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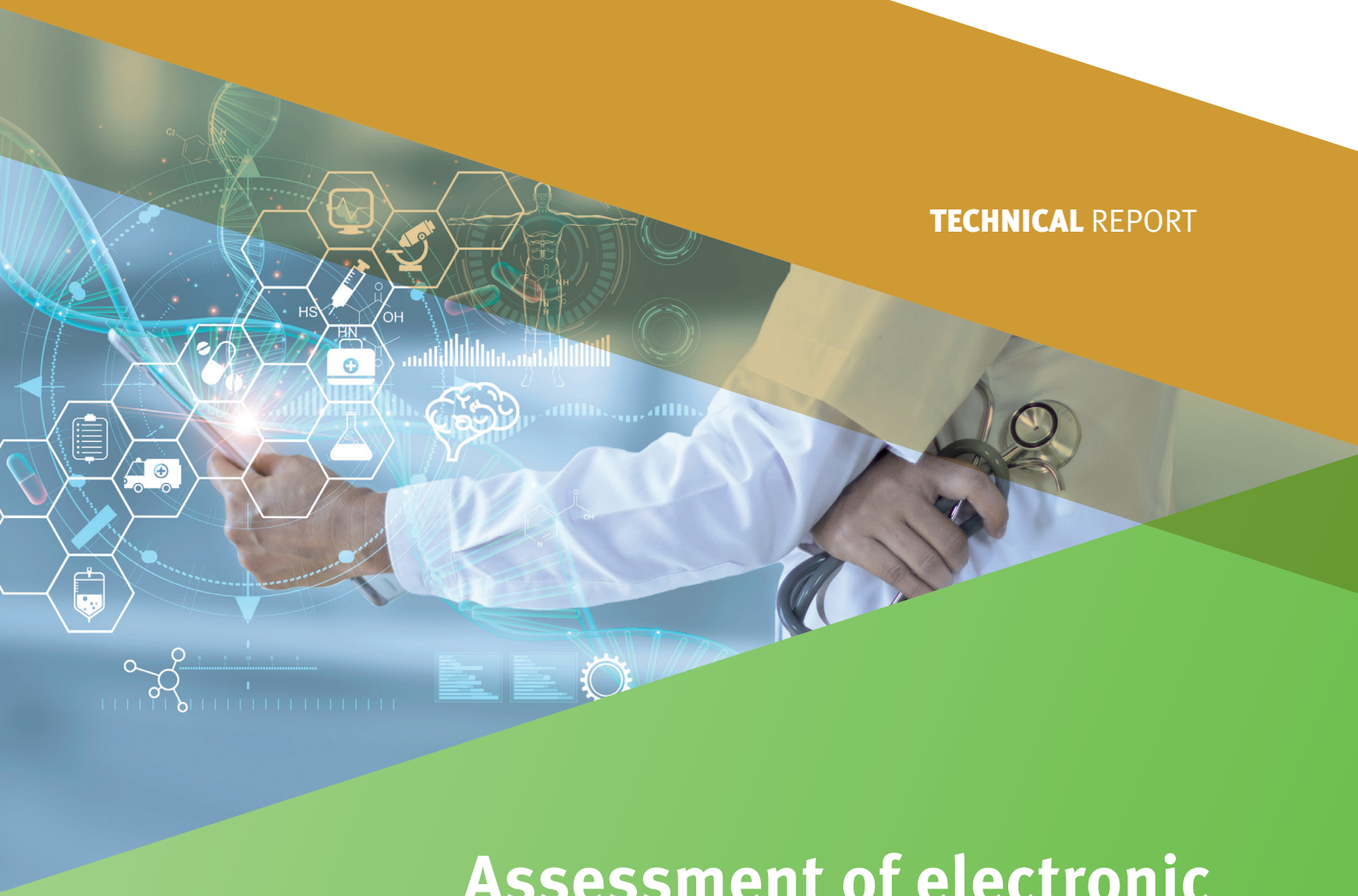

TECHNICAL REPORT

Assessment of electronic health records for infectious disease surveillance

Final mapping exercise report

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Authors
Brandi Leach, Sarah Parkinson, Camilla d'Angelo, Emily Gloinson, Daniela Rodriguez-Rincon, Adam Bertscher, and Katherine Morley

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Abbreviations

EEA	European Economic Area
EHR	Electronic health record
EMA	European Medicines Agency (EMA)
EU	European Union
GDPR	General Data Protection Regulation
GP	General practitioner
LGBT	Lesbian, gay, bisexual, or transgender
NICTIZ	National Information and Communication Technology Institute for Healthcare (The Netherlands)
NIVEL	Netherlands Institute for Health Services Research
OECD	Organisation for Economic Development
PHA	Public health authority
RfS	Request for services
UK	United Kingdom
US	United States
WHO	World Health Organization

Executive summary

The use of electronic health records (EHRs) for infectious disease surveillance purposes has the potential to reduce the burden and improve the timeliness and completeness of reporting infectious disease data. However, EHR use across European countries is heterogeneous, and the scope and content of individual EHR systems is not always well characterised (1). Consequently, the feasibility of using EHR data for infectious disease surveillance in the European Union/European Economic Area (EU/EEA) is currently unclear. In this context, RAND Europe undertook a study on behalf of ECDC to investigate the current status of EHR systems in the EU/EEA and the potential capacity for the use of these data for surveillance of infectious diseases.

The focus of the study is the degree of EHR implementation, characteristics of the data that are held on population members, and the ability to share these data. It involved a survey of key experts across EU/EEA countries to understand EHR use in Europe and its potential for disease surveillance. This was supported by scoping interviews with experts in EHRs and infectious diseases, follow-up desk-based research, including in-depth case studies of three countries with well-developed EHR systems (Finland, Estonia, and the Netherlands), and a mapping exercise to consolidate the information. We invited over 183 people to participate in the survey, including 30 ECDC national focal point representatives. Responses were received from 27 participants from 17 countries (Austria, Belgium, Croatia, Cyprus, Denmark, Estonia, Finland, Greece, Ireland, Italy, Malta, the Netherlands, Norway, Portugal, Romania, Slovenia, and the United Kingdom).

Our results suggest that unified national EHR systems across primary and secondary care are not common among EU/EEA countries, with only six of the 17 countries reporting unified systems across primary and secondary care. There is also wide variability in the degree of transition from paper-based to fully electronic systems within EU/EEA countries, with only four countries (Estonia, Finland, the Netherlands, and Norway) reporting a high degree of implementation of electronic systems.

However, we also find that the presence of a unified EHR system and the level of transition to a completely computerised medical record system are not directly related to using the EHR system to share data with public health authorities or engage in infectious disease reporting. Although the six countries our analysis ranked as having the best-developed EHR systems based on degree of system transition from paper-based to fully electronic systems (Denmark, Estonia, Finland, the Netherlands, Norway, and the United Kingdom) reported using EHRs for infectious disease surveillance, so did five countries ranked as having among the least-developed systems (Austria, Belgium, Croatia, Malta, Portugal, and Romania). Most participants report that key timepoints are routinely reported for at least some infectious diseases, but the level of EHR system implementation may affect data completeness; countries with the highest levels of transition to electronic systems were also the most likely to report that information was always recorded in EHR systems.

Participants reported that only around one third (35%) of the included countries have processes in place to support interoperability – the sharing of different types of information – between national or subnational systems and public health authorities (PHAs). However, the degree of EHR system implementation within a country does not appear to be closely tied to the number of linkages between the EHR system and other systems (e.g. pharmacy, laboratory information, disease or vaccine registries, pathology, or automatic vaccination alerting systems). Almost half of the countries (Austria, Croatia, Estonia, Finland, Malta, Portugal, Romania, and the United Kingdom) appear to share some data with external public health organisations such as ECDC, even though many respondents were unsure about secondary use of EHR data by PHAs for disease surveillance, or what mechanisms were in place to permit data sharing. Respondents also report that PHAs may not currently play a prominent role in ensuring the quality of data recorded in EHR systems, which may be one avenue by which PHAs could encourage system development towards supporting disease surveillance.

The study highlighted some barriers and enablers of EHR implementation and its use for infectious disease surveillance. From the survey, we saw that as countries move toward fully electronic systems, issues with system usability and lack of staff time and finances seem to be the most significant barrier to EHR implementation. Barriers to the use of EHR data, in contrast, encompass concerns over confidentiality and privacy, as well as data quality issues such as the completeness and timeliness of data, and lack of data sharing between organisations. Our case studies of Finland, Estonia, and the Netherlands suggest that mandating uptake of EHR systems at a national level via legislation is a key component to achieving national implementation. However, they also demonstrate that uptake of EHR systems at the national level is not directly linked with EHR use for infectious disease reporting; we found clear evidence of the use of EHR systems for routine infectious disease reporting in the Netherlands despite the lack of a unified national system.

There are some limitations of the current study. Firstly, the survey administration coincided with the COVID-19 pandemic, which affected the availability of potential participants to fill in the survey, particularly given that many people with the relevant expertise would also have been key to COVID-19 response efforts. This left us without responses from 14 European countries (Bulgaria, Czechia, France, Germany, Hungary, Iceland, Latvia, Lithuania, Luxembourg, Poland, Slovakia, Spain, Sweden, and Liechtenstein). Furthermore, there are limitations due to the

breadth of the survey questions and the level and area of expertise of any given respondent. We received contradictory responses from country representatives for some survey questions, which may reflect differing areas of expertise or, for systems in transition, different experiences of the system. To address these limitations, we combined the evidence from the survey, the scoping interviews, and desk-based research to inform our results and conclusions.

The COVID-19 pandemic has brought new focus to the need for rapid turn-around clinical information that can be aggregated at a national and international level. There are likely to have been rapid implementations of strategies for using EHR data for infectious disease surveillance, prevention and control in this area since March 2020 and going forward. The COVID-19 pandemic may provide EU/EEA governments with an incentive to develop strategies to strengthen national EHR systems in order to optimise their use for infectious disease surveillance.

Future research should seek to identify how Member States have responded to COVID-19 and whether and how any barriers to EHR development and interoperability may have been overcome to support national and European responses to the pandemic. It could also be beneficial to better understand the role of EU-wide and cross-national initiatives, such as the EU's eHealth programme, in facilitating and supporting the development of EHRs and their use for infectious disease surveillance. This may provide insights into how countries that are close to accomplishing the implementation of national systems that could be utilised for infectious disease monitoring and prevention could be supported to complete the transition to fully computerised and unified EHR systems.

1. Introduction

This is the final report for the mapping study 'Assessment of electronic health records (EHRs) for infectious disease surveillance, prevention and control'. The study was commissioned by ECDC and was delivered by RAND Europe. The objective of the project is to investigate the current status of EHR systems in the European Union and European Economic Area (EU/EEA) and the potential capacity for the use of these data for surveillance of infectious diseases within ECDC's remit.

The project has four main tasks:

1. **Scoping interviews** with three experts in EHRs and infectious diseases, to inform the development of the mapping survey questions;
2. **Survey** of key experts across EU/EEA countries, to understand EHR use in Europe and its potential for disease surveillance;
3. Follow-up **desk-based research**, to fill in any remaining gaps in the data across EU/EEA countries; and
4. A **mapping exercise**, to assess the current status and trends in the use of EHRs in EU/EEA countries.

This document is the final report for the study. This final report builds on the interim report, final mapping protocol, the final material and tools for data collection (including the survey on the EUSurvey platform), and discussions with the commissioning team at ECDC.

Note on COVID-19

This mapping exercise was undertaken between October 2019 and July 2020, with the mapping survey, the core research method of the exercise, undertaken between March 2020 and July 2020. The study period therefore coincided directly with the escalation of the COVID-19 pandemic. It should be noted from the outset that this timing had a considerable impact on the implementation of this study. Most significantly, the COVID-19 pandemic meant that many experts in public health and infectious diseases were occupied with the coordination of national responses to it. This significantly affected the number of responses received by the survey. The impact of the pandemic on the implementation of this study is discussed further in the limitations section of this report. The pandemic also brings new urgency to the issue of improving cross-border surveillance capabilities for communicable diseases, such as through the use of EHRs.

1.1 Background and context

EHRs consist of longitudinal data in electronic format concerning a patient's health that are generated during routine medical care (1). This is in contrast to the type of data that might be created through bespoke research initiatives, genomics, or mobile phones that are not collected by healthcare professionals, may not be longitudinal, may only focus on a specific disease or health condition, and are frequently limited to a small subsection of the population. EHR systems aim to improve the quality, and reduce the costs, of healthcare by facilitating the sharing of patients' medical history across health settings (1).

The use of EHRs for infectious disease surveillance purposes may offer great opportunities for improving timeliness, completeness, and lessening the burden for reporting infectious disease data. However, EHR use across EU/EEA countries is heterogeneous, and the scope and content of individual EHR systems is not always well characterised (2). As a result, the feasibility of using EHR data for infectious disease surveillance in the EU/EEA is currently unclear. In this context, RAND Europe undertook a study on behalf of ECDC to investigate the current status of EHR systems in the EU/EEA and the potential capacity for the use of these data for the surveillance of infectious diseases within ECDC's remit.

1.2 Overview of EHR use in EU/EEA countries and its potential for disease surveillance

As of 2016, not all EU/EEA Member States had national EHR systems, and of those that did, their use in primary, secondary, and tertiary healthcare settings varied (3). The legislation that regulates EHRs also varies from country to country.[1] One study reviewing national laws on EHRs in EU Member States found major disparities between countries, in particular with respect to the ability to deploy EHRs as part of an interoperable infrastructure to support cross-border eHealth services (4). Notably, fewer than half the countries included in the

[1] See https://ec.europa.eu/health/ehealth/projects/nationallaws_electronichealthrecords_en for reports on the legal requirements applying to EHRs and potential future legislation for each EU Member State and Norway.

study had legal obligations in place to use standardised terminology or codification strategies in EHRs, which has been identified as one of the most significant barriers to transferring health data across borders (5).

EU countries also have different approaches to ensuring data security: some countries have put specific legislation in place to regulate EHR data, while others rely only on existing legislation originally designed to protect patients rather than specifically govern data security.[2] Member States also adopt a variety of approaches to the secondary use of health data, with differential impacts on its potential use for public health functions such as infectious disease surveillance, prevention, and control.[3] The differences in EHR use and legislation between European countries may impact the ability to transfer health data between countries, understand health data that are transferred, and combine data and analyse them at a supranational level to create a broader understanding of public health and the spread of infectious diseases.

1.3 Using EHR data for public health surveillance

There are currently few documented examples in the academic literature of EHR use for infectious disease surveillance in Europe. However, EHRs have been used for other secondary use cases in EU/EEA Member States. For example, EHRs from primary, secondary, and tertiary care have been used in the regulation of medicines in post-authorisation safety studies, which monitor the safety of medicinal products once they are already in use for the European Medicines Agency (EMA) (6). Using routinely collected health data for other purposes reduces the cost and burden of data collection and can help test the safety of medicines 'in the real world' as they are routinely used.

Outside of Europe, EHRs have been used for infectious disease surveillance, and these experiences can help inform the European approach to using EHRs for infectious disease surveillance. In the United States (US), legislation has been put in place to incentivise the 'meaningful use' of EHRs, which has led to improved EHR capabilities and greater interchange of data between different sources (7). This has resulted in EHRs being used in infectious disease surveillance efforts, enhancing laboratory-based and provider-based results in terms of detecting outbreaks and understanding the spread of infectious diseases (8). Rather than relying solely on laboratories to report a disease case once a positive diagnosis has been confirmed, or on healthcare providers to manually input information, EHR-based algorithms are able to integrate data from a combination of laboratory reports, diagnostic codes, medication orders, and other information recorded in EHRs. Along with allowing for more complete reporting of infectious diseases, EHRs have also allowed disease surveillance efforts to capture richer data about infectious disease incidences, including confounders such as concurrent infections and a patient's number of sexual partners (if recorded in EHRs), patient-level health outcomes, and temporal trends to help understand the spread of diseases. EHRs have also helped capture infectious disease incidence that occurs in marginalised and hard-to-reach populations who are not picked up in traditional reporting mechanisms, such as native or indigenous populations, lesbian, gay, bisexual, or transgender (LGBT) people, and people with substance use disorders (8).

1.4 Current obstacles to the use of EHRs in infectious disease surveillance

Despite the progress that has been accomplished in developing EHR use in infectious disease surveillance, there are still limitations to its use in the US that also apply to the EU/EEA context, despite differences in healthcare systems. Although EHRs enhance traditional surveillance efforts, they still do not include all data needed in surveillance, such as consistently capturing exposure data, such as travel, sexual activity, and drug use. It is also unclear how surveillance efforts should treat free-text in EHRs, although the possibility of using machine-based learning techniques such as natural language processing has been discussed (9). The US system also faces challenges associated with the interoperability of EHR systems between different healthcare providers and different healthcare systems, which is an issue that is also likely to be encountered in using EHRs in European infectious disease surveillance efforts. In response to this challenge, health authorities can help facilitate the sharing of EHR data across healthcare systems within their jurisdiction (9).

[2] Ibid. EU/EEA countries that have adopted specific rules to regulate EHR data include Croatia, Estonia, Finland, France, Lithuania, and Norway. A few additional countries have adopted legislation creating the legal framework for shared EHR systems while still relying on general data protection rules for aspects of EHR data governance. These countries include Austria, Belgium, Germany, and Luxembourg. It is important to note that this is a rapidly evolving area and that specific legislation around the use of EHR data may have changed since the time of the publication of the underlying source material (i.e. 2014).

[3] Ibid.

Although EHRs have not yet been adopted into routine infectious disease surveillance, prevention and control at a European level, EU-level plans and recommendations have been put in place to help facilitate eHealth, EHR use and the exchange of health data across national borders, which may help pave the way to European-level use of EHRs for infectious disease control. The European Commission's eHealth strategy highlights several pillars that will guide their efforts to promote eHealth across the EU: secure data access and cross-border sharing; connecting and sharing health data for research, faster diagnosis and improved health (including addressing cross-border health threats); and strengthening citizen empowerment and individual care through digital services (10). The European Commission has also established platforms that enable collaboration and cooperation between Member States, including the eHealth network and the eHealth Digital Services Infrastructure (eHDSI), to help facilitate cross-border exchange of health data (11). The European Commission also provides financial support at EU-level to help facilitate the implementation of eHealth policies (11). The European Commission also supports projects to facilitate EHR exchange and the secondary use of EHRs for research. For example, the Electronic Health Records for Clinical Research (EHR4CR) project (12) has developed a platform that can use de-identified data from hospital EHR systems in compliance with EU-level and national-level legislation on data protection in order to identify patients who may be eligible for clinical trials.

Previous studies have pointed to the need to establish EU-level recommendations to facilitate interoperable infrastructure around EHRs, such as guidelines around the content of EHRs, common security requirements for the cross-border sharing of eHealth data, and guidelines on the secondary use of EHRs for public health (4). The European Commission has acknowledged the need for more EU action in facilitating cross-border EHR transfer (13), as well as creating open standards for a European EHR exchange format and putting in place data safeguards (including compliance with General Data Protection Regulation (GDPR) legislation) (14). The European Commission's recommendation on a European EHR exchange supports existing resources around eHealth interoperability and sets out a framework for Member States to be able to exchange EHR data in a consistent way that lends itself to meaningful interpretation across borders. This recommendation sets out information to be included in the European EHR exchange format: patient summary; ePrescription and eDispensation; laboratory results; medical imaging and reports; and hospital discharge reports (15). The European Commission has also proposed a common data space in the EU to facilitate the efficient use of public and private sector data across the EU, emphasising the need for data sharing between businesses, and between businesses and the public sector (16). The common data space proposal argues for the importance of access to and re-use of public and private data for innovation and policy-making, including within the health sector, and the need to develop common operating principles that will facilitate data sharing across organisations and governments. In its 2018 communication, the Commission took the first steps in developing a set of such principles (16). However, the impact of these different EU initiatives and recommendations on EHR implementation within each EU/EEA country is currently unclear; characterisation of the current *status quo* will provide some insight into the feasibility of secondary use of EHR data for infectious disease, surveillance, and control at the EU/EEA level.

1.5 Study objectives

This aim of this mapping study is to investigate the current status of EHR systems in EU/EEA countries and their potential for use in the surveillance of infectious diseases. Mapping exercises constitute mixed methods research (17) to map variation across EU/EEA countries to develop a better understanding of areas where the size and strength of the literature alone would not facilitate a systematic review and/or where inputs from a wider variety of sources is warranted. This type of research is designed to characterise variation between EU/EEA countries, rather than provide an in-depth analysis of individual countries. For the current project, the focus is on the degree of EHR implementation, characteristics of both the populations included and the data that is held on population members, and the legal status of secondary use of these data.

The implications of the project results for key public health functions will be assessed in relation to ECDC's mandate to work with national health institutes in the EU to identify, assess and communicate regarding current and emerging infectious diseases. This includes implications for ECDC's disease surveillance networks and early-warning systems for potential outbreaks. A key aim of the project is to provide evidence on the status of EHR use and the feasibility of using EHRs for infectious disease surveillance. The results will serve as a source of information for ECDC and key experts to support further research and decision-making in this area.

Following the Request for Services (RfS), the overarching aim of the study can be broken down into four objectives, which are to collate evidence on:

1. **The current status and trends in the use of EHRs in EU/EEA countries**
   We investigated the implementation of EHRs within each EU/EEA country with particular reference to geographic scope, population coverage, and healthcare sector coverage.
2. **The characteristics of the EHRs implemented in each EU/EEA country**
   We investigated processes underlying data generation and input, the type and origin of collected data and their characteristics, including format, metadata, quality, content, and capacity for data linkage.
3. **Legislation governing use of EHRs**
   We provide a high-level overview of the governance arrangements for EHR data in each country, particularly access and/or sharing requirements.
4. **Documented examples of public health use of EHRs**
   We created a reference library of documented examples of using EHRs for public health objectives, with particular reference to examples within ECDC's remit (Annex D).

