that empower decision-makers across health system levels. **Chapter 4** presents the development of a context-sensitive tool to enhance resilience in cardiac care pathways, describing a study embedded in a Europe-focused project. Six elements were identified as key to embed resilience in cardiac care pathway design: a well-supported workforce, flexible infrastructure and care models, clear protocols, robust data systems, resilient supply chains, and strong cooperation and trust across healthcare settings. This study's findings informed the development of a resilience assessment tool with four components: 1) the mapping of a context-specific cardiac care pathway, 2) a stakeholder mapping exercise, 3) a self-assessment preparedness checklist addressing the six resilience dimensions and 17 sub-dimensions, and 4) a resource toolkit to support the development of an action plan to strengthen resilience. The tool is currently undergoing pilot testing in selected European hospitals to enhance its practical applicability.

Chapter 5 describes the participatory development of an Action Guide designed to support the embedding of cancer care performance indicators across cancer care pathways globally. Conducted in collaboration with a multi-stakeholder global organisation, this study focus on three clusters of metrics: timeliness of care, coordination of care, and person-centredness. Regulation of standardised cancer

care pathways and legislation supporting data collection were identified as relevant enablers to advance the implementation of cancer metrics. Key barriers were underdeveloped electronic health records and limited database interoperability. This study demonstrates how cross-country exchange can contribute to embedding resilience and person-centredness into performance monitoring. The Action Guide is being piloted in some countries, such as Greece, to offer context-sensitive insights.

Chapter 6 sets out to assess the systematic use of patient-reported outcome measures (PROMs) and to identify barriers and enablers for system-wide implementation from decision-makers' perspectives, specifically involving OECD's country officials. A total of 44 PROMs programmes, spanning 21 countries, were identified. The primary purpose of PROMs implementation was quality improvement. This study's results show that system-wide implementation of PROMs remains constrained by various factors, such as limited resources, insufficient engagement from patients and clinicians, and technological barriers.

Through the integration of the scoping review and co-creation methodological approaches, Parts I and II provide complementary insights into understanding and strengthening of cardiovascular and cancer care pathways. In **Part I**, the scoping review methodology proved a suitable method to identify indicators across these care pathways. The heterogeneity of indicators' definitions, study designs, and sample sizes did not allow to conduct meta-analyses to quantify the impact of the pandemic. In **Part II**, the operationalisation of the principles of Participatory Action Research were adjusted to the organisations and projects in which the studies were embedded. The applicability of the co-created tools is particularly dependent on their contexts of development, requiring contextual adaptation rather than direct replication.

The studies described in **Chapters 1-5** specifically address either the cardiovascular or cancer fields. The performance indicators retrieved in **Chapters 1-3** may inform performance measurement in other clinical conditions, however they need adaptation and validation. Similarly, the tools developed in **Chapter 4-5** provide insights that are potentially transversal to many clinical fields. In both cases, this evidence needs to be tested and tailored before application to other clinical conditions.

The studies of this thesis have an international focus, mostly including high-

and middle-income countries. Considering the commonalities in health systems organisation, their priorities and challenges, the findings of this thesis are most likely applicable to health systems in other high- and middle-income countries. However, heterogenous governance structures and digital maturity could influence the transferability of the findings and tools.

Building on linking decision-making at the micro-, meso- and macro-levels to foster system-level improvements, this thesis provides policy and practice recommendations. For policy-makers, the findings of this thesis underline the importance of prioritising the standardisation of performance indicators and their embedding in data infrastructures, embedding resilience in care pathway design through the six dimensions outlined in this thesis, strengthening patient feedback mechanisms through improved training, as well as investing in co-creation processes to develop trust, ownership and context-sensitive tools. Future research could address the development, standardisation, and assessment of the fitness-for-use and -purpose of the performance indicators identified in this thesis. The co-created tools developed in this thesis may be tested in real-world clinical and policy contexts.

Building on a major global health crisis, this thesis combines data-driven insights in **Part I** with a collaborative development approach in **Part II**. **Part I** provides evidence to foster standardised performance information to support decision-making across health system levels. Building on the insights of Part I, and through the integration of perspectives from stakeholders at the policy, organisational and clinical-levels, **Part II** presents the co-creation of practical tools. These tools were designed to strengthen both the operationalisation of resilience within care pathways and the integration of person-centredness as a fundamental dimension of performance. Additionally, this thesis contributes to leveraging care pathway thinking as a relevant lens to contextualise metrics in performance measurement. Ultimately, the thesis seeks to support improvements in care experiences and outcomes for people living with cardiovascular diseases and cancer, whether in times of crises or within routine care delivery.

Samenvatting

De COVID-19-pandemie heeft kwetsbaarheden blootgelegd in het vermogen van zorgstelsels om tijdens crises de toegankelijkheid en kwaliteit van zorg voor mensen met cardiovasculaire aandoeningen en kanker te waarborgen. Vanuit een systeembrede benadering heeft dit proefschrift tot doel besluitvormers op verschillende niveaus van het zorgstelsel te ondersteunen bij het versterken van de prestaties van cardiovasculaire en oncologische zorgpaden, zowel in crisissituaties als in tijden van reguliere zorgverlening. Met een specifieke focus op veerkracht en persoonsgerichte zorg richt dit proefschrift zich op twee centrale onderzoeksvragen, die richting gaven aan **Deel I** en **Deel II** van het onderzoek:

I) Hoe kan de impact van schokken op de zorgverlening voor mensen met cardiovasculaire aandoeningen en kanker worden gemonitord aan de hand van prestatie-informatie en een zorgpadbenadering?

II) Hoe kunnen de prestaties van cardiovasculaire en oncologische zorgpaden worden versterkt om bij te dragen aan een veerkrachtige en meer persoonsgerichte zorgverlening?

Deel I omvat de studies die zijn beschreven in **hoofdstukken 1 tot en met 3** en richt zich op landen die zijn aangesloten bij de Organisatie voor Economische Samenwerking en Ontwikkeling (OESO). In deze studies worden prestatie-indicatoren in kaart gebracht en trends samengevat over iveranderingen in de kwaliteit van zorg welke tijdens de COVID-19-pandemie werd geleverd binnen acute cardiovasculaire en oncologische zorgpaden. In alle drie de studies is gebruikgemaakt van de scoping review-methodologie. In **hoofdstuk 1** zijn indicatoren geïdentificeerd over het gehele cardiologische zorgpad binnen het ziekenhuis. **Hoofdstuk 2** richt zich op de acute zorgverlening tijdens de COVID-19-pandemie en brengt een groot

aantal prestatie-indicatoren in kaart voor acute cardiovasculaire aandoeningen. In **hoofdstuk 3** wordt het oncologische zorgpad geanalyseerd.

De drie studies laten vergelijkbare patronen zien binnen de acute cardiovasculaire en oncologische zorgpaden. Zo tonen verschillende indicatoren tijdens de pandemie een afname in het aantal ziekenhuisopnames en het volume van diagnostische en therapeutische procedures in vergelijking met eerdere perioden. Andere trends wijzen op een slechtere klinische conditie bij presentatie in het ziekenhuis en op vertragingen in de behandeling. Deze bevindingen benadrukken het belang van het systematisch en regelmatig monitoren van de prestaties van deze zorgpaden. De resultaten bieden aanknopingspunten voor het prioriteren van prestatie-indicatoren voor monitoring, met het oog op verdere standaardisatie en inbedding in zorginformatiesystemen. Dergelijke prestatie-informatie kan klinische, organisatorische en beleidsmatige besluitvorming tijdens crises ondersteunen.

De in **Deel I** geïdentificeerde prestatie-indicatoren verschillen in mate van detail en beschikbaarheid tussen de verschillende fasen van de zorgpaden, zoals diagnostiek, behandeling en nazorg. Dit wijst op beperkingen in bestaande zorginformatiesystemen en is ook deels toe te schrijven aan de gehanteerde zoekstrategie binnen de uitgevoerde literatuurstudies. Daarnaast ontbrak het in de beschikbare prestatie-informatie aan standaardisatie en aan voldoende gedifferentieerde beschikbaarheid van gegevens, hetgeen de mogelijkheden van besluitvormers om effectief te reageren beperkte.

Deel II beschrijft drie empirische studies in **hoofdstukken 4, 5 en 6**. In deze studies is co-creatie toegepast als ontwikkelbenadering voor het creëren van praktische en toepasbare instrumenten welke besluitvormers zoals professionals, managers en beleidsmakers, op verschillende niveaus van het zorgstelsel ondersteunen. **Hoofdstuk 4** presenteert de ontwikkeling van een contextgevoelig instrument ter versterking van de veerkracht in cardiologische zorgpaden, in het kader van een Europees onderzoeksproject. Zes elementen werden geïdentificeerd als essentieel voor het verankeren van veerkracht in het ontwerp van cardiologische zorgpaden: goed ondersteunde zorgprofessionals, flexibele infrastructuur en organisatie- en zorgmodellen, duidelijke protocollen, robuuste datasystemen, veerkrachtige toelever-

ingsketens en sterke samenwerking en onderling vertrouwen tussen de betrokkenen in de verschillende schakels van de keten..

De bevindingen van deze studie vormden de basis voor de ontwikkeling van een instrument voor veerkrachtbeoordeling, bestaande uit vier componenten: (1) het in kaart brengen van een contextspecifiek cardiologisch zorgpad, (2) een stakeholder-
 analyse, (3) een zelfevaluatie-instrument in de vorm van een voorbereidingschecklist die de zes veerkrachtdimensies en zeventien subdimensies omvat, en (4) een set ondersteunende instrumenten voor het ontwikkelen van een actieplan ter versterking van veerkracht. Het instrument wordt momenteel getest in geselecteerde Europese ziekenhuizen om de praktische toepasbaarheid verder te vergroten.