1.6 Structure of this report

The remainder of the report is structured as follows:

- Chapter 2 describes our research approach to the mapping exercise, including a description of the primary tasks and the associated methodologies.
- Chapter 3 presents the results of the mapping study, including key findings from the survey. We also outline the key caveats and limitations associated with the study.
- Chapter 4 presents the results of follow-up desk research conducted following the study, including summaries from case study examples of three EU countries with highly developed EHR systems.
- Chapter 5 offers a summary of the findings and conclusions from the mapping study.
- The annexes contain individual country profiles detailing the status of EHR implementation for each of the countries for which we received participant responses in this study, full case study reports for the three case study countries chosen as exemplars due to their high degree of EHR implementation, the interview protocol that was used in the scoping interviews, the survey protocol that was used to collect data in the mapping exercise, the completed mapping table that collates the results from the various components of this research (i.e. scoping interviews, survey, and desk research), and a reference library of documented examples of EHR use for public health purposes.

2. Research approach

In this chapter, we provide a detailed overview of the approach and methodology for the mapping exercise.

2.1 Overview of methods

This mapping project focused on investigating the current status of EHR systems in EU/EEA countries. We designed a methodology with a mixed methods approach that allows us to assess how the availability and use of EHRs is similar and dissimilar across EU/EEA countries. The mapping exercise involves:

1. Background scoping research by study team and interviews with three experts in EHRs and infectious diseases;
2. A survey sent to individuals across EU/EEA countries;
3. Follow-up desk-based research;
4. Mapping of resulting information gained by country.

The methodology for each of these tasks is described in Sections 2.1.1 to 0 below.

2.1.1 Task 1: Background scoping research and interviews

We conducted interviews with three key experts in EHRs and infectious diseases to inform the development of the mapping survey questions. The three interviewees we spoke to can be found in Table 1. To inform the interview protocol, the study team also conducted targeted searches of the literature using Google and Google Scholar to identify sources related to EHRs and infectious disease surveillance that aligned with the key topic areas specified in the RfS, as outlined below.

The interview protocol is based on the areas specified in the RfS, supplemented by a brief, high-level review of the literature regarding use of EHR data for public health surveillance, with particular focus on its use: (i) with regard to infectious diseases; and (ii) in EU/EEA countries. Data from the scoping interviews, combined with the background scoping research, were used to plan and design the survey questions and also helped to focus and increase the efficiency of later desk-based research (Task 3). We covered the following topics:

- Which characteristics of EHR systems are key to their usability in infectious disease surveillance, and are these widely implemented in EHR systems across EU/EEA countries?
- What legal/governance structures need to be in place to facilitate secondary use of EHRs across Europe, particularly in regard to its potential impact on the use of EHRs for infectious disease surveillance?
- What EHR data standards need to be in place across Europe with regard to the potential use of EHRs for infectious disease surveillance?
- Other known examples of EHR data used for public health purposes.

The interview protocol was semi-structured, which allowed us to ask interviewees standardised questions while providing the flexibility to explore other areas related to EHR use with which they might be familiar. The interview protocol was reviewed by subject matter experts in the project team and was approved by ECDC before starting the interviews. The scoping interview protocol is presented in Annex A.

Interviews and analysis

The interviews were conducted by telephone and recorded, and lasted between 45 and 60 minutes. Notes were taken during the interviews. Participants agreed to be named in reports resulting from the interviews. Data from the interviews were analysed using a framework analysis approach (18). Framework analysis involves developing a thematic framework based on the interview data and the study's guiding research questions. This framework was then used as a tool for coding and categorising the interview data. The combination of a data- and research question-driven framework allowed us to identify key messages related to each interview question, as well as any additional themes emerging from the data.

Participants

Table 1. List of interviewees

Interviewee	Organisation	Reason for interviewing	Country or Region
Dr David J Albers	Columbia University, Data Science Institute	Studies issues in using EHR data for research, including temporal issues and potential biases in laboratory test data.	US
Clayton Hamilton	Coordinator, Digital Health, Division of Country Health Policies and Systems, WHO Regional Office for Europe	Professional role focuses on providing support and guidance on issues of E-health within Europe.	EU
Dr Charlotte Warren-Gash	London School of Hygiene and Tropical Medicine, Faculty of Epidemiology and Population Health	Research investigates the relationship between infections and cardiovascular or neurodegenerative diseases using linked EHRs and biological data.	UK

2.1.2 Task 2: Survey

The central data collection work package in the mapping review is a survey of key experts with knowledge of EHRs, infectious disease surveillance or public health functions, across EU/EEA countries. The survey allowed us to collect a large amount of data over a short space of time. We developed the survey questions based on the data collected from the high-level desk-based research and scoping interviews. Multiple EU/EEA participants from a variety of stakeholder groups were invited to participate in the survey, including national authorities, healthcare practitioners, allied health workers and their associated membership organisations, academics, representatives of advocacy groups, policy-makers, and industry representatives. The survey was broken down into four phases: design, piloting, conduct, and analysis. Each of these is described in more detail below.

Task 2.1 Survey design and development

The survey questions were designed based on data collected from the desk-based research and scoping interviews. To design these questions, the research team and our external expert advisor, Dr Dipak Kara, President of the European Institute for Health Records and of the European Institute for Innovation through Health Data, held an internal workshop to discuss key issues the survey should cover based on the scoping research, and the draft questions were refined in consultation with colleagues at ECDC. Final sign-off from ECDC on the survey design was obtained before the survey was launched.

Our initial survey questions were drawn from the World Health Organization's Third Global Survey on eHealth (19). The survey questions covered the following topics:

- The extent of the use of national EHR systems by countries' primary, secondary, and tertiary healthcare facilities;
- Data linkage and interoperability of national EHR systems;
- The variables captured by EHR systems and their suitability for disease surveillance;
- The quality and validity of the data, and database size (i.e. number of patients and number of years in existence); and
- Accessibility of the database or databases for disease surveillance purposes, in addition to more detailed questions on data linkage and interoperability (20).

The survey was designed to be short, engaging and easy to complete using the online survey platform, EUSurvey (21). To support this, most questions were multiple choice, although a small number were free-text where necessary. These open-ended questions allowed respondents to provide additional explanation for their answers and allowed us to collect more in-depth qualitative data for analysis. We also used free-text questions to enable participants to provide us with information relating to legislation governing use of EHRs and/or examples of EHR use for public health purposes. The survey was designed to take no longer than 30 minutes to complete to maximise response numbers while reducing potential bias and dropout. The survey questions were in English, but respondents could provide answers to free-text questions in any EU/EEA language.

Task 2.2 Survey piloting

The piloting phase of the survey took place in two stages. The first pilot of the survey was conducted within RAND Europe, with those outside of the project team but with relevant knowledge and experience, as well as with a small number of ECDC staff members, selected by ECDC. The RAND Europe team then revised the survey based on feedback and learning from the pilot process. The second stage involved piloting the survey with RAND Europe staff, including two staff members who had not previously viewed the survey previously. We also tested the early draft survey questions during the scoping interviews.

These piloting stages allowed us to check the survey for:

- Technical issues;
- Clarity, flow and logic of questions;
- Appropriateness of language; and
- Time it took to complete the survey.

Task 2.3 Conducting the survey

We conducted stakeholder mapping to identify appropriate people to approach to complete the survey, encompassing people with backgrounds in medical informatics, public health, clinical care, and policy research. Participants were identified using the following approaches: (1) ECDC's network and national focal points; (2) targeted searches of websites and academic and grey literature; and (3) contacts from our external expert advisor. Survey invitations were sent using an email template that introduced the study, outlined the purpose of the survey and provided contact details of the study team in case the respondent had any questions about the study or the survey. This email also included a unique link for each respondent, which was generated through EU Survey. These unique links provided a us with a mechanism to see which links had been used and who had already filled out the survey. The links also allowed the study team to send reminder messages only to potential respondents who had not yet completed the survey. For the ECDC National Focal Points and the network of our subject matter expert, a different process was followed. For this group, ECDC and the subject matter expert sent an email with a generic survey link generated through EU Survey that encouraged participants to fill out the survey.

The survey was originally scheduled to run in March 2020, and we sent out an initial round of email invitations at this time. However, because of the disruption that had been caused by the COVID-19 outbreak the survey was relaunched in May to increase the number of responses. Potential respondents received up to four reminders to participate (in March, May, June, and July). In total, the survey was open for five and a half months. These reminders were only sent to respondents who had not yet provided a response and who had also not emailed the study team to decline the survey invitation. Thus, we contacted each potential participant who did not respond to us up to six times (each time the survey was launched, plus four reminders) during the survey implementation period.

During the time the survey was open, we monitored responses to ensure they were evenly distributed across EU/EEA countries and looked to see if they were representative of the various stakeholder groups (i.e. national authorities, healthcare practitioners, allied health workers and their associated membership organisations, academics, representatives of advocacy groups, policy-makers, and industry representatives) An Excel file was used to carefully track whether each unique link was used and when, and to log all communication with potential survey respondents. This allowed us to identify where we had gaps in data from particular countries or stakeholders and to focus our efforts on obtaining responses from these groups.

Task 2.4 Survey analysis

The survey responses were analysed after the survey closed. Quantitative analysis was conducted on the multiple-choice questions using the R statistical analysis software package (22). This allowed us to summarise the information provided by participants from each country in relation to each EHR data source mentioned. We generated tables and figures to summarise survey responses and cross-checked information where multiple participants report on the same country or data source. We also created geographically-oriented visualisations to summarise country-level information relating to EHR implementation and characterisation. Information relating to EHR data source governance and/or examples of public health use were extracted from the free-text questions and was explored further as part of the follow-up desk-based research by incorporating any relevant examples into the reference library of documented examples of using EHRs for public health and into the mapping exercise (section 4.1).

2.1.3 Task 3: Follow-up desk-based research

Follow-up desk-based review was used to fill in remaining gaps in the data across EU/EEA countries. It involved two components: (i) targeted search of websites and academic and grey literature; [4] and (ii) reviewing documents provided to us by survey participants. Information from these sources was extracted into a data extraction template based on the original survey structure.

Task 3.1 Targeted literature search and case study development

The purpose of this task was to identify information to: (i) supplement the survey data, particularly where information on EHR systems for an EU/EEA country is missing; and (ii) provide more in-depth information on the use of EHR systems by undertaking case studies of three countries whose EHR systems are well implemented. The case study countries were determined in consultation with ECDC and based on review of the following information provided in the survey: (i) presence of unified EHR systems; (ii) degree of system transition from paper-based to EHR systems; (iii) use of EHRs by local public health authorities (PHA) for identifying high-risk individuals; and (iv) secondary use of EHR data for public health purposes. Countries that were more likely to

[4] Grey literature is produced by organisations outside of academia or commercial publishing channels. Examples of grey literature include: government documents, technical reports, and media articles.

report having unified systems, a high degree of transition to fully electronic systems, and use of EHRs by PHA or for secondary use were classified as having well-implemented systems.

The goal of the case studies is to provide an in-depth look at the level of implementation of EHR systems within these countries, any barriers and facilitators to implementation, the level of integration within the country and any cross-border sharing of data, and other factors that could contribute to infectious disease surveillance. Summaries of the case studies are presented in Chapter 4 (see Boxes 1-3), with full narrative summaries in Annex C. For the targeted literature search, we searched existing publicly available EHR inventories (22, 23) and academic and grey literature.

Task 3.2 Document review

Survey respondents provided information on 19 websites and documents relevant for understanding the status of EHR implementation in their countries. We reviewed these suggested sources and integrated relevant information into the mapping exercise (section 4.1), noting the source of the information.

2.1.4 Task 4: Mapping

To bring together and cross-analyse the data collected from the scoping interviews, survey and desk-based research, we held an internal workshop with the project team and engaged in discussions with a subject matter expert. To facilitate analysis of the data, we created a series of mapping tables (Table 13-15 in Annex C) where we tracked what was known from the various data sources about the status of EHRs in each country. The mapping tables provide an overview of which countries use EHRs, in which sector(s) (primary care, secondary care), and information available within each country that is relevant to infectious disease surveillance. The mapping exercise revealed gaps in the data where our methods were able to uncover little or no information about the status of EHRs in some countries.

As part of the mapping exercise, we also created a reference library (Table 16 in Annex D) with the documented examples of EHRs being used for public health purposes that were uncovered through this research. These examples were provided by survey participants in reference to their home countries, as well as encountered through our desk research.

3. Analysis of survey results

3.1 Survey respondents

We invited over 183 people from the following stakeholder groups to complete the survey: policy-makers, clinicians, relevant European association members, clinical scientists/microbiologists, infectious disease specialists, healthcare informatics researchers, representatives from national authorities, or representatives from learned societies. Thirty people were invited from ECDC's network and national focal points; 153 from the list of experts generated through targeted searches of websites and academic and grey literature; and a small but unknown number were invited through contacts from our external expert advisor.[5] In total, we received 27 valid responses from EU/EEA countries. As previously noted, we engaged in data collection for the survey (March-July 2020) during the COVID-19 pandemic, which likely affected our response rate.

Respondents came from 17 different EU/EEA countries with the number of responses per country ranging from one to four. We received no responses from Bulgaria, Czechia, France, Germany, Hungary, Latvia, Lithuania, Luxembourg, Poland, Slovakia, Spain, Sweden, Iceland, and Liechtenstein. As a result, these countries were not represented in the survey analysis. Table 2 below provides a grouping of countries based on the number of survey responses per country.

Table 2. Number of survey responses per country

Country	Responses
Romania	4
Austria, Cyprus, Estonia, Finland, the Netherlands, Portugal, the UK	2
Belgium, Croatia, Denmark, Greece, Ireland, Italy, Malta, Slovenia, Norway	1
Bulgaria, Czechia, France, Germany, Hungary, Latvia, Lithuania, Luxembourg, Poland, Slovakia, Spain, Sweden, Iceland, and Liechtenstein	0

Source: RAND Europe analysis
Respondents also came from a variety of professional backgrounds. Medical informaticians made up the largest group of respondents (33%), followed by: public health professionals (21%); epidemiologists (15%); infectious disease experts (13%); clinicians (8%); policy professionals (6%); and health economists (4%).

3.2 Use of EHRs in infectious disease reporting and notification

Survey respondents were asked if EHRs were currently used for infectious disease reporting, or by public health authorities (PHAs) to identify people at high risk of contracting an infectious disease. Respondents were also asked if PHAs were involved in ensuring the quality of EHR data. These data help us to address the following research question: *What are the current status and trends in the use of EHRs in EU/EEA countries*?

Key messages of this section

- Respondents from 12 out of 17 EU/EEA countries report that their countries currently use EHRs for infectious disease reporting.
- Respondents from seven out of 17 EU/EEA countries report that PHAs in their countries use EHR systems to identify people at high-risk for contracting an infectious disease.

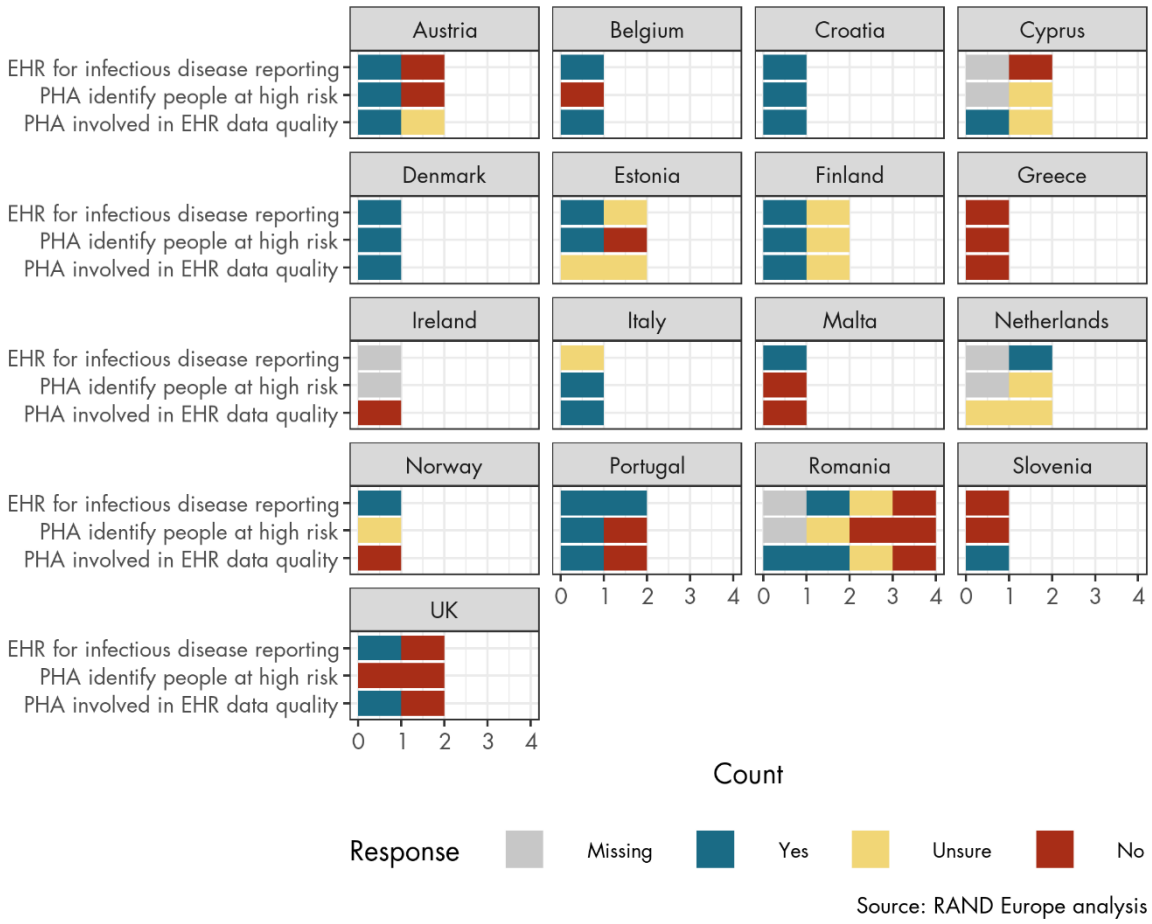
For 12 of the 17 countries covered by the survey (Austria, Belgium, Croatia, Denmark, Estonia, Finland, Malta, Netherlands, Norway, Portugal, Romania, and the UK), at least one respondent reported that EHRs are used to fulfil infectious disease reporting requirements (see Figure 1 below and Table 9 in Annex B), although only a few provided specific examples and respondents in several countries disagreed about whether EHRs were used for infectious disease reporting (Austria, Estonia, Finland, Romania, and the UK). A respondent familiar with Dutch systems mentioned the use of the HPzone software (25) to manage COVID-19 reporting based on EHR data, while

[5] The number of additional participants invited through contacts from the external expert advisor is unknown because the advisor asked contacts to share the information on the survey and the survey link with additional contacts in their networks, via a snowballing method. During this phase of survey recruitment, we were especially focused on trying to recruit participants from EU/EEA countries for which we had received no responses.

another participant mentioned the Austrian *Epidemiologisches Meldesystem* (26) which consolidates EHR information from all levels of the Austrian health administration, including laboratory test results, and uses them to provide real-time infectious disease surveillance. An additional respondent noted that in Denmark information is shared with the eHealth agency (Sundhedsdatastyrelsen), Danish Health Authority, and Danish Ministry of Health.

Participants reported that PHAs use EHR systems to identify people at high-risk for infectious diseases[6] in less than half of the countries included in the survey; Austria, Croatia, Denmark, Estonia, Finland, Italy, and Portugal all reported the EHR systems were used it in this way. However, it is likely that both the level of knowledge of respondents and understanding of what they regard as an EHR system[7] likely impacted on the responses to this question. For just over half the countries included (65%; Austria, Belgium, Croatia, Cyprus, Denmark, Finland, Italy, Portugal, Romania, Slovenia and the UK), respondents viewed PHAs as having an involvement in ensuring the quality of EHR data.

Figure 1. Use of EHR systems for infectious disease reporting and prevention, and involvement of public health authorities (PHA) in electronic health record (EHR) data quality



Source: RAND Europe analysis

[6] Participants were asked if public health authorities in their country of expertise provided information about infectious diseases to healthcare providers through electronic health systems to enable them to identify people at high risk of infectious disease (for example, identifying people for screening, or prompting re-testing for treatment of people at high risk).

[7] The survey did not define minimum characteristics of electronic health record systems so that respondents were able to apply their own understanding of the term when completing the survey.

3.3 Current status of EHR systems in the EU/EEA by country

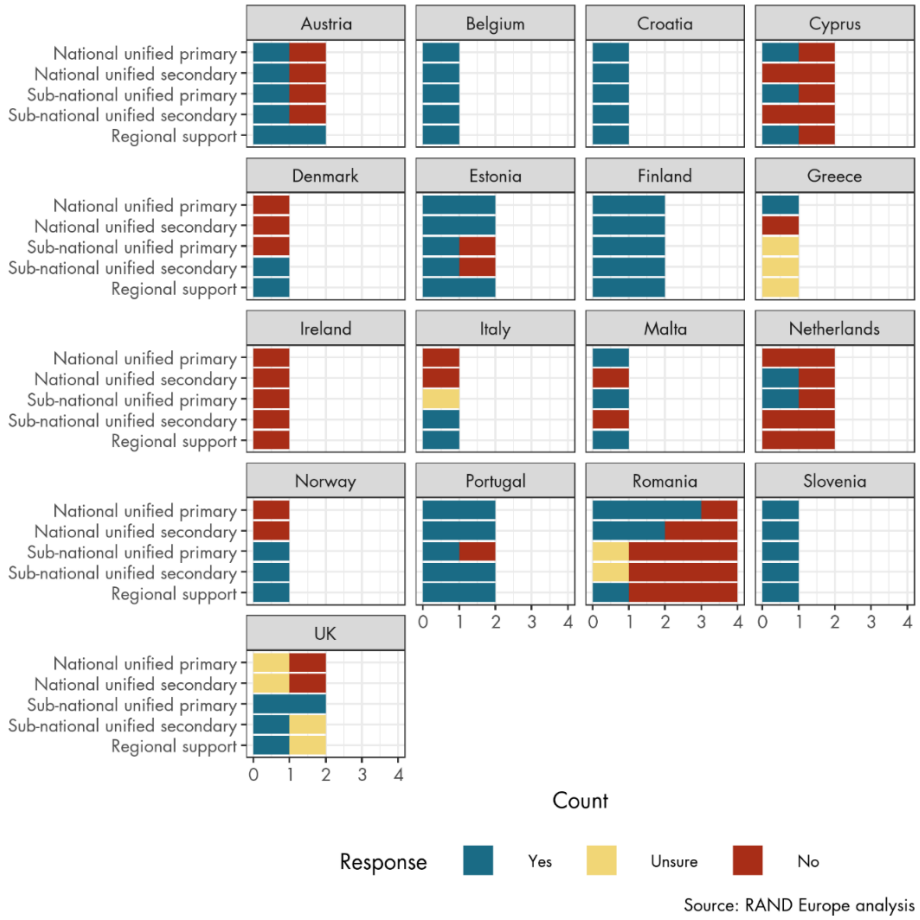
Survey respondents were asked if there were unified EHR systems at the national level for primary and secondary health sectors, and about the degree to which primary and secondary healthcare systems have transitioned to the use of electronic systems from paper-based systems. These data help us to address the following research question: *What are the current status and trends in the use of EHRs in EU/EEA countries*?

Key messages of this section

- Unified national EHR systems are not commonly reported by EU/EEA survey respondents.
- There is wide variability in the degree of transition to fully electronic systems within EU/EEA countries, with four countries (Estonia, Finland, the Netherlands, and Norway) exhibiting a high degree of implementation of electronic systems.

Unification of EHRs[8] at a national level was only consistently reported at both primary and secondary care levels for Belgium, Croatia, Estonia, Finland, Portugal, and Slovenia (see Figure 2 below and Table 10 in Annex B), although of these countries, only Estonia and Finland were reported to have also made substantial progress on a related indicator – that of having completely electronic systems for primary and secondary care (discussed further below; see Figure 3). In contrast, respondents from Italy, Ireland, Denmark, and Norway consistently report that their countries do not have unified national EHR systems in primary or secondary care. However, the observed variation in responses, even within countries, suggests differences between respondents in understanding or conceptualisation of the word 'unified' in relation to EHR systems.

Figure 2. Presence of unified EHR systems for primary and secondary care at national and sub-national levels, and presence of regional support for EHR systems

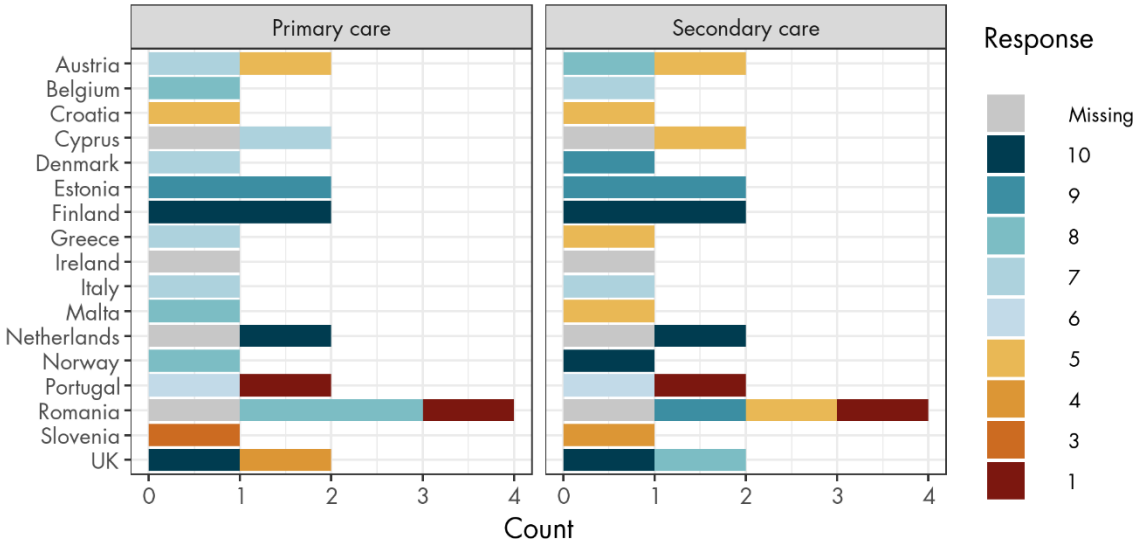


Source: RAND Europe analysis

[8] 'Unification' was defined as sharing the same computer system across multiple *care* providers (e.g. hospitals). This is distinct from linkage with other electronic systems such as laboratory, pathology, or pharmacy information systems; or public health registry or alert systems which were asked about later in the survey.

As shown in Figure 3, EU/EEA countries differ substantially regarding the degree to which primary and secondary healthcare systems have transitioned to the use of electronic systems. Responses suggest that four countries have transitioned to largely electronically based systems: Estonia, Finland, the Netherlands, and Norway. However, participant responses did differ somewhat within countries with multiple respondents, apart from Estonia and Finland.

Figure 3. Respondent perspectives of status of primary and secondary care systems regarding the transition from paper-based system (1) to completely electronic systems (10)



Despite the limitations of this measure, it provides an indication of the level of implementation of electronic medical record systems across countries. To enable cross-question analysis of how the degree of EHR implementation may impact other factors, such as data sharing or barriers to use, we used this information to create a 2-level categorisation of implementation (low/medium, high; see Table 3) that we refer to in this report as transition categories.

Table 3. Degree of implementation of EHR systems for each country included in the survey

Transition Category	
Low/Medium	**High**
Austria Belgium Croatia Cyprus Denmark Greece Italy Malta Portugal Romania Slovenia UK	Estonia Finland The Netherlands Norway

Note: No data available for Ireland on this measure.

Methods note

We created the degree of implementation measure by taking the average score across all respondents within a single country for primary and secondary sectors combined. This continuous measure was then categorised into: low/medium=0-8, high=9-10.

3.4 EHR data format and completeness

Survey respondents were asked about the format, including whether it is structured, unstructured or both, within primary and secondary care, for different categories of information. They were also asked about the completeness of EHR data within primary and secondary care for different types of information (e.g. sociodemographic data, laboratory reports, treatment details, etc.), and information on key timepoints within EHR systems (i.e. timing of exposure, infection, symptoms and diagnosis). This will help to address the following research question: *What are the characteristics of the EHRs implemented in each EU/EEA country?*

Key messages of this section

- Data within EHR systems is frequently provided in unstructured formats, presenting challenges for its use in disease surveillance; although, data structure varies by the category of information, with information on sociodemographics, diagnosis and prescriptions being the most likely to be structured.
- The level of completeness of EHR data varies by information type with sociodemographic and diagnosis data being the most likely to be 'always' completed.
- The level of completeness is also related to data format with categories of data that are most likely to be reported in structured format also most likely to be 'always' completed.
- Those countries that report high levels of EHR implementation were also the most likely to report that information was always recorded in EHR systems, although this varies by the type of information being recorded (e.g. sociodemographic, laboratory, etc.).
- Most countries report that key timepoints are routinely reported for at least some infectious diseases.

3.4.1 Format of EHR data

Although there was substantial variability within and between countries regarding the format in which information is captured in EHR systems (see Figure 10 in Annex B for detailed results), there are consistent patterns in terms of which data are more or less likely to be captured in structured versus unstructured format. To highlight these patterns, we used a summary measure that collapsed information from multiple respondents per country into a single estimate for each type of EHR information (see methods note). Based on these results (see Table 4) information on sociodemographics, diagnosis and prescriptions are most likely to be captured in a structured format whereas non-pharmacological treatments, consequences, and medical history were more likely to be captured using a combination of structured and unstructured data. Differences between primary and secondary care systems suggest that disease consequences, treatment, and medical history may be more likely to be captured in unstructured form in primary compared to secondary care.

Table 4. Respondent perspectives on how information is recorded (structured or unstructured fields) in primary care and secondary care EHR systems for each of the included countries (n = 17), summarised as the percentage of countries recording data in each format by type of data

Care sector	Data	Structured	Structured and unstructured	Unstructured	Not included	Missing/Unsure
Primary Care	Sociodemographic	53%	29%	0%	0%	18%
	Laboratory	29%	41%	6%	6%	18%
	Diagnosis	47%	35%	0%	0%	18%
	Disease consequences	12%	59%	6%	0%	24%
	Treatment	6%	71%	0%	0%	24%
	Prescription	53%	29%	0%	0%	18%
	Medical history	18%	53%	6%	6%	18%
Secondary Care	Sociodemographic	65%	18%	0%	0%	18%
	Laboratory	47%	29%	6%	0%	18%
	Diagnosis	59%	18%	6%	0%	18%
	Disease consequences	18%	47%	6%	6%	24%
	Treatment	18%	47%	6%	0%	29%
	Prescription	47%	29%	6%	0%	18%
	Medical history	12%	53%	12%	0%	24%

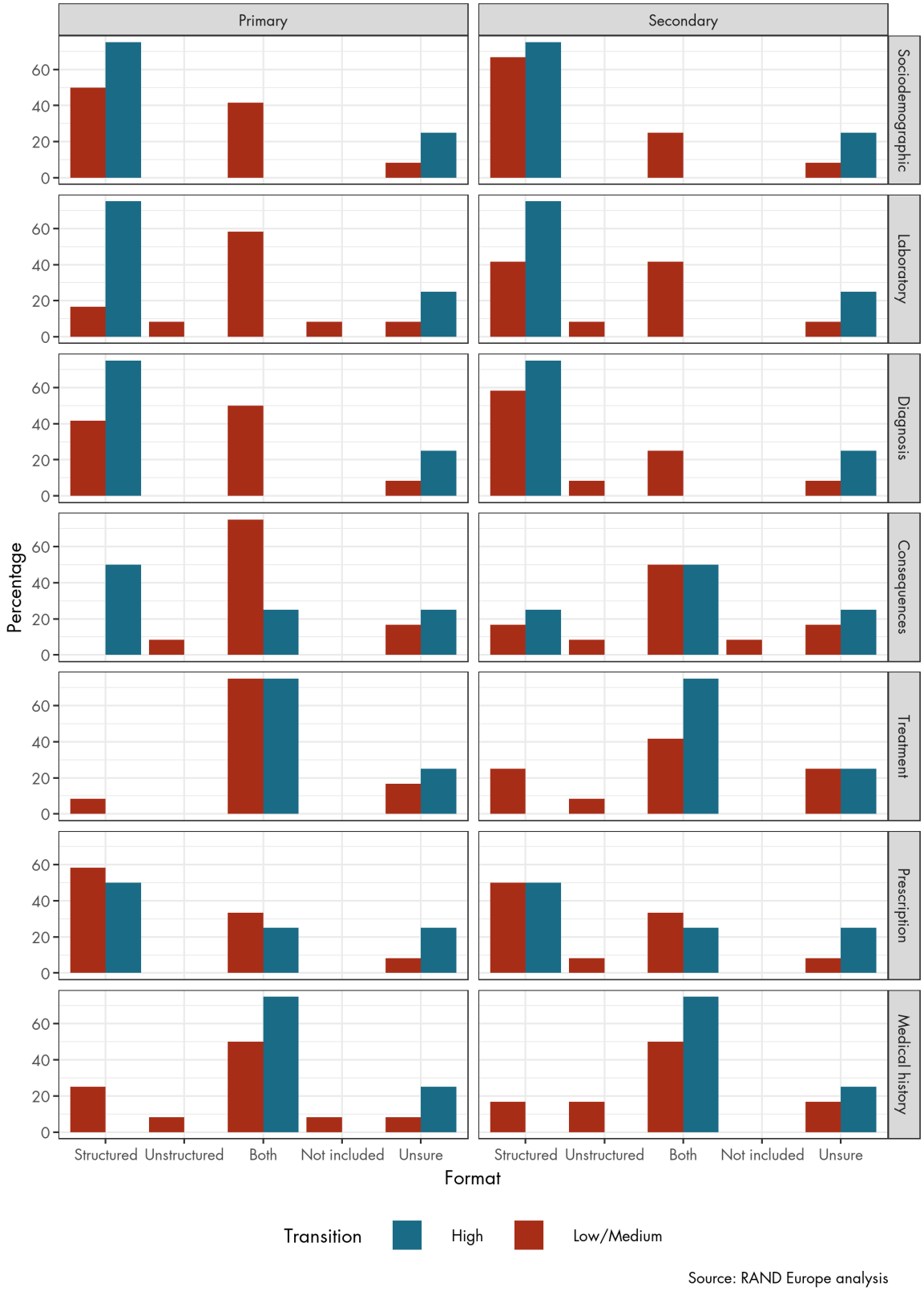
Note: 'Not included' indicates the information is not captured in the EHR system.
Source: RAND Europe analysis

Methods note

Responses from multiple respondents within a single country were collapsed into a summary measure. If all respondents agreed, then the value of that response was recorded. If there was disagreement among respondents (e.g. 'Structured' and 'Unstructured'; or 'Structured' and 'Structured and unstructured', the middle value (i.e. 'Structured and unstructured') was recorded based on the logic that if the knowledge/experiences of both respondents was assumed to be true then the value would be 'both, structured and unstructured'.

Grouping the countries by the degree of transition to completely electronic systems (Figure 4) illustrates how the level of EHR implementation is associated with the format of the data that is captured. Those countries that report high levels of EHR implementation were also the most likely to report use of structured formats for sociodemographics, laboratory information, and diagnoses while those with a low/medium level of implementation were less likely to report this. However, this pattern was not always observed for the other types of information, particularly treatment and prescription information where there did not appear to be a clear relationship between level of EHR implementation and format for recording data (see Estonia, Portugal, and Romania, for example in Figure 10 in Annex B).

Figure 4. Percentage of countries within each transition category that report use of different formats for information capture, by type of information



Source: RAND Europe analysis

Note: no response to these questions was received from Ireland.

3.4.2 Completeness of EHR data

Completeness of different types of information in primary and secondary care

Overall, the responses indicate that there is considerable variation between countries in Europe in terms of completeness of EHR data, and also within countries in terms of primary *versus* secondary care (see Figure 11 in Annex B for per-country responses). Aggregating these data within and across countries, as done for the information on the format of the data described in section 3.4.1 above, demonstrates that the majority of countries reported that sociodemographic information is the type of information most likely to be consistently completed (65% of countries reporting it is 'always' completed in primary care, and 76% in secondary care; Table 5). Information on diagnoses is the next most likely to be consistently completed, with 47% of countries reporting this is 'always' completed in primary care, and 71% reporting it is 'always' completed in secondary care. In contrast, treatment data, patient history and disease consequences (such as the outcomes following treatment) were reported to be captured the least consistently. This may be partially due to the breadth of these categories; for example, disease consequences included both death and disease complications, which are not necessarily captured equally well in EHR systems.

Table 5. Percentage of countries (n = 17) reporting that data for each type of information are always, sometimes, or never complete in EHR systems

Care sector	Information type	Always complete	Sometimes complete	Never complete	Missing/ unsure
Primary care	Sociodemographic	65%	29%	0%	6%
	Laboratory	29%	53%	12%	6%
	Diagnosis	47%	47%	0%	6%
	Disease consequences	29%	59%	6%	6%
	Treatment	24%	65%	6%	6%
	Prescription	41%	47%	6%	6%
	Medical history	18%	76%	0%	6%
Secondary care	Sociodemographic	76%	18%	0%	6%
	Laboratory	53%	35%	6%	6%
	Diagnosis	71%	24%	0%	6%
	Disease consequences	35%	53%	6%	6%
	Treatment	35%	59%	0%	6%
	Prescription	53%	41%	0%	6%
	Medical history	29%	59%	6%	6%

Source: RAND Europe analysis

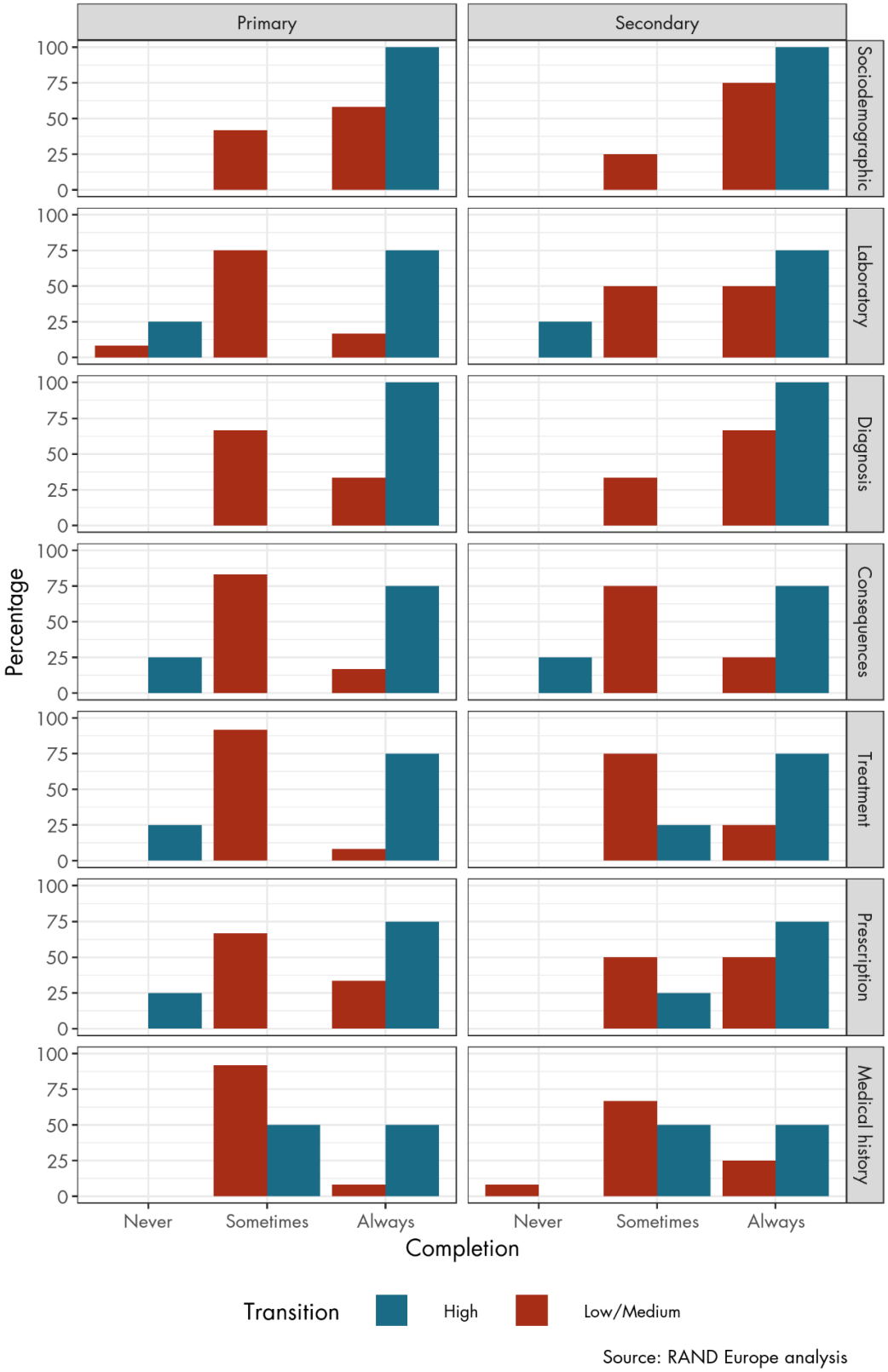
Methods note

To create an overall summary of the level of completeness for each type of information across countries, we collapsed the information from multiple respondents to estimate the level of completeness of EHRs in each country for each type of information; if all respondents in a country agreed on one level of completeness this was the level assigned to that country, but if respondents disagreed this was taken to indicate that information was 'sometimes' completed.

Separating the countries by the degree of transition to completely electronic systems (Figure 5) illustrates how the level of EHR implementation is associated with data completeness. Those countries that report high levels of EHR implementation were also the most likely to report that information was always recorded, although this was not consistent across all information types. For some, such as prescription information and medical history, particularly in primary care, completeness of information only appears to be marginally better in countries with

high levels of implementation compared to countries with low/medium levels. Information types that were more likely to be reported as 'always' being recorded are also those that are most likely to be entered in structured data formats, namely information on patient sociodemographics, laboratory information and diagnosis.

Figure 5. Percentage of countries within each transition category that report different frequencies of information capture, by type of information



Source: RAND Europe analysis

Recording of key timepoints for infectious disease surveillance

As shown in Table 6, almost one quarter (24%) of responding countries reported that key timepoints [9] were not recorded in EHR systems (see Figure 12 in Annex B for per country responses). However, most countries reported that key timepoints are routinely reported for at least some infectious diseases (routinely reported for all infectious diseases: 24% primary care; 18% secondary care; routinely reported for some infectious diseases: 29% primary and secondary care). This differed, as expected, by level of EHR implementation with countries at a higher level being more likely to report recording of timepoints for some or all infectious diseases (Table 7). We should note that there was high variability within country responses to this question (see Figure 12 in Annex B) and many (n = 18) did not provide a response for this question. The variability in responses may reflect different considerations regarding reporting for different timepoints in the clinical course, with positive outcomes (i.e. symptom-free recovery) typically not well documented in clinical systems compared with diagnosis and treatment. Few participants provided information on which specific infectious diseases their responses related to, but those who did mentioned COVID-19 and polio.

Table 6. Percentage of countries (n = 17) reporting recording of key timepoints relating to development and course of an infectious disease to support disease surveillance

Response	Primary Care	Secondary Care
No	24%	24%
Yes - but only for some infectious diseases	29%	29%
Yes - routine for all infectious disease	24%	18%
Missing/unsure	24%	29%

Source: RAND Europe analysis

Methods note

We created a summary measure showing the recording of key timepoints by country by collapsing the information from multiple respondents per country into a single estimate. If all respondents in a country agreed on one level of reporting this was the level assigned to that country, but if respondents disagreed this was taken to indicate that information was 'sometimes' reported.

[9] Key timepoints were defined specifically in relation to the development and course of infectious diseases in support of disease surveillance. Examples of key timepoints given to respondents included: information on timing of exposure, infection, symptoms, and diagnosis.

Table 7. Percentage of countries in each transition group reporting recording of key timepoints relating to development and course of an infectious disease to support disease surveillance

Care	Response	Transition level	
		Low/Medium	High
Primary care	No	53%	25%
	Yes - but only for some infectious diseases	24%	50%
	Yes - routine for all infectious disease	24%	25%
Secondary care	No	53%	25%
	Yes - but only for some infectious diseases	24%	50%
	Yes - routine for all infectious disease	24%	25%

Note: missing values are omitted.
Source: RAND Europe analysis

3.5 Data linkage and sharing

Survey respondents were asked about interoperability, the sharing and linkage of different types of information between national or subnational systems and public health authorities.