Hoofdstuk 5 beschrijft de participatieve ontwikkeling van een Action Guide, bedoeld om de structurele inbedding en toepassing van prestatie-indicatoren voor kankerzorg binnen oncologische zorgpaden wereldwijd te ondersteunen. Dit onderzoek werd uitgevoerd in samenwerking met een internationale organisatie met meerdere stakeholders en richtte zich op drie clusters van indicatoren: tijdigheid van zorg, coördinatie van zorg en persoonsgerichte zorg. Regulering van gestandaardiseerde oncologische zorgpaden en wet- en regelgeving die dataverzameling ondersteunen, werden geïdentificeerd als belangrijke randvoorwaarden voor het bevorderen van de implementatie van kankerzorgindicatoren. Belangrijke belemmeringen waren onvoldoende ontwikkelde elektronische patiëntendossiers en beperkte interoperabiliteit tussen datasystemen. Deze studie laat zien hoe internationale kennisuitwisseling kan bijdragen aan het structureel integreren van veerkracht en persoonsgerichtheid in prestatiemonitoring. De Action Guide wordt momenteel in enkele landen, waaronder Griekenland, getest om inzicht te krijgen in situatie specifieke aanpassingen.

Hoofdstuk 6 had tot doel het systematisch gebruik van patiëntgerapporteerde uitkomstmaten (Patient-Reported Outcome Measures; PROMs) in kaart te brengen en belemmerende en bevorderende factoren voor systeem-brede implementatie te identificeren vanuit het perspectief van besluitvormers, in het bijzonder beleidsvertegenwoordigers van OESO-landen. In totaal werden 44 PROMs-programma's in 21 landen geïdentificeerd. Het primaire doel van de implementatie van PROMs was kwaliteitsverbetering. De resultaten van deze studie laten zien dat systeem-brede

implementatie van PROMs nog steeds wordt beperkt door verschillende factoren, waaronder beperkte middelen, onvoldoende betrokkenheid van patiënten en zorgprofessionals en technologische belemmeringen.

Door de combinatie van literatuuronderzoek in de vorm van scoping reviews (**Deel I**) en co-creatiemethodologieën (**Deel II**) boden beide delen complementaire inzichten in het begrijpen en versterken van cardiovasculaire en oncologische zorgpaden. In **Deel I** bleek de scoping review-methodologie geschikt om prestatie-indicatoren over deze zorgpaden te identificeren. De heterogeniteit in definities van indicatoren, studie designs en steekproefomvang maakte het echter niet mogelijk om meta-analyses uit te voeren om de impact van de pandemie kwantitatief vast te stellen. In **Deel II** werd de operationalisering van de principes van Participatory Action Research aangepast aan de organisaties en projecten waarin de studies waren ingebed. De toepasbaarheid van de via co-creatie ontwikkelde instrumenten is in sterke mate afhankelijk van de situatie waarin zij zijn ontwikkeld, wat vraagt om contextuele aanpassing in plaats van directe replicatie.

De studies die zijn beschreven in **hoofdstukken 1 tot en met 5** richtten zich specifiek op het cardiovasculaire of oncologische domein. De in **hoofdstukken 1 tot en met 3** geïdentificeerde prestatie-indicatoren kunnen aanknopingspunten bieden voor prestatiemeting in andere klinische domeinen en zorgpaden, maar vereisen aanpassing en validatie voordat zij elders kunnen worden toegepast. Op vergelijkbare wijze bieden de in **hoofdstukken 4 en 5** ontwikkelde instrumenten inzichten die potentieel toepasbaar zijn in meerdere klinische contexten. In beide gevallen is verdere toetsing en situatie specifieke afstemming noodzakelijk alvorens toepassing in andere klinische zorggebieden kan plaatsvinden.

De studies in dit proefschrift hadden een internationaal karakter en richtten zich voornamelijk op hoge- en middeninkomenslanden. Gezien de overeenkomsten in de organisatie van zorgstelsels, evenals in hun prioriteiten en uitdagingen, zijn de bevindingen van dit proefschrift naar verwachting goed toepasbaar op zorgstelsels in andere hoge- en middeninkomenslanden. Tegelijkertijd kunnen verschillen in beheer en sturing van zorgstelsels, en de mate van digitale volwassenheid, de overdraagbaarheid van de bevindingen en ontwikkelde instrumenten beïnvloeden.