Key messages of this section

- Only about a third (35%) of the included countries reported that they have processes in place to support interoperability.
- The degree of implementation of EHR systems within a country does not appear to be closely tied to the number of linkages between the EHR system and other systems (e.g. pharmacy, laboratory information, disease or vaccine registries, pathology, or automatic vaccination alerting systems).
- Almost half of the countries (Austria, Croatia, Estonia, Finland, Malta, Portugal, Romania, and the UK) reported sharing some data with external public health organisations such as ECDC.

3.5.1 Data mechanisms

Linkage to additional data sources

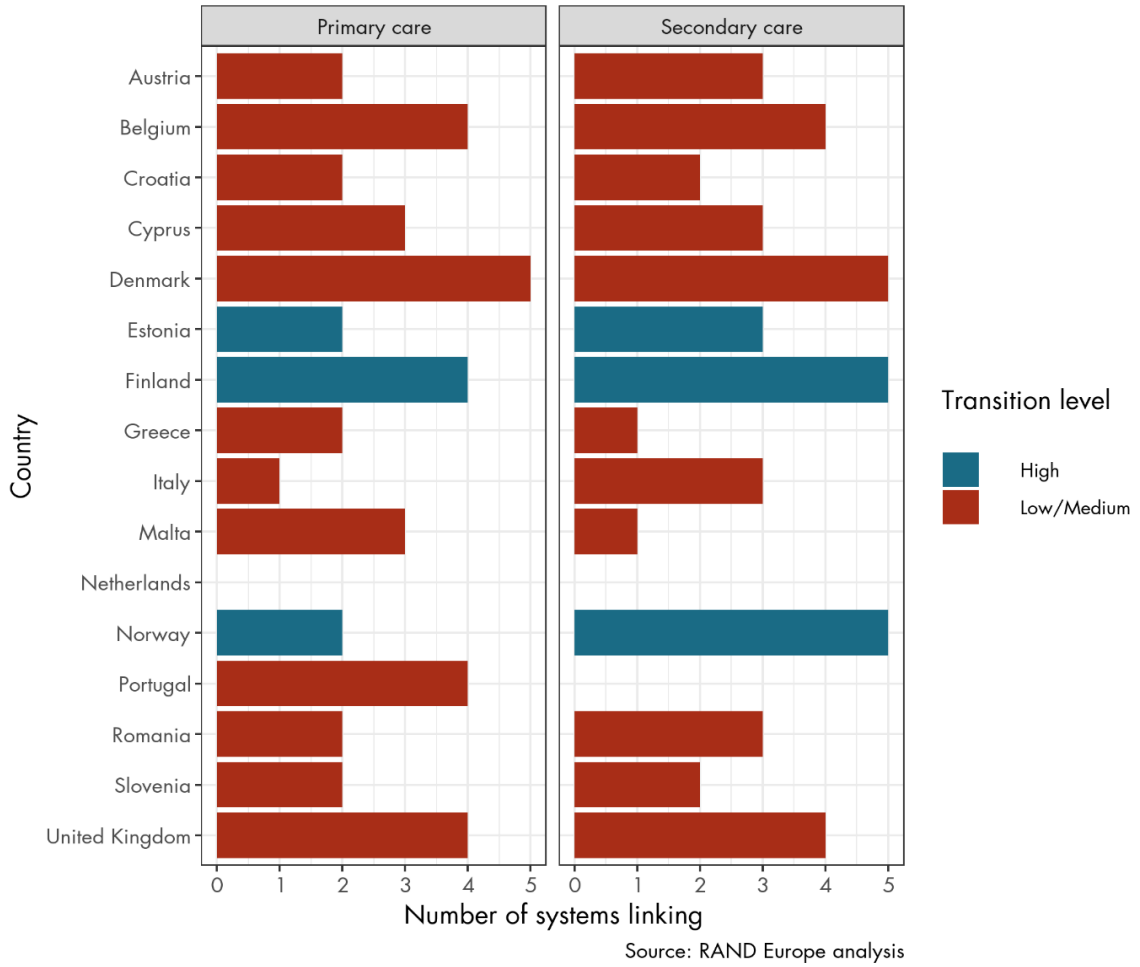
Survey respondents indicated whether their country's EHR systems linked to automatic vaccination alerting systems, disease or vaccination registries, laboratory information systems, pathology information systems, pharmacy information systems, or other types of systems. We assessed how the degree of EHR implementation potentially influences the linkage of EHR systems to these other sources by cross-analysing country-level responses to the question on data linkage with the variable showing a country's level of EHR implementation (Figure 6). As shown in Figure 6, there is not a clear pattern between the degree of EHR implementation and degree of data linkage with other systems; although within secondary care, countries with high levels of implementation (Finland and Norway) report the highest number of system linkages with their EHR systems (five for Finland and Norway) along with Denmark (five linkages). The pattern is less clear in primary care where Estonia and Norway, two countries at the highest level of transition, report some of the lowest number of system linkages (two and one, respectively).

The most common systems for which respondents reported linkage to EHR systems (Figure 13 in Annex B) to were those relating to pharmacy systems (reported in at least one of primary or secondary care by all countries except the Netherlands and Ireland) or laboratory information (all countries except Slovenia, the Netherlands, Italy, and Ireland; Figure 13 in Annex B). There was also some reporting of linkage to disease/vaccination registries for Belgium, Denmark, Finland, Greece, Italy, Malta, Romania, Norway, and Slovenia. Only the UK and Portugal reported linkage to automatic vaccination alert systems.

Methods note

For this analysis, we created a summary variable measuring the number of different system linkages within each country. This variable counted any report of a unique system linkage by a respondent as a new system linkage and then summed the total number of unique system linkages.

Figure 6. Degree of implementation of EHR systems and number of different types of systems EHR system links with, primary and secondary care, by country



Note: Ireland did not provide data for this question.

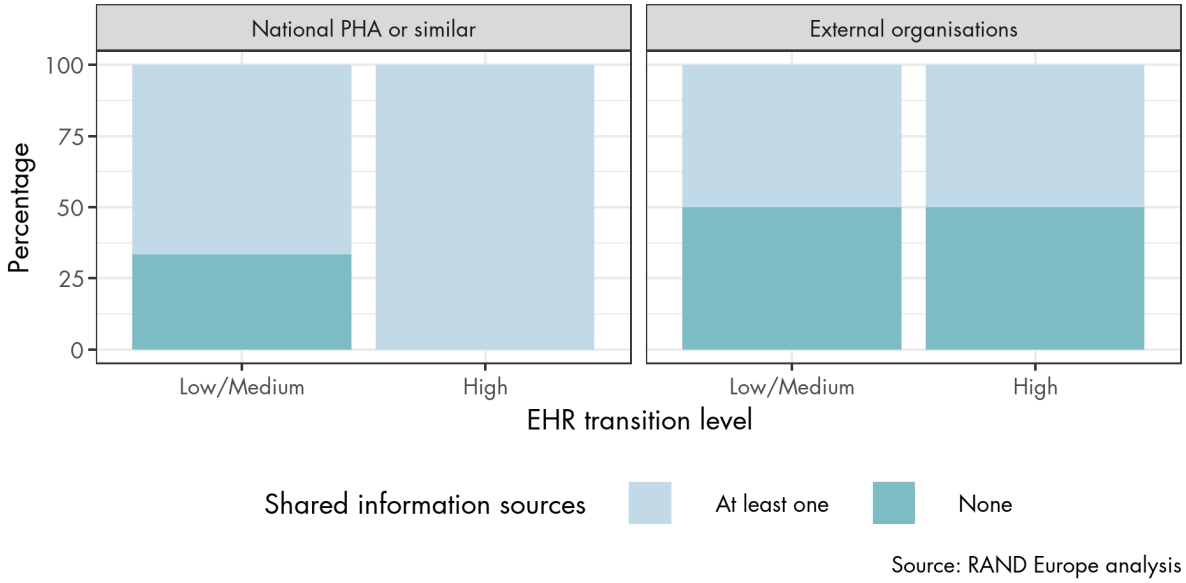
Data sharing

Recipients were asked to consider whether EHR systems were used to share information with the national PHA and/or external organisations such as ECDC (either via the national PHA or directly with the external organisations). The types of information respondents could report on included: sociodemographic, laboratory, diagnoses, disease consequences, disease treatment, prescriptions, and medical history. The responses to this set of questions were variable and did not appear to be directly related to implementation of electronic systems (Figure 8). For example, no sharing outside the country was reported for Denmark or Norway (Table 8). However, this may have reflected lack of participant knowledge rather than a definitive lack of sharing. Of more interest is that in almost half of the countries (Austria, Croatia, Estonia, Malta, Portugal, Romania and the UK) participants reported sharing of some data with external organisations, and 12 countries (Austria, Croatia, Denmark, Estonia, Finland, Italy, Malta, Netherlands, Norway, Portugal, Romania, and the UK) reported sharing some data with a national PHA authority or similar body.

Table 8. Number of countries where at least one type of data is shared with external and national PHAs (or similar) organisations

Organisation type	Number of data types shared	Number of countries	Countries
External organisations	At least one	8	Austria, Croatia, Estonia, Finland, Malta, Portugal, Romania, UK
	None/missing	9	Belgium, Cyprus, Denmark, Greece, Ireland, Italy, Netherlands, Norway, Slovenia
National PHA or similar	At least one	12	Austria, Croatia, Denmark, Estonia, Finland, Italy, Malta, Netherlands, Norway, Portugal, Romania, UK
	None/missing	5	Belgium, Cyprus, Greece, Ireland, Slovenia

Figure 7. Sharing with PHAs and external organisations by countries in different stages of transition to EHR systems



Source: RAND Europe analysis

Sharing of at least one type of information is shown

Participants were also asked if there were processes in place to support interoperability. Only about a third (35%) of the countries that responded to the survey reported that they have processes in place to support interoperability, namely Portugal, Italy, Finland, Estonia, Denmark and Belgium (Figure 14 in Annex B). This does not appear to be linked to how advanced countries were in moving to completely electronic systems (see Figure 3 above). Responses to the question may also reflect differences in the professional background of the respondents for each country and their familiarity with technical concepts related to data sharing (e.g. medical informatics *versus* clinical medicine or infectious disease). Most respondents also reported the use of a unique patient identification system (Figure 16 in Annex B). For all countries where such a system was in use, the same identification number was reported to be used for primary and secondary care.

3.5.2 Legislation and governance

Survey respondents were asked about specific legislation and mechanisms governing access and sharing of EHR data. This will help to addresses the following research question: *What legislation exists that governs the use of EHRs in each EU/EEA country?*

Key messages of this section

- Most countries report having specific legislation governing the secondary use of EHR data.
- Many respondents were unsure about the secondary use of EHR data by public health authorities for disease surveillance, or what mechanisms were in place to permit data sharing.

Access to EHR data for secondary use

Most countries reported having specific legislation governing the secondary use, or the use of data for a purpose other than that for which it was originally collected, of EHR data, in addition to GDPR (Figure 17 in Annex B). Many respondents were unsure about secondary use of EHR data from primary or secondary care for disease surveillance by public health authorities; only two countries, Finland and Croatia, reported that direct access to these data was possible for this purpose (Figure 18 in Annex B).

Mechanisms for consent to EHR data sharing

Respondents also reported several different mechanisms for permitting data sharing within different countries (Figure 19 in Annex B). In most countries, respondents reported either an 'opt-out' or 'opt-in' consent model was in operation, with five countries reporting both (Norway, Finland, Denmark, Cyprus, and Austria). Respondents said there was no specific legislation covering consent in Croatia or Belgium. There was also high variability within country responses, suggesting uncertainty in respondents' knowledge. A caveat to this question is likely the limited knowledge of respondents concerning the legal basis for data sharing, given that no participants reported extensive expertise in legal regulations. Given this, and the high variability, it is difficult to draw any conclusions from responses to this question and the topic could merit further investigation.

3.6 Barriers to the use of EHR systems

Survey respondents were asked about potential barriers to record and access data within EHR systems within primary and secondary care. The list of barriers was provided to respondents7 and adapted from a similar question in the WHO survey on eHealth (3). This information will help to addresses the following research question: *What is the current status and trends in the use of EHRs in EU/EEA countries?*

Key messages of this section

- The degree of implementation of EHRs seems to be related to barriers cited to recording and using EHR data.
- Lack of time and difficulties with using the EHR system are the most likely barriers to be cited by high transition level countries; whereas it not being a staff priority is among the least likely barriers to be cited by those same countries.
- Countries at a low/medium transition level were the most likely to indicate that lack of confidentiality or a privacy framework was a barrier to using data stored in EHR systems.
- Countries with a high level of EHR implementation were more likely to cite data quality issues (e.g. completeness and timeliness of stored data) as a barrier to using EHR data.

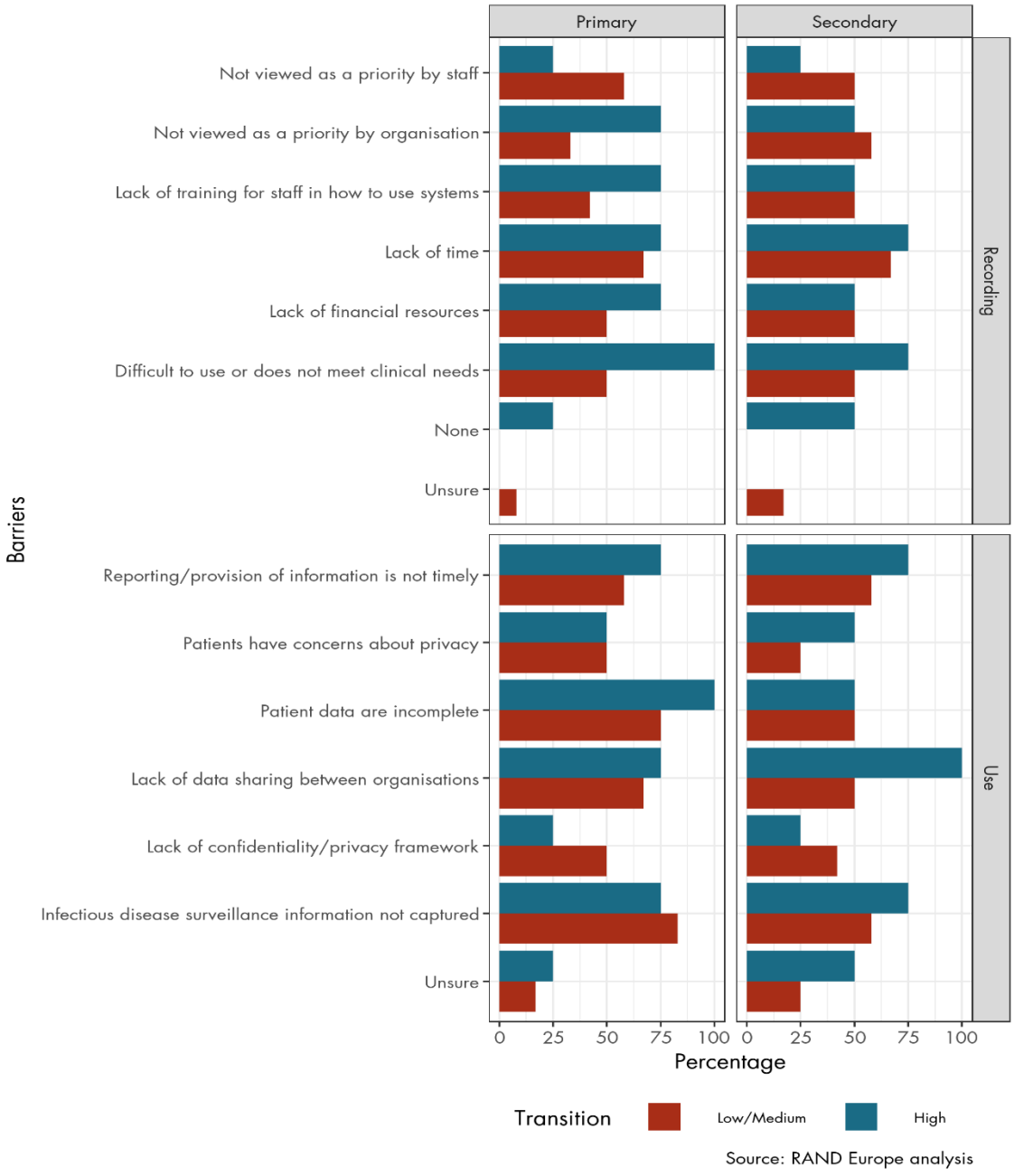
Barriers to recording and using information in EHR systems appear to be loosely related to the level of transition from a paper-based to an EHR system (Figure 8). Countries with the highest level of transition are the least likely to say recording in EHR systems is not a staff priority, but the most likely to cite difficulties with using the EHR system as a barrier to recording data. High transition level countries are also slightly more likely to cite a lack of financial resources as a barrier to recording data in EHR systems. This suggests that perceived barriers to the use of EHRs for recording clinical information may change along with the level of transition to a fully electronic system. Initial barriers may be around getting staff buy-in, but as systems mature, issues with system usability, lack of time and finances become larger concerns. The varying responses may indicate that expectations around usability and efficiency of systems grows along with the level of system transition.

When considering the use of information in EHR systems (Figure 8), differences are again evident by level of transition. Countries at a low/medium transition level were the most likely to indicate that lack of confidentiality or a privacy framework was a barrier to using data stored in EHR systems. In contrast, countries with a high level of EHR implementation were more likely to cite data quality issues (e.g. completeness and timeliness of stored data) and a lack of data sharing between organisations. It is important to note that the survey did not allow for a free-text response to this question so some specific barriers to the recording and use of EHRs may not have been captured.

Methods note

For this analysis, we created a summary variable indicating each unique barrier reported by country-level respondents. This variable counted any report of a unique barrier by a respondent as a new barrier. This summary variable was then used to calculate the percentage of countries within each transition level that reported barriers to recording and using information in EHR systems.

Figure 8. Barriers to the recording of data in EHRs or use of data in EHR systems in primary and secondary care



Percentage of countries in each transition level endorsing each barrier shown

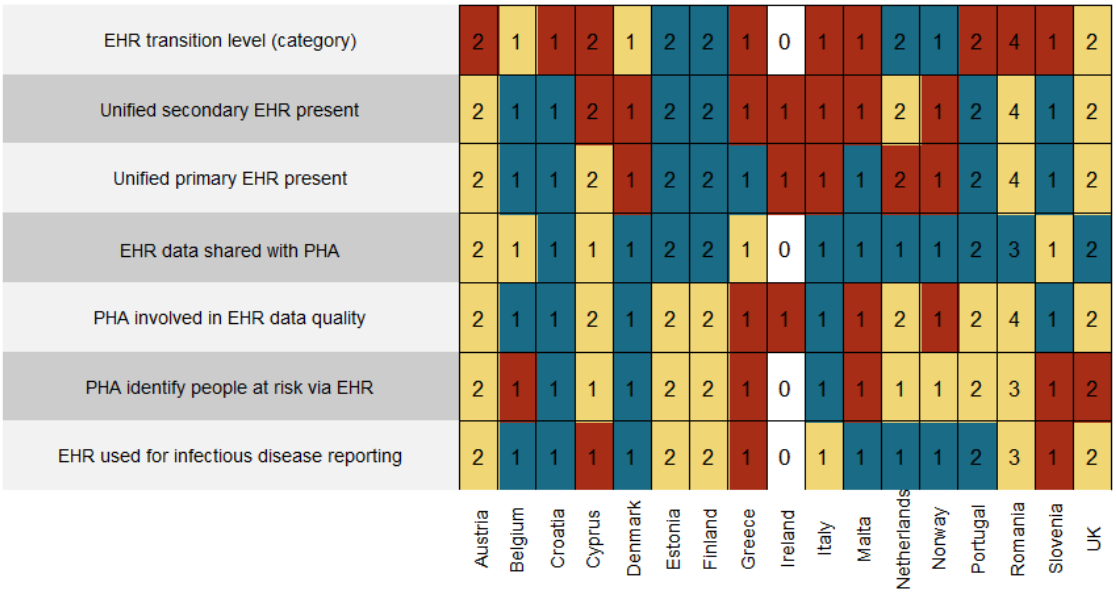
4. Mapping and EHR implementation case studies

4.1 Mapping

In order to provide a summary of the key characteristics of EHR systems by country, we mapped country-level responses according to the number of responses received and the degree of certainty from respondents. We provide extended mapping tables in Annex C that indicate country-level responses for all of the characteristics detailed in this report, combining information captured through the survey and desk research, including the case studies and targeted desk research intended to fill the gaps for those countries for which we received no responses to the survey. We briefly summarise the key elements of EHR systems and their use for infectious disease surveillance, prevention and control in Figure 9.

These results illustrate that presence of a unified EHR system and the level of transition to a completely computerised medical record system are not directly related to using the EHR system to share data with public health authorities or engage in infectious disease reporting. The results also suggest that PHAs may not currently play a prominent role in ensuring the quality of data recorded in EHR systems, which may be one avenue by which PHAs could encourage system development towards supporting disease surveillance.

Figure 9. Mapping summary of EHR system characteristics for EU/EEA countries



Note: The mapping summary shows the number of responses received for each question, per country. The colour coding indicates the degree of certainty from the respondents regarding EHRs' characteristics or use in their country. Affirmative respondent concordance (i.e. all respondents agreed a characteristic was present) is indicated by blue, negative concordance (i.e. all respondents agreed a characteristic was absent) by red, and respondents conflicting or being unsure by yellow. For the transition level, the colours correspond to low (red), medium (yellow), and high (blue).
Source: RAND Europe analysis

4.2 Case studies

In order to provide a more in-depth look at how individual countries have implemented EHR systems, we selected three countries with more fully implemented EHR systems on which to conduct case studies (Finland, Estonia and the Netherlands; see Methods for details). For each case study country, we identified examples of EHRs used for infectious disease surveillance, and any barriers and facilitators towards doing so. Overviews of the case study findings are presented in Boxes 1-3 below. The full case study findings are available in Annex C.