Door besluitvorming op micro-, meso- en macroniveau met elkaar te verbinden ten behoeve van systeemverbetering, formuleerde dit proefschrift aanbevelingen voor beleid en praktijk. Voor beleidsmakers onderstrepen de bevindingen het belang van het prioriteren van de standaardisatie van prestatie-indicatoren en de inbedding daarvan in de data-infrastruur, het verankeren van veerkracht in het ontwerp van zorgpaden aan de hand van de zes in dit proefschrift beschreven dimensies, het versterken van mechanismen voor patiënten feedback via gerichte scholing, en het investeren in co-creatieprocessen om vertrouwen, eigenaarschap en contextgevoelige instrumenten te bevorderen. Toekomstig onderzoek kan zich richten op de verdere ontwikkeling, standaardisatie en beoordeling van de geschiktheid voor gebruik en doel (fitness for use en fitness for purpose) van de in dit proefschrift geïdentificeerde prestatie-indicatoren. De via co-creatie ontwikkelde instrumenten kunnen daarnaast verder worden getest in de praktijk van kliniek en beleid.

Voortbouwend op een mondiale gezondheidscrisis combineert dit proefschrift data gedreven inzichten in **Deel I** met een participatieve ontwikkelbenadering in **Deel II**. **Deel I** levert empirisch bewijs ter ondersteuning van gestandaardiseerde prestatie-informatie voor besluitvorming op verschillende niveaus van het zorgstelsel. Op basis van deze inzichten en door de integratie van perspectieven van beleidsmatige, organisatorische en klinische stakeholders presenteert **Deel II** de co-creatie van praktische instrumenten. Deze instrumenten zijn ontworpen om veerkracht binnen zorgpaden concreet toepasbaar te maken en persoonsgerichte zorg structureel onderdeel te laten zijn van prestatiemeting. Daarnaast draagt dit proefschrift bij aan het benutten van het zorgpad als relevant analytisch kader voor het gebruik van indicatoren binnen prestatiemeting. Uiteindelijk beoogt dit proefschrift bij te dragen aan verbeteringen in zorgervaringen en zorguitkomsten voor mensen met cardiovasculaire aandoeningen en kanker, zowel tijdens crises als in de reguliere zorgverlening.

PhD Portfolio

PhD candidate	Ana Sofia Valente Cardoso Dias Carvalho Pais Silva
Supervisors	prof. dr. N.S. Klazinga (AMC-UvA)
	prof. dr. D.S. Kringos (AMC-UvA)
Co-supervisor	dr. Ó.R. Brito Fernandes (AMC-UvA)
PhD period	August 2020 – January 2026

1. PhD training

PhD training—General courses	Year	ECTS
Principles of Research in Medicine and Epidemiology (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	0,7
Gender and Health (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,7
Scientific Integrity (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,3
Intervision/Peer to peer group coaching (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,4
Intercultural communication (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,2
Science Communication (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	0,7
Performing Scientific Peer Review (Karger course)	2022	
Negotiation Skills (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	0,3
Scientific Writing in English for Publication (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	2,0
World of Science (Amsterdam UMC, University of Amsterdam)	2022	0,5

Research Data management: Writing a Data Management Plan (Amsterdam UMC, University of Amsterdam)	2022	1,0
Peer to peer group coaching (Amsterdam UMC, University of Amsterdam)	2025	0,5
Launch your career (Amsterdam UMC, University of Amsterdam)	2025	0,5
PhD training—Specific courses	**Year**	**ECTS**
Study Design (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	4,3
Social Epidemiology (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	0,7
Quality of Life Measurement (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,9
Methods of Public Health Research (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	0,7
Methods of Health Services Research (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	0,7
Public Health Research: Analysis of Population Health (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	1,9
Public Health Research: Analysis of Determinants (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	1,9
Public Health Research: Intervention Development and Evaluation (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	1,9
The Practice of Epidemiologic Analysis (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	0,7
Biostatistical Methods I: Basic Principles (Faculty of Medicine and Health Sciences, Erasmus MC)	2020	5,7
Biostatistical Methods II: Classical Regression Models (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	4,3
Advances in Clinical Epidemiology (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,7
Fundamentals of Medical Decision Making (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,7

Using R for Statistics in Medical Research (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	1,4
Planning and Evaluation of Screening (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	1,4
Implementation Science (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	1,4
Qualitative Research Methods in Medicine (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	1,4
Data Science in Epidemiology (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,7
Advanced Analysis of Prognosis Studies (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	0,9
Advanced Clinical Trials (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	1,9
Clinical Epidemiology (Faculty of Medicine and Health Sciences, Erasmus MC)	2021	3,0
Topics in Medical Decision-making (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	1,4
Using R for Decision Modeling, Simulation, and Health Technology Assessment (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	1,7
Advanced Decision Modeling (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	1,4
Sustainable Public Health (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	2,0
Public Health Across the Lifecourse (Faculty of Medicine and Health Sciences, Erasmus MC)	2022	2,1
Member of discussion panel at conferences	**Year**	**ECTS**
'The Impact of the COVID-19 on clinical pathways for acute myocardial infarct, cancer and acute care', co-presenter and member of discussion panel at the European Hospital and Healthcare Federation (HOPE)'s AGORA 2022 'Using evidence in healthcare management', 03 June 2022, Brussels, Belgium	2022	0,2

'The path towards efficient cancer care: Global challenges, local solutions': presentation of preliminary findings of the Action Guide for Efficient Cancer Care, co-presenter and member of discussion panel at the All.Can International Strategy Day, 20 Nov 2023, Brussels, Belgium	2023	0,2
'Unveiling the efficiency path in cancer care: a step-by-step guide', co-presenter and member of the discussion panel at the EU Health Policy Platform Webinar, 25 April 2024, online	2024	0,1
'Implementing efficiency measures (metrics) for better outcomes in cancer care', co-presenter at the session of the launch of the All.Can International Action Guide for Efficient Cancer Care, at the All.Can Global Summit, 16 September 2024, Geneva, Switzerland	2024	0,2
Presentations at workshops, meetings, and webinars	**Year**	**ECTS**
'The impact of the COVID-19 pandemic on hospital services for patients with cardiac diseases – preliminary results', co-presenter at the Working Party on Health Care Quality and Outcomes, Organisation for Economic Cooperation and Development (OECD), 04 October 2021, online	2021	0,1
'The impact of the COVID-19 pandemic on hospital services for patients with cardiac diseases and patients with cancer', co-presenter at the Quality of Care Section meeting, Department of Public and Occupational Health, 21-02-2022, online	2022	0,1
'How COVID-19 impacted cancer care (performance) indicators: A scoping review covering OECD countries', co-presenter at High-Level Policy Forum 'Addressing Cancer Injustice in CEE Countries', 14 Nov 2022, online	2022	0,1
Monthly update presentations at the project meetings with All.Can International, September 2023 – May 2024 , online	2023-2024	1
'Resolutions for the Quality of care research section in 2024—What do you expect and wish for the New Year?', workshop moderator at the Quality of Care Section meeting, Department of Public and Occupational Health, 15-01-2024, Amsterdam, the Netherlands	2024	0,1

Monthly update presentations at the RESIL-Card Consortium meetings (January 2024-January 2025), including the first General Assembly (21 October 2024), online and in Paris, France	2024-2025	1
'Preliminary findings of the All.Can International Action Guide for Efficient Cancer Care', co-presenter at the General Assembly of the European Union of Private Hospitals (UEHP), 2 Feb 2024, Brussels, Belgium	2024	0,1
'Presentation of the All.Can International Action Guide for Efficient Cancer Care', presenter at the All.Can Switzerland General Assembly, 25 Mar 2024, online	2024	0,1
'Presentation of the All.Can International Action Guide for Efficient Cancer Care', presenter at the Webinar 'The General Practitioner In The Route Of The Oncology Patient' organized by the National Association of the General Practitioners – Bulgaria And Bulgarian Joint Cancer Network, 08 June 2024, online	2024	0,1
'Presentation of the All.Can International Action Guide for Efficient Cancer Care', presenter at the All.Can Mexico symposium at the National Academy of Medicine of Mexico, 29 August 2024, online	2024	0,1
'Presentation of the All.Can International Action Guide for Efficient Cancer Care', co-presenter at the Panhellenic Congress on Health Economics and Policy 2024, at the session 'Evidence and policies in cancer: what we need, and where we want to go', 3 December 2024	2024	0,1
'Presentation of the RESIL-Card resilience assessment tool', co-presenter at the Monthly Meeting of the EU Joint Action on cardiovascular diseases and diabetes (JACARDI), 23 September 2025, online	2025	0,1
'Policy Dialogue: the Burden of Cardiovascular Disease in the EU', organized by the OECD, co-presenter at the session 'The Policy Environment for CVD Prevention and Management', 5 May 2025, Paris, France	2025	0,3
Presentations at conferences	**Year**	**ECTS**
'Opportunities and challenges to improve efficiency in cancer care', Spotlight Talk presentation at the World Cancer Congress 2024, 17-19 September 2024, Geneva, Switzerland	2024	0,5