Box 1. Finland case study summary

Summary

- Finland has a national EHR system and interoperable data system. This system has been obligatory for all public healthcare providers since 2014 and most private healthcare providers since 2018. The functionality of the national system includes sharing full plain text and structured medical records, ePrescriptions, an overview of critical risk factors, sending and receiving laboratory tests and medical images, and medication lists.
- The EHR system has reportedly been used for infectious disease surveillance, but we could not identify any specific examples at the time of data collection. The EHR system has been used to implement the EU COVID-19 certificates. The EHR system has also been used for other secondary use cases (including for monitoring of the primary and secondary care system) but has not yet been rolled out extensively for clinical trials and research.
- Finland has used a regional approach to the development and implementation of EHRs, which has become more unified with the introduction of the national system, Kanta.
- There is an act on EHRs ('Laki sosiaali- ja terveydenhuollon asiakastietojen sähköisestä käsittelystä', 159/2007) and a decree on national EHR systems ('Sosiaali- ja terveysministeriön asetus terveydenhuollon valtakunnallisista tietojärjestelmäpalveluista', 165/2012) that together with other general legislation on healthcare, health records, and data protection, regulates EHRs in Finland.
- Facilitators to the implementation of the EHR system in Finland include: i) legislation that mandates the involvement of healthcare providers in the EHR system; ii) use of common dose sets and classifications; iii) ease of obtaining prescription data from other organisations; iv) strengthening of skills and competences using organisational and regional actions; v) data sharing perceived as mutually beneficial and valid; v) accessibility to the EHR system for patients; vi) using EHRs to support the work practices of health professionals; and vii) the interoperability of the EHR system.
- Barriers to the implementation and use of the EHR system in Finland include: i) data quality; ii) high financial charges; iii) cumbersome data request procedures; iv) lack of incentives to use privacy preserving mechanisms; v) lack of implementation and procedures for open access to EHR data; vi) lack of interoperability; and vii) fragmentation of the healthcare system between regional and national providers.

Box 2. Estonia case study summary

Summary

Estonia was the first European country to implement a national health information system in 2008, and has achieved near universal coverage (99% of patients) by mandating that all licensed medical providers upload selected data held in provider-based health records to the national health information system.

Estonia maintains a separate infectious disease database, the Communicable Diseases Register, managed by the Health Board. The Health Board is considered a data consumer of the national health information system, and may draw on data from this system while completing national reporting requirements. However, providers are also required to report information to the Communicable Diseases Register separately, and it is unclear from the available literature to what extent the communicable diseases register draws on the national system in practice.

The national health information system in Estonia links to other public databases through a data exchange layer called X-tee, which is enabled through block chain technology. Patients are identified in all databases through their national ID number.

Data from the national health information system can be used for secondary research and development purposes. If data is anonymised, no patient consent is needed. For non-anonymised dataset, patients may opt-out of their data being provided for secondary use.

The national EHR system in Estonia has been enabled by extensive 'e-state' infrastructure, including electronically enabled national ID cards and X-tee, a data-exchange layer to share data between public and third parties.

Current challenges in Estonia's national health information system include implementing standardised and machine-readable data formats across providers, which is time and resource intensive. There are also challenges with sharing data internationally, and challenges related to the quality and completeness of data in the system.

Box 3. The Netherlands case study summary

Summary

- The Netherlands have a widely used EHRs system. In 2013, 93% of GPs and 66%of medical specialists claimed to update their records primarily or exclusively electronically.
- The EHR system is used for infectious disease reporting, including for European influenza surveillance under the database hosted by the European Surveillance System (TESSy).
- The Netherlands also have the NIVEL primary care database, which comprises a weekly collection of data from EHRs from general practices and other primary healthcare providers, that is used for influenza-like illness reporting.
- The Netherlands use a regional approach to development and implementation of EHRs, as well as an opt-in approach requiring patient consent.
- There are no specific laws or action plans to regulate EHRs in the Netherlands, rather they rely on general health and data protection law for the use of EHRs.
- Enablers to implementation include gradual integration and co-existence with existing healthcare information technology solutions, involvement of healthcare providers in regional initiatives, and the use of open competition model.
- Barriers to implementation include the lack of a uniform e-health strategy within a fragmented system and lack of political transparency in the development of system components that limited buy-in from service providers.

When considering potential lessons to be learned from the case studies, some common themes relating to the challenges to implementing EHR systems emerge. Mandating the uptake of EHR systems at a national level via legislation appeared to be a key component to achieving national implementation. Both Finland and Estonia used this approach, making it a requirement for both public and private providers and specifying a deadline for implementation. In contrast, the Netherlands has not implemented any legislation at a national level and has not achieved universal adoption of an EHR system.

Even with national legislation mandating use, unless a national system is provided fragmentation of infrastructure to support use of electronic records is likely. Although Finland initially began with regional systems, it has recently implemented a national system, while Estonia has implemented a national information exchange system that includes health records. These approaches support interoperability of EHRs with other systems (e.g. other healthcare providers, pharmacies, public health systems), which can act as an enabler of system uptake and development.

Although EHR systems are apparently used for infectious disease surveillance in Finland, Estonia, and the Netherlands, we could only find detailed evidence of the use of Dutch EHR systems for surveillance. In the Netherlands, several sources of information are used for infectious disease surveillance, including EHR data kept by general practitioners (GPs). The Netherlands Institute for Health Services Research ('NIVEL') database contains longitudinal data from EHRs of approximately 500 general practices and other primary healthcare providers, around 300 of which use an information system that allows automatic pseudonymised weekly data extraction from medical records. Deviations from normal disease patterns are reported to the RIVM Early Warning Committee and regional signals are notified to the municipal health services. Weekly numbers on acute respiratory infections collected from EHR systems and cases of acute influenza-like illness collected from sentinel practices are submitted to the database hosted by the European Surveillance System (TESSy), jointly coordinated by ECDC and the WHO Regional Office for Europe, for European influenza surveillance. It was noted that a strength of the Netherlands' system was its use of different data sources, which allows epidemiologists at the RIVM Early Warning Committee to form a more complete picture of the state of infectious diseases in the country (27). As well as data from GPs, this includes laboratory test results and zoonotic disease information. Using multiple data sources is beneficial, for example, because the EHR data from GPs increases the timeliness of reporting by identifying disease outbreaks earlier than laboratory information; however, it is not seen to be as accurate as laboratory surveillance when identifying the causes of symptoms such as fever or cough.

5. Summarising the EHR landscape in the EU/EEA and its implications for infectious disease surveillance, prevention, and control

Mapping the status and characteristics of EHR systems in the EU/EEA shows that countries' systems are at varying degrees of development, across multiple domains. If we consider two indicators that, from a theoretical perspective at least, would seem to indicate readiness for use of EHR systems for disease surveillance – the degree of system transition from paper-based to EHR systems and the presence of unified EHR systems – only two countries report indications of highly developed EHR systems for both indicators (Estonia and Finland). The WHO *Atlas of eHealth country profiles* (3), the most recent comparable international study examining EHR system implementation, provides a degree of comparison with the research presented here. This study assessed whether countries had implemented a national EHR system, and the extent to which it was used in primary, secondary, and tertiary care. Although the survey contained information on barriers to the use of EHR systems, result on this topic were not included in the published country profiles so we could not make a direct comparison.

Comparing the WHO results to those of the present study, Estonia and Finland were similarly identified as having unified national EHR systems with a high degree of implementation. The survey did not report on these aspects for the Netherlands, but reported the presence of a national EHR system and high uptake in Norway. For Belgium, Denmark and the UK, the survey only had complete information for Belgium, for which it showed the presence of a national system and a moderate to high degree of uptake across all sectors which again supports what was reported by respondents to our survey. For Denmark and the UK, the WHO survey has incomplete information on implementation, but reports the presence of a national EHR system in Denmark and the absence of one in the UK. Our survey suggested that Denmark does not have a national unified EHR system for primary and secondary care. Follow-up desk-based research found evidence of a patient-facing national eHealth portal; although, it is unclear if this is a unified system of EHRs across primary and secondary care (28).

For the remaining countries in the low/medium transition category, the information reported in the WHO survey partially conforms to that captured in our survey. For example, in accordance with our survey, Austria and Romania are reported to have national EHR systems, but at a low level of implementation; and Greece and Ireland are reported as not having national EHR systems. However, for Cyprus and Italy the WHO survey reports the presence of a national EHR system but our survey does not; for Croatia, Malta and Slovenia, our survey reports the presence of a national EHR system in primary care but the WHO survey does not; and for Portugal which is reported by the WHO to have a national EHR system at relatively high level of implementation whereas in our survey it is reported to have a very low level of implementation. The WHO survey was published in 2015 and as EHR implementation has been actively pursued in many countries over the past five years, we do not expect complete concordance between the WHO research and the present study. However, the differences between the WHO survey and our survey are not in a single direction reflective of improvements in EHR systems across the EU/EEA. It is therefore difficult to make inferences about how the situation has changed between 2015 and today. Instead, differences between the two surveys could stem from respondents' knowledge, as highlighted in the discussion of the study limitations.

When considering the presence of national unified EHR systems and the degree of transition to an electronic system; however, results from our survey suggest that these factors are not necessarily predictive of whether countries use EHR systems for infectious disease surveillance. For example, Denmark, Malta, the Netherlands and Norway report that they use EHRs for infectious disease reporting in the absence of unified national EHR systems. Furthermore, although the six countries that our analysis ranked as having the most well-developed EHR systems based on their degree of system transition from paper-based to EHRs (Denmark, Estonia, Finland, the Netherlands, Norway, and the UK) reported using EHRs for infectious disease surveillance, so did five countries that were ranked as having among the least developed systems (Austria, Belgium, Croatia, Malta, Portugal, and Romania).

The three case study countries profiled (section 4.2 above and in Annex C) provide further evidence of how the maturity of EHR systems alone does not appear to translate into their use in infectious disease surveillance, but instead may interact with policy factors. When considering Estonia, Finland, and the Netherlands, all three have widely used EHR systems, yet we only found clear evidence of the use of EHR systems for routine infectious disease reporting in the Netherlands where its incorporation contributed to the timeliness of reporting. In contrast, in Estonia, where there is a national health information system providing data on 99% of patients (Box 2), data for infectious disease reporting appears to come from direct reporting by healthcare providers rather than by drawing upon the data in the national health information system. In Finland, our research found a relatively high degree of participation within European e-health initiatives, including the sharing of EHR data at a European and bilateral level; however, there was no clear evidence that Finland currently uses EHRs for infectious disease surveillance.

The degree of implementation of EHR systems within a country also does not appear to be closely tied to issues of data sharing and linkage. This includes whether countries share EHR data with external public health authorities and the systems' ability to link with other systems (e.g. pharmacy or laboratory information systems, disease or vaccine registries, pathology systems, or automatic vaccination alerting systems). In both instances we found that countries at low and high levels of EHR implementation reported sharing data and linking with other systems.

Factors other than degree of system implementation are also potentially relevant for understanding the potential of countries to use EHRs for infectious disease surveillance. These include the format and completeness of data within EHR systems. Evidence from our mapping study suggests that data within EHR systems is frequently provided in unstructured formats, presenting challenges for its use in disease surveillance. However, data structure varies by the category of information recorded, with information on socio-demographics, diagnosis and prescriptions being the most likely to be structured. When considering the completeness of EHR data, sociodemographic and diagnosis data are among the most likely types of data to be completed, especially within the secondary care sector. Diagnosis is a key variable for infectious disease reporting, so it is therefore promising that it has a relatively high level of completion and likelihood of being provided in a structured format within the responding countries. However, details such as disease consequences, treatment, and laboratory results may be more challenging to use for infectious disease surveillance given their higher likelihood of being in an unstructured format or of not always being completed.

The mapping study also highlighted some barriers and enablers of EHR implementation and its use for infectious disease surveillance. From the survey, we saw that as countries transition to more fully electronic systems, issues with system usability, lack of staff time and finances seem to be the largest barrier to EHR implementation. Barriers to the use of EHR data, in contrast, encompass concerns over confidentiality and privacy, as well as data quality issues such as the completeness and timeliness of data and a lack of data sharing between organisations.

Some of these barriers were evident in the case study examples as well. For instance, although there is a national health information system in Estonia with near universal coverage, the country is still working towards implementing standardised data formats across all service providers. As a result, the quality and completeness of the data in the national system are limited, with implications for its potential use in infectious disease surveillance. In Finland, concerns over interoperability and data quality act as barriers to the secondary use of EHR data.

The case study examples also highlight additional potential barriers to EHR system implementation and its use in infectious disease reporting. Most notably, issues of system fragmentation in Finland and the Netherlands are reported as barriers to implementation and data sharing. As discussed in Section 4, the case study examples suggest that both a national EHR system and legislation mandating its use may be needed to avoid this type of fragmentation, but also that having a national EHR system is not a prerequisite for using EHRs for infectious disease reporting.

The case study countries were selected because they provided examples of well-developed EHR systems, and as such, they offer insights into enablers of successful implementation and use for infectious disease reporting. In Estonia and Finland, the involvement of national legislatures was important for enabling EHR system components. In Estonia, the legislature contributed to the success of the national EHR system not only through its initial creation, but through legislation mandating its use and through the provision of the extensive e-state infrastructure that is critical for allowing data sharing among various actors in the health system. In Finland, national legislation mandating the involvement of healthcare providers in the EHR system ensures a high degree of participation in the system by healthcare providers.

When considering the Netherlands, several factors appear to have enabled the success of their EHR system. These include gradual implementation to allow the existing system time to integrate with new healthcare information technology components, the use of an open competition model that allows a variety of technology providers to offer services and products, and the involvement of healthcare providers in regional initiatives to ensure that the needs of healthcare providers are taken into account.

Meeting the needs of healthcare professionals also emerges as an enabler of EHR implementation in Finland. There, the EHR system was viewed by healthcare professionals as helping with information exchange, reducing instances of information duplication, and making it easier to search for and find information on patients. These benefits were made possible because of the interoperability of EHR systems enabled through efforts such as the national archiving system, Kanta, and the increased use of common dose sets and classifications within EHR systems.

5.1 Limitations of the research

The limitations of the study are described here, along with the steps that the study team has taken to mitigate against these limitations.

Firstly, there are limitations due to the number of responses received to the survey. The survey administration coincided with the COVID-19 pandemic, which affected the availability of potential participants to fill in the survey, particularly given that many people with the relevant expertise would also have been key to COVID-19 response efforts. To increase response rates, the study team extended the deadline for the survey twice and sent reminders to potential participants that had not yet completed the survey, including a recognition that the COVID-19 outbreak may have limited respondents' ability to fill it in. The results therefore give an indication of EHR use for public health functions within each EU/EEA country, but due to the limited number of responses from all countries the full picture requires additional research.

Similarly, there are limitations related to the geographic diversity of survey respondents. This study sought to map the current status and trends in the use of EHRs in clinical infectious disease management and public health practice in EU/EEA countries. As such, a single response from a well-informed respondent with knowledge of all EHR availability and use would theoretically be sufficient to create this map. However, survey responses across EU/EEA countries varied, and we received no responses for 14 European countries (Bulgaria, Czechia, France, Germany, Hungary, Latvia, Lithuania, Luxembourg, Poland, Slovakia, Spain, Sweden, Iceland, and Liechtenstein). [10] As noted, we engaged in follow-up desk-based research to fill-in some gaps in our knowledge related to the countries for which we received no response.

Furthermore, there are also limitations due to the breadth of the survey questions, the level and area of expertise of any given respondent, and potential differential interpretations of survey questions and key terms. As described above, a single good response from each country would be sufficient to map EHR availability and use across EU/EEA countries. However, it is also unlikely that any single respondent has complete knowledge of EHR use within their respective countries. For some countries, we received contradictory responses for some questions. There are several potential explanations for this. One explanation may be that the contradictory responses reflect different levels of development of EHR systems within countries. In countries where EHR systems are either not at all developed or very highly developed, the level of contradiction may be much lower than in countries that are transitioning from paper-based to fully electronic systems. For countries in transition, different respondents may have differing experiences of the system. Alternatively, contradictory responses may be reflective of the fact that the survey likely sits in between different competencies rather than squarely in the domain of any one stakeholder. Most respondents came from a medical informatics background, and the second largest group from public health – it is possible that the respondents in either of those domains had a variable understanding of the other domain. This creates two risks: one of collecting contradictory evidence from different respondents, and another of us being unaware of any inaccuracies in the responses. To mitigate against this, we combined the evidence from the survey, scoping interviews, and desk-based research to inform our results and conclusions in the final report. A final limitation is the potential for important terms (e.g. EHR, unified systems) to be misinterpreted or differentially interpreted by respondents, leading to challenges comparing responses.

5.2 Implications for infectious disease surveillance, prevention, and control in the EU/EEA

The current study found evidence to suggest that the development of unified national electronic systems that can support infectious disease surveillance is feasible (see Estonia and Finland) and in at least one instance (i.e. the Netherlands) had been used for that purpose. The development of strong national EHR systems in these countries seem to have been enabled by national legislation mandating their use by healthcare providers and a focus on interoperability of EHRs with existing systems and digital infrastructure. However, our research also highlighted barriers to the development and use of EHRs for infectious disease surveillance in Europe. These include fragmented systems and issues with data linkage, data quality issues such as unstructured and incomplete data, and concerns over patient privacy. Our mapping of the level of EHR implementation across the EU/EEA suggests that the level of implementation that has currently been achieved in most countries appears to be moderate. In their current form, most EHR systems are not generally set up to facilitate infectious disease surveillance, although this is not unexpected given that most are developed primarily to focus on overall patient care with use for infectious disease surveillance as a secondary consideration.

However, this does not preclude the rapid implementation of strategies for using these EHR data for infectious disease surveillance, prevention and control. There are likely to have been quick developments in this area over the last six months, and going forward, due to COVID-19 and its impact on the need for rapid turn-around clinical information that can be aggregated at a national and international level. As an example, Denmark has

[10] For the number of responses received from each country, see Section 3.2.

established a prospective cohort of all Danish residents who are tested for SARS-CoV-2 through reverse transcriptase polymerase chain reactions by linking existing health and administrative databases, including EHR data (29). Individually linked data on the cohort includes patient demographics, vital statistics, current and previous drug treatments, and coexisting medical conditions, and these data will be made available to researchers according to existing national guidelines for access to pseudonymised registry-based data. EHR data from the US is also being used to facilitate epidemiological research associated with COVID-19, with researchers using diagnosis data to conduct a retrospective cohort study examining comorbidities associated with mortality in COVID-19 patients (30). Additionally, we saw from the examples of Estonia, Finland, and the Netherlands that national legislation and infrastructure can be powerful enablers of system development and adoption. The COVID-19 pandemic may provide EU/EEA governments with an incentive to develop strategies to strengthen national EHR systems in order to optimise their use for infectious disease surveillance.

Future research should seek to identify how Member States have responded to COVID-19 and whether and how any barriers to EHR development and interoperability may have been overcome to support national and European responses to the pandemic. It could also be beneficial to better understand the role of EU-wide and cross-national initiatives, such as the EU's e-health programme, in facilitating and supporting the development of EHRs and their use for infectious disease surveillance. This may provide insights in how countries that are close to accomplishing the implementation of national systems that could utilised for infectious disease monitoring and prevention could be supported to complete the transition to fully computerised and unified EHR systems.

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Annex A. Scoping interview protocol

Preamble and background

RAND Europe (a not-for-profit research institute) is conducting an assessment of the use of electronic health records (EHRs) for infectious disease surveillance, prevention and control within EU/EEA countries. This work has been commissioned by ECDC as part of the framework contract on the Assessment of new technologies for infectious disease surveillance, prevention and control. The study seeks to map the current status of the use of EHRs and their feasibility for surveillance of infectious diseases and related special health issues in EU/EEA countries for the 56 diseases under EU surveillance.

As part of this assessment, we are conducting a series of scoping interviews with experts on the use of EHRs for public health purposes and experts in infectious disease surveillance. The purpose of the scoping interviews is to inform the development of a survey on the current status of EHR systems across EU/EEA Member States and the feasibility of using them for infectious disease surveillance.

Do you have any questions for us before we begin?

Information on usability of EHRs for infectious disease surveillance

1. What are the characteristics of EHR systems that could, or are, being used for infectious disease surveillance?

[Prompt: For example, what populations do they cover, what healthcare sectors do they include, where do data originate from?]

2. What type of information should be included in EHR systems that are used for, or could be used for, infectious disease surveillance?

[Prompt: For example, are there considerations around the population covered, route and type of infection, treatment and treatment outcomes, vaccination histories, lab results, or any other types of information that would be important for disease surveillance?]

3. Of the things that you have just described as being important to include in EHRs for infectious disease surveillance, to the best of your knowledge, is this information currently included in most EHR systems?

[Probe on specific areas if interviewee does not speak to all information mentioned in first question]

4. Are there differences between EHR systems in terms of how infectious diseases are classified or coded that could mean they are unsuitable or difficult to use for disease surveillance?

[Prompt: For example, one potential area of concern for using EHRs for infectious disease surveillance is that diseases may be classified and coded differently across different electronic systems, and in some cases this means that a single disease may be represented by potentially many different codes.]

5. In addition to having the necessary types of data, EHR systems and the data within them need to meet some type of minimum quality standards to be useable for infectious disease surveillance. In your view, what would be some important quality consideration of EHR systems and data?

[Prompt: If interviewee doesn't offer them, prompt for specific potential measures of quality. These could include validation studies, completeness of data, etc.]

6. Are there other factors that you believe are important for the usability of EHRs for infectious disease surveillance that we haven't discussed so far?

Information on legislative landscape

7. We are interested in understanding the extent of EHR implementation and use across Europe. We are considering asking about EHR implementation and use at the regional versus national level, and across primary care, secondary care, and tertiary healthcare services. Do these distinctions make sense EU-wide? If not, what would?
8. In your understanding, are there aspects of legislation and governance, including GDPR, that are especially relevant for using EHRs for infectious disease surveillance?

[Prompt: For example, legislation governing privacy, consent for data sharing, security of stored data, or liability for health professionals who share data.]

9. OPTIONAL BASED ON RESPONSE TO 8: Could you speak to the current state of legislation and governance around access to EHR data for secondary use, particularly in the legislative areas we just discussed? This could be at the EU-level or national/sub-national level.
10. The European Commission and the Member States have engaged in a number of efforts to improve the interoperability of EHRs across Member States (14), culminating in a Recommendation (15) for a European EHR data exchange format to facilitate the sharing of health data across borders. Do you know the extent to which [participant country/the European system] has taken concrete steps towards interoperability?

a. What else do you think it is important for us to understand about sharing EHR data across Europe?
b. Are you aware of any upcoming EU or Member State initiatives around EHR data interoperability?

Information on other public health uses of EHRs

11. Are you aware of any specific examples of uses of EHR data within Europe for infectious disease surveillance?

[Prompt: If no – are you aware of any relating to non-communicable disease surveillance? Or other public health uses?]

Annex B. Results tables and figures

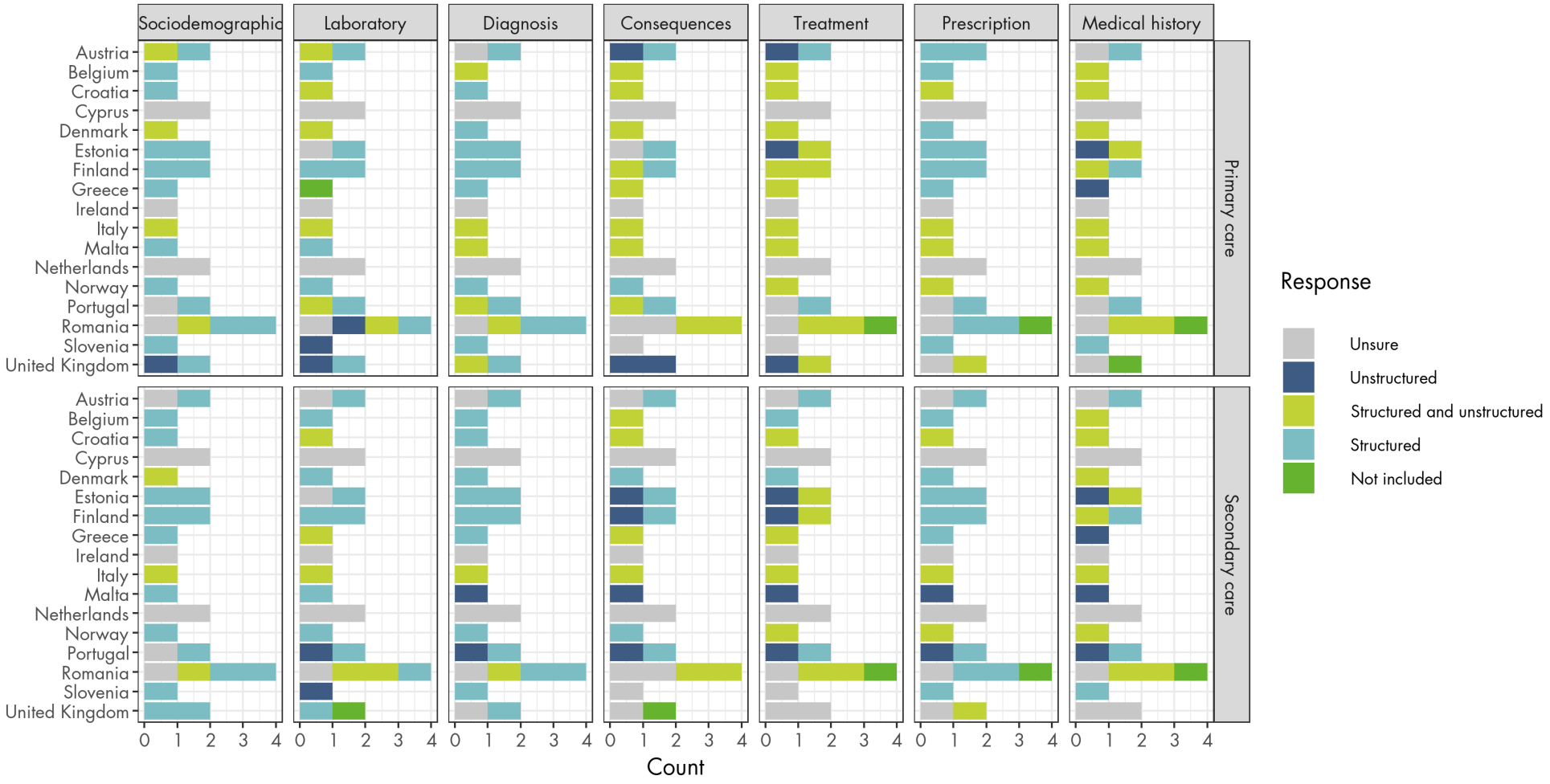
Table 9. Summary of use of EHR systems for infectious disease reporting and identification of individuals at high risk of infectious disease exposure, and involvement of the local public health authority (PHA) in ensuring the quality of EHR data (numbers indicate number of responses) (data table for Figure 1)

Country	EHR for infectious disease reporting				PHA identified at-risk individuals				PHA involved in EHR data quality		
	No	Unsure	Yes	Missing	No	Unsure	Yes	Missing	No	Unsure	Yes
Austria	1	0	1	0	1	0	1	0	0	1	1
Belgium	0	0	1	0	1	0	0	0	0	0	1
Croatia	0	0	1	0	0	0	1	0	0	0	1
Cyprus	1	0	0	1	0	1	0	1	0	1	1
Denmark	0	0	1	0	0	0	1	0	0	0	1
Estonia	0	1	1	0	1	0	1	0	0	2	0
Finland	0	1	1	0	0	1	1	0	0	1	1
Greece	1	0	0	0	1	0	0	0	1	0	0
Ireland	0	0	0	1	0	0	0	1	1	0	0
Italy	0	1	0	0	0	0	1	0	0	0	1
Malta	0	0	1	0	1	0	0	0	1	0	0
Netherlands	0	0	1	1	0	1	0	1	0	2	0
Norway	0	0	1	0	0	1	0	0	1	0	0
Portugal	0	0	2	0	1	0	1	0	1	0	1
Romania	1	1	1	1	2	1	0	1	1	1	2
Slovenia	1	0	0	0	1	0	0	0	0	0	1
UK	1	0	1	0	2	0	0	0	1	0	1

Table 10. Status of EHR systems by country and level of unification (numbers indicate number of responses) (data table for Figure 2)

Country	Unified national primary care			Unified national secondary care			Unified sub-national primary care			Unified sub-national secondary care			Regional support		
	No	Unsure	Yes	No	Unsure	Yes	No	Unsure	Yes	No	Unsure	Yes	No	Unsure	Yes
Austria	1	0	1	1	0	1	1	0	1	1	0	1	0	0	2
Belgium	0	0	1	0	0	1	0	0	1	0	0	1	0	0	1
Croatia	0	0	1	0	0	1	0	0	1	0	0	1	0	0	1
Cyprus	1	0	1	2	0	0	1	0	1	2	0	0	1	0	1
Denmark	1	0	0	1	0	0	1	0	0	0	0	1	0	0	1
Estonia	0	0	2	0	0	2	1	0	1	1	0	1	0	0	2
Finland	0	0	2	0	0	2	0	0	2	0	0	2	0	0	2
Greece	0	0	1	1	0	0	0	1	0	0	1	0	0	1	0
Ireland	1	0	0	1	0	0	1	0	0	1	0	0	1	0	0
Italy	1	0	0	1	0	0	0	1	0	0	0	1	0	0	1
Malta	0	0	1	1	0	0	0	0	1	1	0	0	0	0	1
Netherlands	2	0	0	1	0	1	1	0	1	2	0	0	2	0	0
Norway	1	0	0	1	0	0	0	0	1	0	0	1	0	0	1
Portugal	0	0	2	0	0	2	1	0	1	0	0	2	0	0	2
Romania	1	0	3	2	0	2	3	1	0	3	1	0	3	0	1
Slovenia	0	0	1	0	0	1	0	0	1	0	0	1	0	0	1
UK	1	1	0	1	1	0	0	0	2	0	1	1	0	1	1

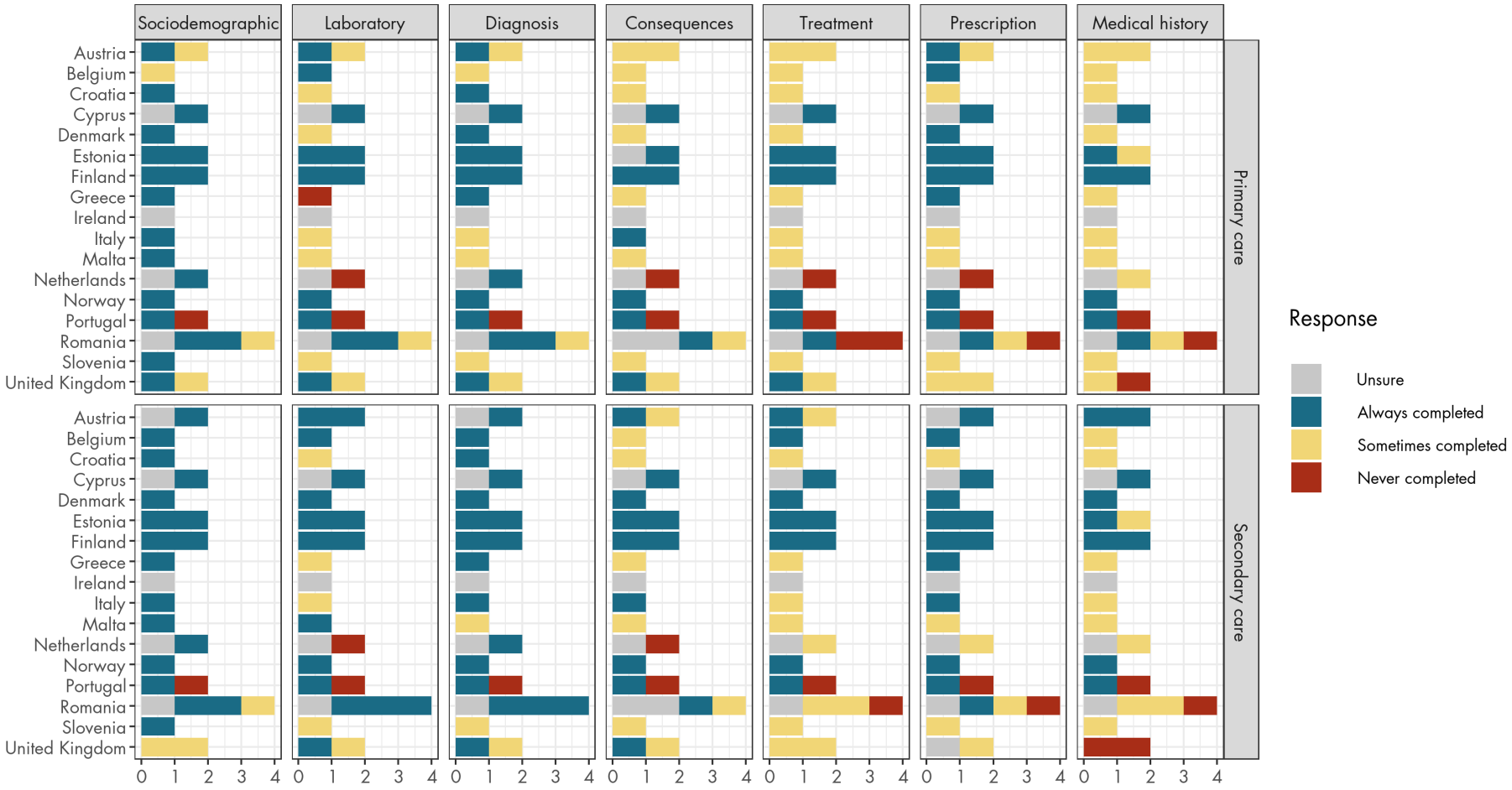
Figure 10. Respondent views on whether EHR systems in their country of expertise collect information in structured or unstructured format, by primary or secondary care and country



Source: RAND Europe analysis

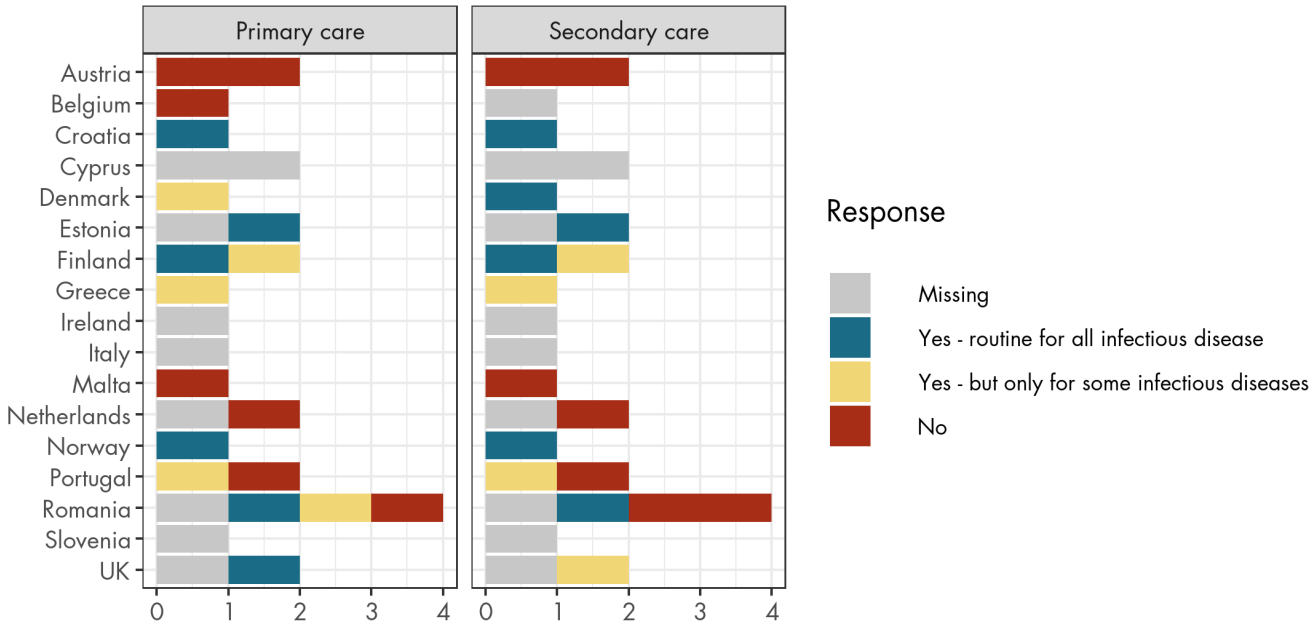
Note: 'Not included' indicates there is no scope to capture the information in the EHR system.

Figure 11. Respondent views of completeness of data on different patient and care characteristics in primary and secondary care EHR systems



Source: RAND Europe analysis

Figure 12. Recording of key timepoints relating to development and course of an infectious disease to support disease surveillance

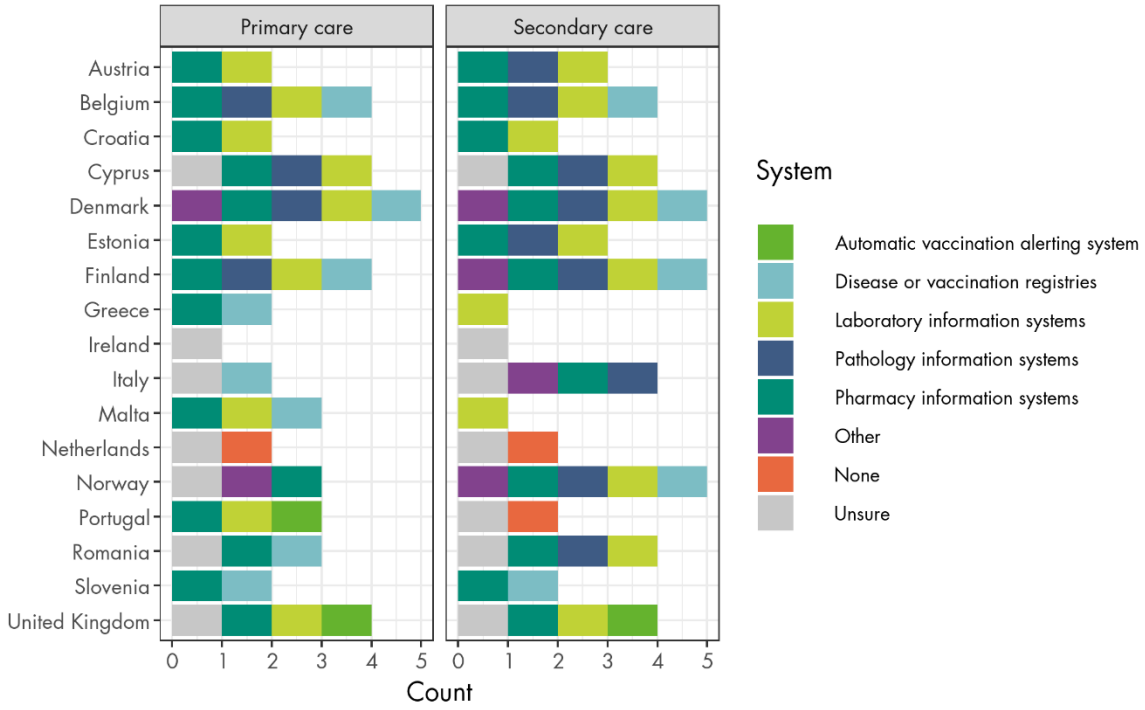


Source: RAND Europe analysis

Table 11. Reported potential barriers to the recording of data in EHR systems in primary and secondary care (numbers indicate number of responses) (data table for Figure 9)

Care	Barrier	Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Slovenia	UK
Primary	Unsure	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Primary	None	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
Primary	Difficult to use or does not meet clinical needs	1	0	0	1	0	1	1	0	1	1	0	1	1	1	3	0	1
Primary	Lack of financial resources	1	0	0	1	0	0	1	0	1	1	0	1	1	0	1	1	2
Primary	Lack of time	2	1	1	0	1	1	1	1	1	0	1	2	0	1	4	0	0
Primary	Lack of training for staff in how to use systems	0	0	1	2	0	1	1	0	1	1	0	1	0	0	4	0	1
Primary	Not viewed as a priority by organisation	1	0	0	1	0	0	1	1	1	1	0	1	1	0	0	0	0
Primary	Not viewed as a priority by staff	2	1	0	2	0	0	0	1	1	0	1	2	0	0	3	0	1
Secondary	Unsure	2	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0
Secondary	None	0	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0
Secondary	Difficult to use or does not meet clinical needs	1	0	0	1	1	1	1	0	1	1	0	2	0	1	2	0	0
Secondary	Lack of financial resources	1	0	0	0	0	0	1	1	1	1	0	1	0	0	3	1	2
Secondary	Lack of time	1	1	1	1	1	1	1	1	1	1	0	2	0	0	4	0	0
Secondary	Lack of training for staff in how to use systems	0	1	0	1	0	1	0	0	1	1	0	1	0	1	4	0	1
Secondary	Not viewed as a priority by organisation	1	1	0	1	0	0	1	1	1	1	0	2	0	0	1	0	1
Secondary	Not viewed as a priority by staff	1	1	1	1	0	0	0	1	1	0	0	2	0	0	3	0	0

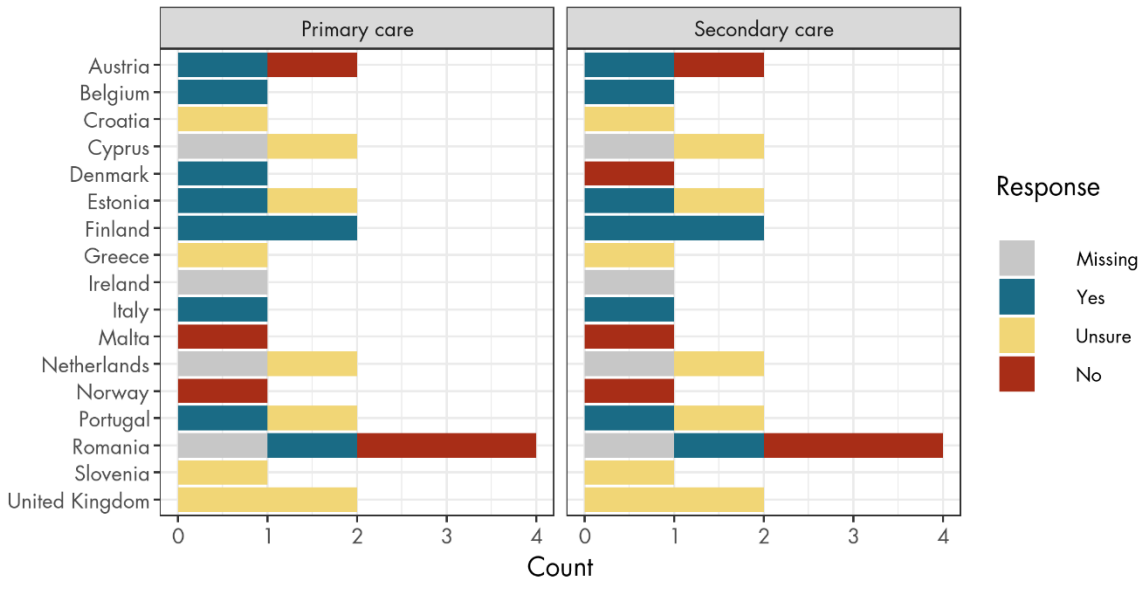
Figure 13. Respondent views of linkage between primary or secondary care EHR systems and other systems



Source: RAND Europe analysis

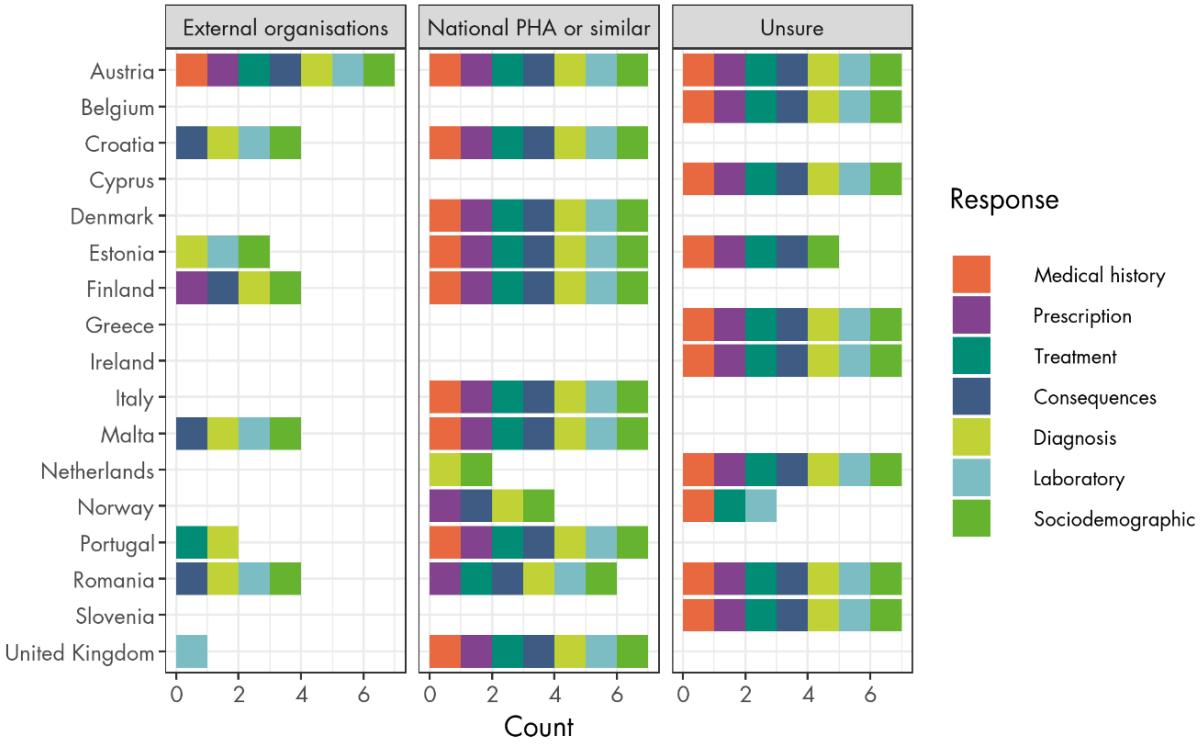
Note: non-unique responses from each country are collapsed into a single response.