'Resilience and continuity of cardiovascular care in times of crises: the RESIL-Card project', co-presenter at the EuroPCR congress 2025, 20 May 2025, Paris, France	2025	0,3
Poster presentations at conferences	**Year**	**ECTS**
'The Impact of the COVID-19 pandemic on hospital services for patients with cardiac diseases: A Scoping Review', poster presenter at the Academy Health Annual Research Meeting, 4-7 June 2022, Washington DC, USA	2022	1
'Bridging the gap: Enablers and barriers in implementing global cancer care efficiency metrics—A qualitative implementation study', poster presenter at the European Cancer Summit 2024, 20-21 November 2024, Brussels	2024	0,5
'Empowering hospital managers and care providers to build resilience in cardiovascular care: A study to develop a practical resilience tool', poster presenter at the 48th World Hospital Congress, 10-13 November 2025, Geneva, Switzerland	2025	0,7
Other conferences or workshops attended	**Year**	**ECTS**
14th European Public Health Conference, 'Public health futures in a changing world', 10 – 12 November 2021, online	2021	0,9
Amsterdam Public Health research institute Annual Meeting, 1 November 2022, Amsterdam, The Netherlands	2022	0,3
European Cancer Organization Summit, 15-16 November 2023, Brussels, Belgium	2023	0,3
'How to adapt to future pandemics cognizant of deep uncertainty & multi-modelling' workshop, Institute for Advanced Study, University of Amsterdam, 18 March 2024, Amsterdam, the Netherlands	2024	0,3
'Strengthening Health Systems: A Practical Handbook for Resilience Testing', co-organised by the OECD, Observatory on Health Systems and Policies, and the European Commission, 19 March 2024, Brussels, Belgium	2024	0,2

'Tailoring Implementation Strategies to Determinants', Amsterdam Center Implementation Science, 21 May 2024, VU Medical Faculty, Amsterdam, the Netherlands	2024	0,1
The Dutch Implementation Science Symposium 2024, 'Methodological challenges in implementation research', 12 June 2024, Utrecht, the Netherlands	2024	0,3
'Designing a Process Evaluation' workshop, Amsterdam Center Implementation Science, 4 November 2024, Amsterdam, the Netherlands	2024	0,1
'Delphi Workshop—introduction into design and conduct of Delphi studies', Amsterdam Public Health Methodology, 29 September 2025, Amsterdam, the Netherlands	2025	0,1

2. Teaching

Lecturing	**Year**	**ECTS**
Public health and health care course of the Bachelor Medical Information Science, University of Amsterdam, 27 January 2022	2022	0,2
Public health and health care course of the Bachelor Medical Information Science, University of Amsterdam, 24 January 2023	2023	0,2
Public health and health care course of the Bachelor Medical Information Science, University of Amsterdam, 24 January 2024	2024	0,2
Public health and health care course of the Bachelor Medical Information Science, University of Amsterdam, 21 January 2025	2025	0,2
Supervising	**Year**	**ECTS**
Co-supervisor for Master in Medicine thesis 'The impact of the COVID-19 pandemic on hospital services for patients with cardiac diseases: a scoping review', Mats de Lange, Amsterdam UMC, May-October 2021, Amsterdam, the Netherlands	2021	2
Co-supervisor for Master in Medicine thesis 'The impact of the COVID-19 pandemic on acute care delivery assessed through performance indicators: a systematic review', Bente Broekema, Amsterdam UMC, January-June 2022, Amsterdam, the Netherlands	2022	2

Supervisor of 6 first-year Medical Students in the course 'Kennismaking Wetenschappelijk Onderzoek' (Introduction to Research), first year of the Bachelor of Medicine at the Faculty of Medicine, Vrije Universiteit Amsterdam, September 2022 – April 2023, Amsterdam, the Netherlands	2022-2023	1
Supervisor of 6 first-year Medical Students in the course 'Kennismaking Wetenschappelijk Onderzoek' (Introduction to Research), first year of the Bachelor of Medicine at the Faculty of Medicine, Vrije Universiteit Amsterdam, September 2024 – April 2025, Amsterdam, the Netherlands	2024-2025	1

Reviewing and editing	**Year**	**ECTS**
Monthly PhD Health Systems Research group peer review meetings, Utrecht and Amsterdam, the Netherlands	2021-2025	5

Reviewer for scientific journals	**Year**	**ECTS**
Medical Principles and Practice	2022	0,5
International Journal for Quality in Health Care (IJQHC)	2022-2023	0,4
Journal of Medical Internet Research	2023	0,2
International Journal of Health Planning and Management 2024 0,3 Reviewer for conferences Year ECTS 17th World Congress on Public Health, 2-6 May 2023, Rome, Italy	2023	0,2
Academy Health Annual Research Meeting 2023, 24-27 June 2023, Seattle, WA, USA	2023	0,3

3. Parameters of Esteem

Funding	**Year**
'Development of the All.Can International Action Guide for Efficient Cancer Care', funded by All.Can International Role: Lead researcher Deliverable: All.Can 'Action Guide for Efficient Cancer Care'	2023-2024

Team: Dr. Óscar Brito Fernandes, Dr. Damir Ivanković, Dr. Erica Barbazza, Prof Dr Dionne Kringos, Prof Dr Niek Klazinga	
RESIL-Card project, funded by the European Union's EU4Health Programme under grant agreement Nr. 101129203 Role: Lead researcher Deliverable: RESIL-Card resilience assessment tool for cardiac care pathways Team: Dr. Óscar Brito Fernandes, Prof Dr Dionne Kringos, Prof Dr Niek Klazinga and the RESIL-Card Consortium	2023-2026

Team member of other funded projects	**Year**
'Strengthening actionable primary health care performance measurement and management: Tailored training and mentorship programme, funded by the World Health Organization, Regional Office for Europe, 2023 (cohort 3) Role: Expert supporting the organisation of the programme, presenter and moderator Main outcome: Training and coaching sessions to professionals from participating countries to support the development of primary health care performance measurement projects Participating countries: Armenia, Kyrgyzstan, Moldova, Tajikistan, Turkmenistan, Azerbaijan Team: WHO Collaborating Centre for Quality and Equity in Primary Health Care Systems, Amsterdam—Dr. Óscar Brito Fernandes (direct supervisor on the project), Prof Dr Niek Klazinga, Prof Dr Dionne Kringos	2023-2024
European Cancer Inequalities Registry (flagship initiative part of Europe's Beating Cancer Plan)—EU Analytical Report 2024 'Beating Cancer Inequalities in the EU—Spotlight on Cancer Prevention and Early Detection', funded by the European Commission Role: Lead author of one chapter and expert at the team meetings Deliverable: Chapter 4 of the report: 'Improving early diagnosis and screening programmes' Team: Dr. Óscar Brito Fernandes (co-author) and OECD Health Division	2023

European Cancer Inequalities Registry (flagship initiative part of Europe's Beating Cancer Plan)—EU Cancer country profiles, funded by the European Commission Role: Lead author of a country profile and expert at the team meetings Deliverable: OECD/EU Belgium cancer profile Team: Dr. Óscar Brito Fernandes (co-author) and OECD Health Division	2024

'The State of Cardiovascular Health in the European Union', funded by the European Commission Role: Co-author of one chapter and expert at the team meetings Deliverable: Chapter 6 of the report: 'Designing and implementing effective policies for CVD prevention and control' Team: OECD Health Division 2025	2025

Awards	**Year**
Poster 'Bridging the gap: Enablers and barriers in implementing global cancer care efficiency metrics—A qualitative implementation study', selected as one of the top 16 abstracts by a panel of ECO Board members and Focused Topic Network Co-Chair reviewers, at the European Cancer Summit 2024, 20-21 November 2024, Brussels	2024

Other	**Year**
Interviewee for the Euractiv's special report 'How can cancer-care efficiency improve patient outcomes and deliver healthcare value?', resulting in the publication of 3 articles by Nicole Verbeeck, December-January 2025	2025

4. Other activities — Miscellaneous

Other activities	**Year**
Carvalho, A.S., Ivanković, D., Barbazza, E., Brito Fernandes, Ó., Klazinga, N., Kringos, D. All.Can Action Guide For Efficient Cancer Care, May 2024 [Project deliverable]	2024

Speaker and member of the discussion panel at the session 'Clinical Research In Portugal: Challenges And Opportunities: Possible solutions from the perspective of implementation science', joint session of the Portuguese Society of Oncology/European Organisation for Research and Treatment of Cancer, National Congress of the Portuguese Society of Oncology, 13 November 2024, Coimbra, Portugal	2024
Carvalho, A.S., Brito Fernandes, Ó., Klazinga, N., Kringos, D. WP1 | Diagnosis & Resilience Assessment Tool Development, D1.1 (D1) Scoping Review – Interim report, May 2024 [Project deliverable]	2024
Carvalho, A.S., Brito Fernandes, Ó., Klazinga, N., Kringos, D. Work Package 1, Diagnosis & Resilience Assessment Tool Development, D1.2 (D2) RESIL-Card survey report, July 2024 [Project deliverable]	2024
Carvalho, A.S., Brito Fernandes, Ó., Klazinga, N., Kringos, D. Work Package 1, Diagnosis & Resilience Assessment Tool Development, D1.3 (D3)—Focus group report, November 2024 [Project deliverable]	2024
Carvalho, A.S., Brito Fernandes, Ó., Klazinga, N., Kringos, D. Work Package 1, Deliverable 1.4, RESIL-Card Resilience Assessment Tool, January 2025 [Project deliverable]	2025
Presenter at the Webinar 'Improving cancer care globally: International efforts to enhance the quality and efficiency of care to people with cancer', cycle of online conferences 'Portuguese people around the World', organized by the Portuguese League Against Cancer—Northern Regional Unit, 10 February 2025, online	2025

List of publications

Publications included in this thesis

de Lange, M.*, **Carvalho, A.S.***, Fernandes, Ó.B., Lingsma, H., Klazinga, N., Kringos, D. The Impact of the COVID-19 Pandemic on Hospital Services for Patients with Cardiac Diseases: A Scoping Review. Int. J. Environ. Res. Public Health 2022, 19, 3172. *https://doi.org/10.3390/ijerph19063172*