Figure 14. Respondent views on existence of processes to convert EHR system data to a common data model to support interoperability



Source: RAND Europe analysis

Figure 15. Respondent views on whether EHR systems are used to share different types of information with the national public health authority (PHA) and/or similar organisations external to the country



Note: Non-unique responses are collapsed.

Figure 16. Respondent views of use of unique patient identification system

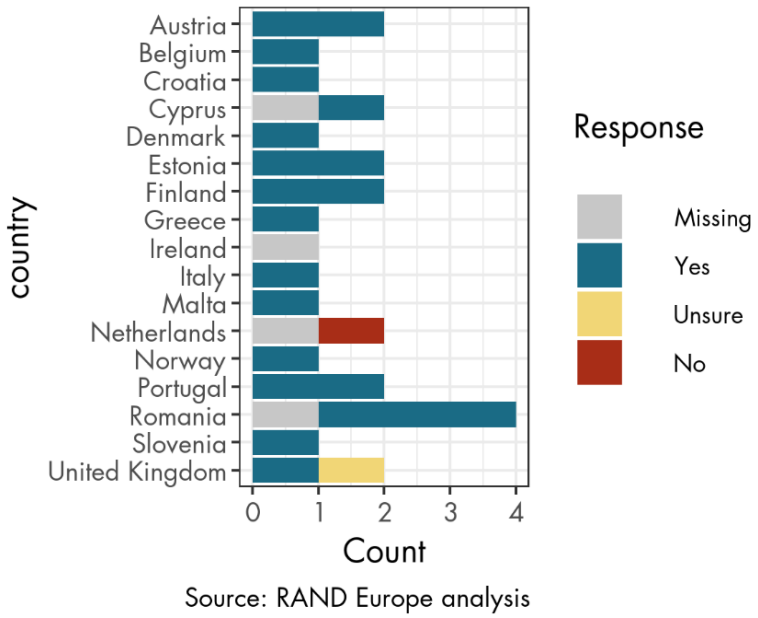
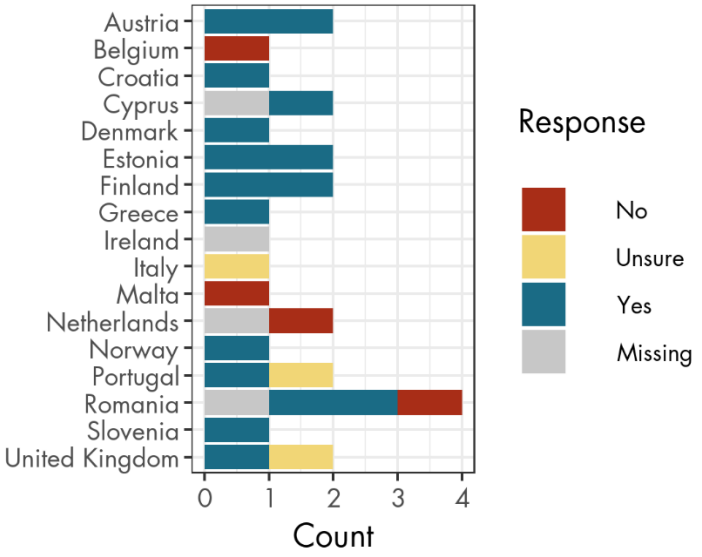
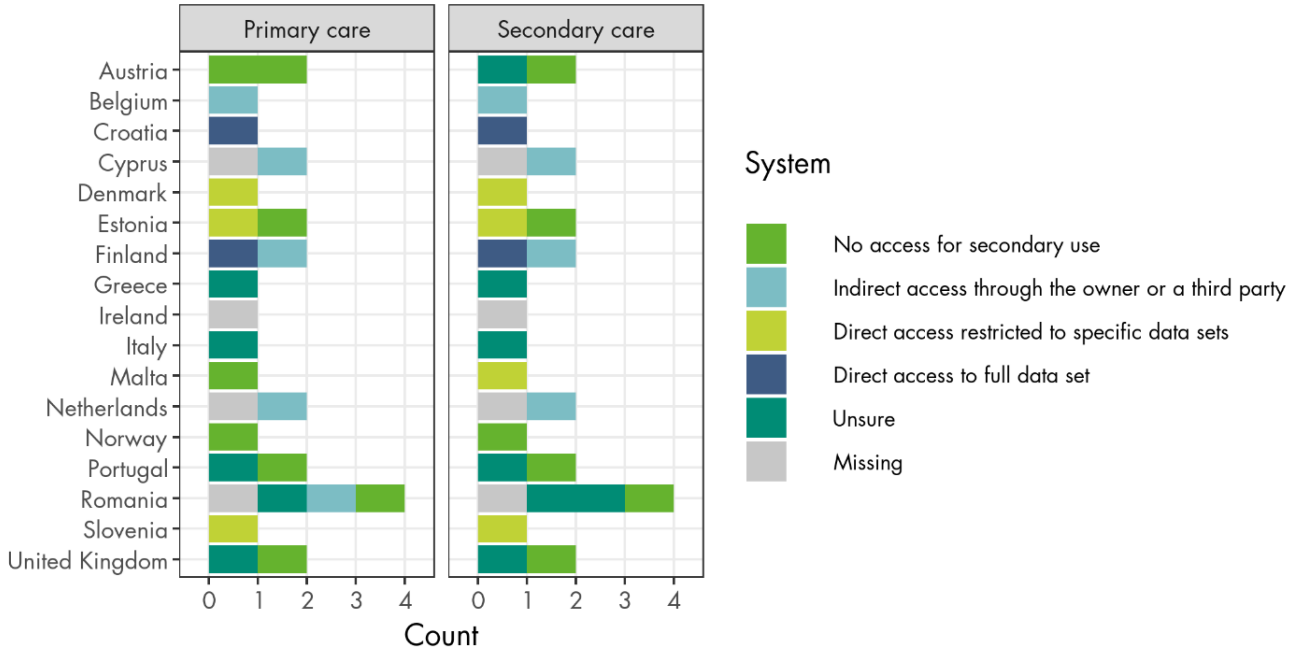


Figure 17. Respondent views on whether countries have legislation governing access to EHR data in addition to GDPR



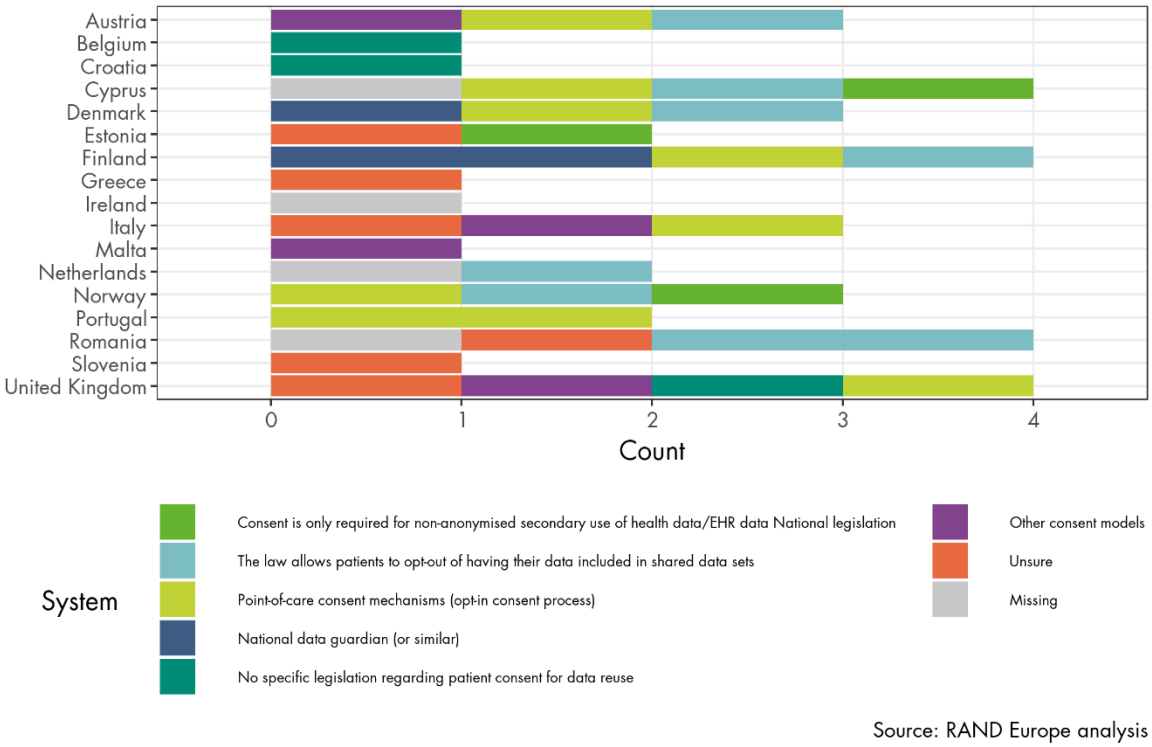
Source: RAND Europe analysis

Figure 18. Respondent perspectives on the extent to which EHR data are available for secondary use



Source: RAND Europe analysis

Figure 19. Respondent views of mechanisms to permit sharing of EHR data for public health purposes operating in their country



Source: RAND Europe analysis

Note: Respondents could select more than one mechanism per country

Table 12. Reported potential barriers to the use of data stored in EHR systems in primary and secondary care (numbers indicate number of responses) (data table for Figure 9)

Care	Barrier	Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Slovenia	UK
Primary	Unsure	1	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0
Primary	Infectious disease surveillance information not captured	2	1	0	1	1	1	1	1	0	0	1	2	0	1	2	1	1
Primary	Lack of confidentiality/privacy framework	1	1	0	2	0	0	0	0	1	0	1	0	1	0	3	1	0
Primary	Lack of data sharing between organisations	2	0	0	2	0	0	1	1	1	1	1	1	1	1	4	0	1
Primary	Patient data are incomplete	1	1	0	2	1	1	1	1	1	0	1	1	1	0	3	1	1
Primary	Patients have concerns about privacy	1	1	0	0	1	0	0	0	1	1	0	1	1	1	1	0	0
Primary	Reporting/provision of information is not timely	1	0	1	0	0	1	0	1	0	1	1	2	1	0	2	0	1
Secondary	Unsure	2	0	0	0	0	1	1	0	0	1	1	0	0	0	0	0	0
Secondary	Infectious disease surveillance information not captured	1	0	0	1	1	1	1	1	0	0	0	1	0	1	3	1	0
Secondary	Lack of confidentiality/privacy framework	1	1	0	2	0	0	0	0	1	0	0	0	1	0	3	1	0
Secondary	Lack of data sharing between organisations	1	0	0	2	0	1	1	1	1	1	0	1	1	0	4	0	2
Secondary	Patient data are incomplete	0	1	0	2	0	1	0	1	1	0	0	0	1	0	3	1	1
Secondary	Patients have concerns about privacy	0	1	0	0	0	0	0	0	1	0	0	1	1	1	1	0	0
Secondary	Reporting/provision of information is not timely	1	1	1	1	0	1	0	1	0	0	0	1	1	0	2	0	1

Annex C. Mapping

Table 13. Mapping table 1 – system characteristics

Electronic health records for infectious disease surveillance, prevention and control		Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	France	Germany	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Spain	Slovenia	UK
Presence of unified EHR systems and presence of regional support for EHR systems																					
National unified primary		√	√	√	√		√	√	†		√			√			√	√		√	
National unified secondary		√	√	√			√	√	†						√		√	√		√	
Sub-national unified primary		√	√	√	√		√	√						√	√	√	√		†	√	√
Sub-national unified secondary		√	√	√		√	√	√					√			√	√		†	√	√
Regional support		√	√	√	√	√	√	√					√	√		√	√	√		√	√
Format of EHR data - if data is in a structured format at primary or secondary care level..[11]																					
Primary care	Sociodemographic	√	√	√		√	√	√			√		√	√		√	√	√		√	√
	Laboratory	√	√	√		√	√	√					√	√		√	√	√			√
	Diagnosis	√	√	√		√	√	√			√		√	√		√	√	√		√	√
	Consequences	√	√	√		√	√	√			√		√	√		√	√	√			
	Treatment	√	√	√		√	√	√			√		√	√		√	√	√			√
	Prescription	√	√	√		√	√	√			√		√	√		√	√	√		√	
	Medical history	√	√	√		√	√	√					√	√		√	√	√		√	
Secondary care	Sociodemographic	√	√	√		√	√	√			√		√	√		√	√	√		√	√
	Laboratory	√	√	√		√	√	√			√		√	√		√	√	√			√
	Diagnosis	√	√	√		√	√	√			√		√			√	√	√		√	√
	Consequences	√	√	√		√	√	√			√		√			√	√	√			
	Treatment	√	√	√		√	√	√			√		√			√	√	√			
	Prescription	√	√	√		√	√	√			√		√			√	√	√		√	√
	Medical history	√	√	√		√	√	√					√			√	√	√		√	

[11] Data might also exist in an unstructured form in the below categories; we focus on whether there is data in each in a structured form.

Electronic health records for infectious disease surveillance, prevention and control		Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	France	Germany	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Spain	Slovenia	UK
Always or sometimes completed data on different patient and care characteristics[12]																					
Primary care	Sociodemographic	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	√
	Laboratory	√	√	√	√	√	√	√					√	√		√	√	√		√	√
	Diagnosis	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	√
	Consequences	√	√	√	√	√	√	√			√		√	√		√	√	√		√	√
	Treatment	√	√	√	√	√	√	√			√		√	√		√	√	√		√	√
	Prescription	√	√	√	√	√	√	√			√		√	√		√	√	√		√	√
	Medical history	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	√
Secondary care	Sociodemographic	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	√
	Laboratory	√	√	√	√	√	√	√			√		√	√		√	√	√		√	√
	Diagnosis	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	√
	Consequences	√	√	√	√	√	√	√			√		√	√		√	√	√		√	√
	Treatment	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	√
	Prescription	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	√
	Medical history	√	√	√	√	√	√	√			√		√	√	√	√	√	√		√	
Recording of key timepoints relating to development and course of an infectious desease to support disease surveillance - for some or all infectious diseases																					
Primary care	Routine for all infectious disease			√		√	√	√								√		√			√
	Only for some infectious diseases				√						√						√	√			
Secondary care	Routine for all infectious disease			√		√	√	√								√		√			
	Only for some infectious diseases										√						√				√
Linkage between primary or secondary care EHR systems and other systems																					
Primary care	Automatic Vaccination alerting system																√				√
	Disease or vaccination registries		√			√		√			√		√	√				√		√	
	Laboratory information systems	√	√	√	√	√	√	√						√			√				√
	Pathology information systems		√		√	√		√													

[12] Data might also exist in incomplete forms in the below categories; we mark those countries where data are always or sometimes completed on different patient and care characteristics.

Electronic health records for infectious disease surveillance, prevention and control		Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	France	Germany	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Spain	Slovenia	UK
	Pharmacy information systems	√	√	√	√	√	√	√			√			√		√	√	√		√	√
	Other					√										√					
Secondary care	Automatic Vaccination alerting system																				√
	Disease or vaccination registries		√			√		√								√				√	
	Laboratory information systems	√	√	√	√	√	√	√			√			√		√		√			√
	Pathology information systems	√	√		√	√	√	√					√			√		√			
	Pharmacy information systems	√	√	√	√	√	√	√					√			√		√		√	√
	Other					√		√					√			√					
Use of unique patient identification system																					
In place		√	√	√	√	√	√	√	†		√		√	√		√	√	√		√	√

√ indicates presence of the concept based on survey results; † indicates the information was drawn from desk research; √† indicates it was determined by both survey data and desk research.

Table 14. Mapping table 2 – reporting and sharing data

Electronic health records for infectious disease, surveillance, prevention and control		Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	France	Germany	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Spain	Slovenia	UK
Use of EHR systems for infectious disease reporting and prevention, and involvement of public health authorities (PHA) in EHR data quality																					
EHR for infectious disease reporting		√	√	√		√	√	√						√	√	√	√	√			√
PHA identified people at high risk		√		√		√	√	√					†				√				
PHA involved in EHR data quality		√	√	√	√	√		√					†				√	√		√	√
Existence of processes to convert EHR system data to a common data model to support interoperability																					
Primary Care		√	√			√	√	√					√†				√	√	†		
Secondary Care		√	√				√	√					√†				√	√	†		
EHR systems used to share different types of information with national public health authority and/or similar organisations external to the country																					
External organisations	Medical History	√																			
	Prescription	√						√													
	Treatment	√															√				
	Consequences	√		√										√				√			
	Diagnosis	√		√			√	√						√			√	√			
	Laboratory	√		√			√	√						√				√			√
	Sociodemographic	√		√			√	√						√				√			
National PHA or similar	Medical History	√		√		√	√	√					√	√			√				√
	Prescription	√		√		√	√	√					√	√		√	√	√			√
	Treatment	√		√		√	√	√					√	√			√	√			√
	Consequences	√		√		√	√	√					√	√		√	√	√			√
	Diagnosis	√		√		√	√	√					√	√	√	√	√	√			√
	Laboratory	√		√		√	√	√					√	√			√	√			√
	Sociodemographic	√		√		√	√	√					√	√	√	√	√	√			√

Electronic health records for infectious disease, surveillance, prevention and control		Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	France	Germany	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Spain	Slovenia	UK
Legislation governing access to EHR data in addition to GDPR																					
In place		√		√	√	√	√	√	†		√					√	√	√			√
Extent to which EHR data are available for secondary use																					
Primary care	Indirect access through the owner or third party		√		√			√							√			√			
	Direct access restricted to specific data sets						√													√	
	Direct access to full data set			√				√													
	No access for secondary use	√				√	√							√		√	√	√			√
Secondary care	Indirect access through the owner or third party		√		√			√							√						
	Direct access restricted to specific data sets						√							√						√	
	Direct access to full data set			√				√													
	No access for secondary use	√				√	√									√	√	√			√
Mechanisms to permit sharing of EHR data for public health purposes operating in their country																					
Consent is only required for non-anonymised secondary use of health data/EHR data national legislation					√		√									√					
The law allows patients to opt-out of having their data included in shared data sets		√			√	√		√							√	√	√				
Point-of-care consent mechanisms (opt-in consent mechanisms)		√			√	√		√					√			√	√				
National data guardian (or similar)						√		√													
No specific legislation regarding patient consent for data reuse			√	√																	√
Other consent models		√											√	√							√

√ indicates presence of the concept based on survey results; † indicates the information was drawn from desk research; √† indicates it was determined by both survey data and desk research.

Table 15. Mapping table 3 – barriers

Electronic health records for infectious disease, surveillance, prevention and control		Austria	Belgium	Croatia	Cyprus	Denmark	Estonia	Finland	France	Germany	Greece	Ireland	Italy	Malta	Netherlands	Norway	Portugal	Romania	Spain	Slovenia	UK
Reported potential barriers to the recording of data in EHR systems in primary and secondary care																					
Primary care	None						√														
	Difficult to use or does not meet clinical needs	√			√		√	√	†	†		√	√		√	√	√	√			√
	Lack of financial resources	√			√			√				√	√		√	√		√	†	√	√
	Lack of time	√	√	√		√	√	√		†	√	√		√	√		√	√			
	Lack of training for staff in how to use systems			√	√		√	√	†	†		√	√		√			√			√
	Not viewed as a priority by organisation	√			√			√			√	√	√		√	√					
	Not viewed as priority by staff	√	√		√				†		√	√		√	√			√	†		√
Secondary care	None						√									√					
	Difficult to use or does not meet clinical needs	√			√	√	√	√	†	†		√	√		√		√	√			
	Lack of financial resources	√						√			√	√	√		√			√	†	√	√
	Lack of time	√	√	√	√	√	√	√		†	√	√	√		√			√			
	Lack of training for staff in how to use systems		√		√		√		†	†		√	√		√		√	√			√
	Not viewed as a priority by organisation	√	√		√			√			√	√	√		√			√	†		√
	Not viewed as priority by staff	√	√	√	√				†		√	√			√			√			
Reported potential barriers to the use of data stored in EHR systems																					
Primary care	Infectious disease surveillance information not captured	√	√		√	√	√	√			√			√	√		√	√		√	√
	Lack of confidentiality/privacy framework	√	√		√							√		√		√		√		√	
	Lack of data sharing between organisations	√			√			√	†	†	√	√	√	√	√	√	√	√	†		√
	Patient data are incomplete	√	√		√	√	√	√			√	√		√	√	√		√		√	√
	Patients have concerns about privacy	√	√			√			†			√	√		√	√	√	√			
	Reporting/provision of information is not timely	√		√			√			†	√		√	√	√	√		√			√
Secondary care	Infectious disease surveillance information not captured	√			√	√	√	√			√				√		√	√		√	
	Lack of confidentiality/privacy framework	√	√									√				√		√		√	
	Lack of data sharing between organisations	√					√	√	†	†	√	√	√		√	√		√	†		√
	Patient data are incomplete		√				√				√	√				√		√		√	√
	Patients have concerns about privacy		√						†			√			√	√	√	√			
	Reporting/provision of information is not timely	√	√	√			√			†	√				√	√		√			√

√ indicates presence of the concept based on survey results; † indicates the information was drawn from desk research; √† indicates it was determined by both survey data and desk research.