V. Carvalho, A.S., Broekema B, Brito Fernandes Ó, Klazinga N, Kringos D. Acute care pathway assessed through performance indicators during the COVID-19 pandemic in OECD countries (2020-2021): a scoping review. BMC Emerg Med. 2024 Jan 26;24(1):19. *https://doi.org/10.1186/s12873-024-00938-7*

Carvalho, A.S., Brito Fernandes, Ó., de Lange, M., Lingsma, H., Klazinga, N., Kringos, D. (2022). Changes in the quality of cancer care as assessed through performance indicators during the first wave of the COVID-19 pandemic in 2020: a scoping review. BMC Health Services Research, 22(1), 1-16. *https://doi.org/10.1186/s12913-022-08166-0*

V. Carvalho, A.S., Brito Fernandes Ó, J. Piek J, Mauri J, Sanz Escartín A, Wijns W, Klazinga N, Kringos D. Development of a resilience assessment tool for cardiac care pathways in Europe: a mixed-methods study. BMJ Open 2026;16:e110266. *https://doi.org/10.1136/bmjopen-2025-110266*

V. Carvalho, A.S., Brito Fernandes, Ó, Ivanković, D., Barbazza, E., Pisani, E., Klazinga, N., & Kringos, D. (2025). International multi-stakeholder collaboration to support implementation of cancer care efficiency metrics: A qualitative study to develop the All.Can Action Guide. *Submitted.*

Kendir, C., **V. Carvalho, A.S.**, Tran, S., van den Berg, M., de Bienassis, K., Brito-Fernandes, Ó., Guanais, F., Kringos, D., Valderas, J.M. and Klazinga, N., (2025). Sys-

tem-wide use of Patient Reported Outcome Measures (PROMs) in OECD countries: insights from a health policy survey and key informant workshops. *Value in Health. https://doi.org/10.1016/j.jval.2025.11.008*

*Shared co-first authorship

Other peer-reviewed publications

V. Carvalho, A. S., Cardoso Borges, F., Cardoso, M. J., Oliveira, J., Pais Silva, J., Carvalho, S., Costa, L., Fernandes, I., Gomes, D., Gomes, M., Milagre, T., Rego, S., Soares, M., Sottomayor, C., Joaquim, A., Sousa, N., & Passos Coelho, J. L. (2026). An Implementation Roadmap to Accelerate Academic Clinical Cancer Research in Portugal: A Multistakeholder Perspective. *Acta medica portuguesa*, 39(1), 8–13. *https://doi.org/10.20344/amp.23479*

V. Carvalho, **A. S.**, Brito Fernandes, Ó., Ivanković, D., Barbazza, E., Iamandei, M., Pisani, E., Klazinga, N., Kringos, D. (2025). Bridging the gap: Enablers and barriers in implementing global cancer care efficiency metrics-A qualitative implementation study. Journal of Cancer Policy, 43, 100543. *https://doi.org/10.1016/j.jcpo.2024.100543*

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Chapter 1

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Authors contributions

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Chapter 2

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About the author

Ana Sofia Valente Cardoso Dias Carvalho Pais Silva was born on 22 March 1986 in Lisbon, Portugal. An avid reader and good communicator since her early years, she developed a strong interest in teaching and writing. Over time, medicine became another passion. Sofia has always yearned to combine these interests at some point. Sofia concluded her Medical Doctor degree in 2011 at the Medical Faculty of Nova Medical School in Lisbon, Portugal. She then pursued six years of clinical specialisation in Internal Medicine at the West Hospital Centre of Lisbon. After practising as an Internal Medicine Consultant for two years, she decided to broaden her expertise beyond clinical work.

In January 2020, Sofia started the Public Health medical residency at the Regional Health Administration of Lisbon and Tagus Valley, which was heavily influenced by the first phase of the COVID-19 pandemic. As part of the residency and encouraged by the learnings from this crisis management, she decided to pursue the Research Master in Public Health Epidemiology at the Rotterdam University.

Early in the Master, the Health Services Research course, by Prof. Dr. Klazinga, made her realise that this field was the perfect connection between her acquired clinical expertise and health system knowledge. She started to work supervised by Prof. Dr. Klazinga, Prof. Dr. Lingsma, Prof. Dr. Kringos, and Dr. Brito Fernandes and successfully concluded the Research Master in 2022.

There onwards the opportunity arose within the same research group at Amsterdam UMC for her to continue the line of research started in the Master, this time in a PhD trajectory. This PhD thesis is the result of this work. Supported by her supervisors, alongside her PhD trajectory, Sofia had the opportunity to participate in applied research projects and health policy analysis roles. These experiences have challenged and enriched her trajectory.

Based in Brussels with her husband and two children, Sofia balances a fulfilling family life with enriching professional challenges. Sofia remains highly committed to supporting national and international efforts that foster health systems' resilience and person-centeredness.