Annex D. Reference library of EHR use for public health

Table 16. Reference library of examples of EHR use for infectious disease surveillance or other public health purposes

Country	Name of key system(s) used in collecting or sharing EHR data	Condition(s) reported	Summary	Reference
Austria	Epidemiologisches Meldesystem	All notifiable diseases, including COVID-19	The Epidemiological Reporting System is a real-time disease register through which all laboratories in Austria report test results for notifiable diseases in electronic form.	Observatory of Public Sector Innovation. Epidemiological Reporting System (EMS; a register according to the Epidemic Law §4). Observatory of Public Sector Innovation. 2020 [cited 2020 Sep 2]. Available at: https://oecd-opsi.org/covid-response/epidemiological-reporting-system-ems-a-register-according-to-the-epidemic-law-%C2%A74
Denmark	Danish Microbiology Database, Civil Registration System, National Patient Registry, Register of Causes of Death, National Prescription Registry, Register of Laboratory Results for Research	COVID-19	Through an initiative of the Danish Medicines Agency's Data Analysis Centre, a prospective cohort of every Danish resident tested for SARS-CoV-2 by reverse transcriptase polymerase chain reactions was created. The new registry provides individually linked data by combining existing health and administrative registries. It includes data on patients' demographics, vital status, current and previous drug treatment, and coexisting medical conditions.	Pottegård A, Kristensen KB, Reilev M, Lund LC, Ernst MT, Hallas J, Thomsen RW, Christiansen CF, Sørensen HT, Johansen NB, Støvring H. (2020). Existing data sources in clinical epidemiology: the Danish COVID-19 cohort. Clinical Epidemiology.12:875.
Denmark	Sundhedsdatastyrelsen, Danish Health Authority, and Danish Ministry of Health	Unclear	In Denmark information is shared with the eHealth agency (Sundhedsdatastyrelsen), Danish Health Authority, and Danish Ministry of Health	Information from survey respondent
Estonia	X-tee	Non-specific/any within EHR data	The national health information system in Estonia links to other public databases through a data exchange layer called X-tee, which is enabled through block chain technology. Patients are identified in all databases through their national ID number.	Oderkirk, J. (2017). Readiness of EHR systems to contribute to national health information and research. OECD Health Working Papers No. 99. https://doi.org/10.1787/9e296bf3-en
Finland	Kanta	Non-specific/any within EHR data	The national archiving system, Kanta provides digital services for the social welfare and healthcare system. The Kanta system is integrated with both public healthcare providers at an acute, primary, and social care level, as well as private healthcare providers and pharmacies	Vekho, Tuulikki, Salla Ruotsalainen, and Hannele Hypponen. 2018. 'E-Health and e-Welfare of Finland - Check Point 2018.' Helsinki, Finland: National Institute for Health and Welfare. https://www.julkari.fi/bitstream/handle/10024/138244/RAP2019_7_e-health_and_e-welfare_web_4.pdf?sequence=4&isAllowed=y

Country	Name of key system(s) used in collecting or sharing EHR data	Condition(s) reported	Summary	Reference
Finland	Kanta	COVID-19	The Institute for Health and Welfare (THL) and the Social Insurance Institution of Finland (Kela) use COVID-19 laboratory test results, physicians' diagnoses and vaccination information from the national archiving system Kanta, to implement the EU Digital COVID-19 certificates (certificate for being vaccinated against COVID-19, a certificate of a negative test result and a certificate of having recovered from COVID-19). The certificates are available on the My Kanta Pages.	Ministry of Social Affairs and Health. 2021. 'All three types of EU Digital COVID Certificate now available in My Kanta pages.' The Finnish Institute for Health and Welfare and the Social Insurance Institution of Finland. https://stm.fi/en/-/all-three-types-of-eu-digital-covid-certificate-now-available-in-my-kanta-pages Ministry of Social Affairs and Health. 2021. 'COVID-19 certificates.' https://stm.fi/en/vaccination-certificate
Finland	Sote Areas	Non-specific/any within EHR data	The aim of the 18 Sote Areas will be to integrate care that is currently provided by 192 local municipalities. It is also anticipated that procurement of EHRs will no longer happen at a local level, but in the Sote Areas.	Green, Alex. 2020. 'EMR Market Opportunities in the Nordics: White Paper - Signify Research.' Signify Research. https://www.signifyresearch.net/digital-health/emr-market-opportunities-nordics-white-paper-2
Finland	Virtual Hospital	Non-specific/any within EHR data	Virtual Hospital offers eHealth services at home and involves all university hospitals in Finland. It offers specialised care services online.	Reponen, Jarmo. 2019. 'Finnish National EHR Infrastructure and Digital Health Research in Oulu.' Presented at the ESPON-conference, Oulu, May 22. https://www.espon.eu/sites/default/files/attachments/1_Reponen_0.pdf
Finland	Own DigiAge	Unclear	A flagship project is the Own DigiAge (ODA) care services which offers triage before the emergency home by measuring the situation, gathering information, and displaying results and guidance.	Reponen, Jarmo. 2019. 'Finnish National EHR Infrastructure and Digital Health Research in Oulu.' Presented at the ESPON-conference, Oulu, May 22. https://www.espon.eu/sites/default/files/attachments/1_Reponen_0.pdf
The Netherlands and Germany	HPZone software	COVID-19 (potentially other infectious diseases, unclear)	Use of software to share real-time infectious disease information between regions in the Netherlands and Germany.	ter Waarbeek H, Hoebe C, Freund H, Bochat V, Kara-Zaïtr C. Strengthening infectious disease surveillance in a Dutch-German crossborder area using a real-time information exchange system. J Bus Contin Emerg Plan. 2011 Jun;5(2):173–84.
The Netherlands	NIVEL primary care database	Unclear	In the Netherlands, there is the Netherlands Institute for Health Services Research (NIVEL) primary care database, which comprises a weekly collection of longitudinal data from EHRs of a large sample (approximately 500) of general practices and other primary healthcare providers. Although these practices neither actively report patients nor take laboratory samples for surveillance purposes, around 300 participating practices use an information system that allows automatic pseudonymised weekly data extraction from medical records.	National Institute for Public Health and the Environment. 2016. State of infectious Diseases in the Netherlands. National Institute for Public Health and the Environment. As of 20 October 2020, available at: https://www.rivm.nl/bibliotheek/rapporten/2017-0029.pdf

Country	Name of key system(s) used in collecting or sharing EHR data	Condition(s) reported	Summary	Reference
The Netherlands	National Switch Point (LSP, for *Landelijk Schakelpunt)*	Non-specific/any within EHR data	When a patient gives permission (as described under 'mechanisms for consent to EHR data sharing'), their data will become available for the National Switch Point (LSP, for *Landelijk Schakelpunt)* and can be requested using the patient's citizen service number.	Nictiz. n.d. 'The infrastructure for central exchange.' *Nictiz* n.d. As of 20 October 2020, available at: https://www.nictiz.nl/english/exchange-of-electronic-patient-data-in-the-netherlands/the-infrastructure-for-central-exchange

Annex E. Case studies

Finland

The current status and trends in the use of EHRs in the country

Finland has EHR systems in place at a national, regional and municipal level, which is brought together by the national archiving system, Kanta, that provides digital services for the social welfare and healthcare system. The Kanta system is integrated with both public healthcare providers at an acute, primary, and social care level, as well as private healthcare providers and pharmacies (31). Public healthcare providers were required, according to the Finnish Act on EHRs, to join the national data system services by 2014 (32). A similar obligation was placed on private healthcare organisations that did not use paper-based archives (31). By 2018, the national ePrescription services and MyKanta pages for citizens (national archiving and services system) had been rolled out in all public healthcare institutions and most private healthcare providers (31). Finland is also one of the six leading European countries in e-health adoption (together with Denmark, Spain, Norway, Estonia, and the Netherlands) (31).

EHR content and completeness

In 2002, the Finnish government took the initiative to implement an interoperable and national EHR system in Finland, Kanta. Kanta is the national Finnish data system for healthcare services, pharmacies, and citizens and shares data for the prescription service, the pharmaceutical data, patient data repository, My Kanta pages, Kanta, PHR, and aims to integrate Social Welfare Service Data in the future. Kanta offers interoperability and information exchange with district hospitals and other EHR solutions, discharge letters and electronic referrals, eArchive services, eAccess services, ePrescription services, and access to patient summary data, including diagnoses, vaccinations, radiology results, risks, care plans, medication, and consent management data (33). Finland has made efforts to increase the information flow between primary and secondary health services in recent years (31). For instance, all hospital districts in Finland used the electronic referral system between primary healthcare and specialised medical care in 2018 (31). In addition, primary healthcare centres frequently use regional health information systems, such as for medical imagining and laboratory services (31). This has also been enabled by the use of the national health information exchange, through Kanta services (34).

Finnish e-health strategy documents acknowledge as early as 1998 that there was a need to use structured data in EHRs (31). As a result, a set of core data were defined in cooperation with different interest groups between 2002 and 2007. In addition, a National Code Server was built in 2003-2004 (31). In 2007, a law was put in place that stipulated that EHRs archived in both the national electronic patient record archive and the patient summary have to use standardised data structures available via the National Code Server. These regulations have been made more specific by ministerial acts specifying which structures have to be used in a standardised form by a certain time (Act 159/2007, Ministerial Act 298/2009 and 11.4. 2012/165, 13.10. 2015/1257) (31). The most common healthcare classifications used to structure data in the EHR system include: i) the classification of diseases, ii) radiology examination and procedure classification, iii) diagnoses[xiii], iv) laboratory test codes, v) type of risk data, and vii) register for social and health organisations. Although the increasing use of common code sets and classifications have created a strong foundation for joining information systems at a national level, parts of the patient documents remain in an unstructured format (e.g. narrative clinical and patient information is often still unstructured), with the expectation that new regulations will be put in place to strengthen the structure later on (for example with structuring nursing data) (31). The Act on the Secondary Use of Health and Social Data ('Laki sosiaali- ja terveystietojen toissijaisesta käytöstä', 552/2019) facilitates the effective and safe processing and access to the personal social and health data for steering, supervision, research, statistics and development in the health and social sector (35). The Act on the National Institute for Health and Welfare ('Laki Terveyden ja hyvinvoinnin laitoksesta', 668/2008) gives THL a mandate to utilise EHR data (36).

The national system, Kanta, is also used to record key timepoints relating to an infectious disease. It displays electronic prescriptions, records related to a patient's treatment, laboratory tests and X-ray examinations, the health records for dependants below the age of 10, and the healthcare units and pharmacies that have accessed prescriptions and medical services (37). It is also possible for patients to i) request a repeat prescription, ii) save a living will and organ donation testament, iii) consent or refuse the disclosure of personal data, iv) consent to the disclosure of prescription information to a pharmacy in another country, v) browse one's own wellbeing data, vi) access one's own health and care plan, and vii) get an overview of critical risk factors (37). This data is also available through mobile applications (31).

[xiii] These diagnoses codes are unique to the Finnish system and are available from the National Code Server.

Level of integration within the country and cross-border data sharing

Through the Kanta services, all adult citizens can access one's own EPR-data, prescriptions-data, log information and consent management service, as well as prescription renewal (37). The MyKanta pages can be used by any person who has Finnish personal identity code and can be accesses using online banking codes, mobile identification, or a certificate card (37). A personal identification code is created to build a patient's EHR, and a unique identifying number is also created for healthcare professionals who enter data into the system (38).

The MyKanta personal health record pages also provide an opportunity to monitor wellbeing and save health data in the service(33). Virtual Hospital offers eHealth services at home and involves all university hospitals in Finland. It offers specialised care services online. Big cities in Finland have also been working to create a self-service portal connected to the healthcare system. A flagship project is the Own DigiAge (ODA) care services offers triage before the emergency home by measuring the situation, gathering information, and displaying results and guidance (33).

However, the Finnish healthcare system is decentralised, which has resulted in different EHR solutions being used in different regions and which creates some challenges to interoperability (34). There are 311 municipalities in Finland that all have responsibility for providing health and social care services (31). For instance, the 20 district hospitals in Finland make EHR purchasing decisions locally together with local municipalities (34). The creation of Sote Areas, which are integrated social care networks, in 2020, might alleviate some of the challenges to interoperability. The aim of the 18 Sote Areas will be to integrate care that is currently provided by 192 local municipalities. It is also anticipated that procurement of EHRs will no longer happen at a local level, but in the Sote Areas (34). Moreover, EHR trademarks have reduced since 2002, as health centres in Finland used six EHR trademarks in 2017, compared to nine in 2002 (39). Similarly, while public hospitals used seven EHR data systems in 2001, this was reduced to five in 2017 (39). This reflects that information exchange increased in the years leading up to 2018 and that information flow on a regional level has become more fluent (31).

With regards to sharing data from the EHR systems with the EU and other European Member States, there are no provisions in place that refer to the interoperability of the Finnish system with other systems (32). However, Kanta services enable sharing of data between European countries as it is possible to purchase medicines with a Finnish prescription in Estonia, Croatia and Portugal. Kanta is also looking to expand the scheme with other countries (40). Finland is an active member of the EU e-health Network and has participated in several European e-health projects, including Expan and JAseHN (31). Finland therefore contributes to the European effort to secure data access and sharing across borders in order to improve research, faster diagnosis and improved health (41). Finland also piloted cross-border e-prescription with Sweden (31). In addition, Finland is active in the Ministerial Working Group on e-health under the Nordic Council of Ministers and participates in a research group on common Nordic e-health indicators (31).

Legislation governing EHRs implemented in Finland

The main regulation that governs the use of EHRs in Finland is the Act on EHR ('Laki sosiaali- ja terveydenhuollon asiakastietojen sähköisestä käsittelystä', 159/2007) (32). The Act covers centralised archive services, which includes the Kanta system, for healthcare, encryption and certification, as well as patient access to data (31). EHRs are also regulated by the Decree on National EHR System Services ('Sosiaali- ja terveysministeriön asetus terveydenhuollon valtakunnallisista tietojärjestelmäpalveluista', 165/2012), with other general legislation on healthcare, health records, and data protection also applying to EHRs (31).

For the national system, Kanta, healthcare units, pharmacies and Kela (The Social Insurance Institution) ensures that data protection and data processing complies with legislation (38). Individuals can monitor the use and disclosure of their own prescription and medical details. A patient's consent is necessary in the system if patient data is shared across patient registers from one healthcare unit to another healthcare unit. However, patient data can be used in the healthcare unit where it has been produced without consent and consent is not needed for the common patient register within the hospital district (42). Patients provide written consent on forms created by the government (42).

EHRs for public health surveillance

Analysis is undertaken of EHRs in Finland on a regular basis for infectious disease surveillance (38). In terms of secondary uses, analysis is undertaken of EHRs in Finland to monitor patient safety, and to support physician treatment decisions by making it possible for physicians to investigate datasets (38). In 2013, Finland were also working to use EHRs from the primary care system to monitor performance (38). For secondary care, existing registries were already used for this purpose in 2013. Research to improve patient care, health system efficiency or population healthcare has also been conducted using EHRs on a local or regional level (38). However, in 2018, the availability of EHR systems that support research, development and innovation is still low across Finland (37). This is because data within the national EHR system cannot be accessed directly for research purposes; only data on the local level can be accessed (43). In addition, EHR data cannot be used to facilitate and contribute to clinical trials (43). However, with the recent passage of the Act on the Secondary Use of Health and Social Data and the

Act on the National Institute for Health and Welfare now providing the legal basis for the collection of national monitoring data, the Finnish Institute for Health and Welfare and Kela are investigating ways to use Kanta as a data source for public health surveillance through the Valtava Project, run by the Ministry of Social Affairs and Health. Examples under investigation are surveillance of COVID-19 laboratory testing efforts by age-group, and case ascertainment of serious adverse events in COVID-19 vaccine safety evaluation (44).

Facilitators to the implementation of EHR systems

Finland has been a forerunner with the implementation of EHRs, which has enabled them to make patient records 'electronic from birth' (31). As a result, secondary use of EHRs has become more feasible as Finland has direct access to a source of valuable information for longitudinal health data (31).

The sharing of EHR data in Finland has also been enabled by an environment which has evolved in a way that has made it easier to obtain prescription data from other organisations due to implementation of e-prescription services and the Kanta system at a national level (31). The Finnish government also found that there has been an increasing use of common dose sets and classifications in the EHR system, which has created a strong basis for the joining up of the national information system (31).

The strengthening of skills and competences using organisational and regional actions, through for example guidelines and rules on how to use eHealth tools and instructions on common practices created through cooperation with others is also a facilitator (45). For instance, in interviews with nurses on the use of EHRs, they highlighted the importance of end-user groups to participate in the development of EHR systems and that there is space for them to be involved in improving the system (31).

Another facilitator is that the Finnish data provider perceives that sharing EHR data for the development of products to be mutually beneficial and valid in the context of the information system (46). The perceived shared benefits include successful product development, which has improved factors related to usability and quality, which in turn enhances the cost efficient of information systems. Moreover, the Finnish data provider said in interviews that they will not automatically reject data requests from secondary users (46).

In a qualitative evidence synthesis of facilitators and barriers to EHRs in the Nordic countries, other facilitators that were found included the accessibility of the EHR system for patients (47). Using EHRs as a supportive tool was also found in the evidence synthesis in Nordic countries to support work practices of healthcare professionals (47). For instance, in Finland, user interface characteristics that were important to physicians in using EHR systems, included logical arrangements of the field and functions in the screen and how clear and understandable the terminology is (46). The importance of the usability of the user interface is also reflected in that much of the information exchange in the EHR system in Finland still takes place at the regional level, as the regional systems have a better integration to work processes and better represents some data, such as medical images (31). The national health information exchange is also facilitated by the increasing use of structured code sets and common data exchange standards for EHR data.

Another enabler to the implementation of EHR systems is the interoperability of the EHR systems and the degree to which it can used for social comparison, to improve patient safety, or that data can be re-used in the system (47). An interoperable system that facilitates information exchange can, according healthcare professionals in Finland, minimise multiple documents containing the same data and facilitates the search of available information (31). When primary and secondary healthcare institutions use the same information storage infrastructure (which was enabled by the Kanta system), then healthcare data, such as referrals can also be used differently as a source of additional patient information (31). The Kanta infrastructure also enables a national health information exchange (31).

Barriers to implementation of EHR systems and use of data

Several barriers to the implementation of EHR systems and use of the resulting data in Finland have been noted in the literature. For example, the OECD noted issues with the quality of data in the EHR systems in Finland, which can limit the ability to develop datasets for monitoring and research (43). A specific barrier noted by the OECD was that the coverage of structured patient summaries or minimum datasets were incomplete in 2017 (43).

Another barrier to the use of healthcare data in the EHR system in Finland is that there are high financial charges that can be levied upon healthcare providers by their IT system providers if they update data in the national EHR system (43). The extra charges have been attributed to the fact that Finland uses an external service provider to operate the information system in hospital districts, where the data owner has responsibility to control and evaluate the submitted data inquires while external operators manage the technical process. This creates an additional costs for potential secondary users as they are charged by the service provider for managing the delivery of the data (46). Using external operators also requires more time than having a direct relationship between the data owner and secondary user (46).

The high financial charges with updating data in the national system operates alongside a critique by representatives of scientific research in Finland who considered the request procedure for EHR data in Finland to be extensive and unstructured (46). The difficulty of accessing EHR data relates to the fact that academic research is not a sufficient criteria to access data, as use intentions, research resources, and storage methods must be provided to gain access to EHRs for secondary purposes (46).

There has also been an issue with mechanisms that are used for privacy preservation related to non-trivial personal identifiers in health information (46). There is a general lack of motivation to use the privacy preserving mechanisms because they have an effect on data value and challenges the automation of processes. By leaving information content unaltered, Finnish scientific representatives said in interviews that it was easier to maximise data value (46). Instead, the Finnish representatives suggested making a stronger link between privacy preservation actions and the use purpose of EHR data (46).

Similarly, although the Finnish data provider has recognised the value of providing open access to EHR data, there are no corresponding implementations or relevant procedures because there is inadequate national legislation in place (46). As a result, health data is aggregated before sharing, which limits information diversity (especially for unstructured data in the clinical context)(46).

A lack of interoperability in certain healthcare systems also creates barriers to data sharing in some systems. For instance, the lack of interoperability between information systems can cause additional work for nurses because the information flow in the EHR system does not follow a nurses' work processes (31). Nurses also identified as a barrier the lack of adequate training in operating mode or work processes based on IT (31). Another barrier is the fragmentation of the healthcare system, where healthcare professionals have to simultaneously adapt to a national system (like Kanta) and a regional, decentralised approach (47). According to the study authors, this results in a lack of uniformity when providing holistic information to patients, individuals, researchers, administrators, and vendors (47).

In a qualitative evidence synthesis of facilitators and barriers to EHRs in the Nordic countries, other barriers that were found included a lack of balance between the desire of the patient to be able to immediately access their records and the desire of the healthcare professional to have a certain number of respite days before releasing the data (47). The lack of balance creates limitations on accessibility and the procedure to protect patients from accessing information that is either incorrect or disjointed (47).

What are the implications, if any, for public health functions?

Finland has the building blocks in place to use their current EHR system for identification, assessment and communication regarding infectious diseases. The national healthcare system brings together EHRs from across the Finnish municipalities in a structured format. The system provides information on key timepoints related to infectious diseases and allows individuals to access their own health and care plan, as well as obtain an overview of critical risk factors regarding their own health.

Steps have also been taken by the Finnish government to ensure interoperability and integration on a national level to counter some of the challenges of having a decentralised healthcare system. As a result, information flow between primary and secondary health services, private and public healthcare providers, and local, regional, and national government has increased in the past years.

Finland has also participated in efforts to share EHRs at a European level through the e-health network and through the ePrescription pilots with Estonia, Croatia, Portugal and Sweden. Finland also uses EHRs to monitor the performance of healthcare systems at a primary and secondary level, although national-level data cannot be used for research purposes.

There is therefore evidence that Finland has the right conditions in place to use EHRs for public health functions. Although no evidence was found on how Finland specifically uses EHRs for infectious disease surveillance and the ways this data is used to identify, assess, and communicate regarding current and emerging infectious diseases at the time of data collection, it later emerged that the Institute for Health and Welfare and Kela use COVID-19 laboratory test results, physicians diagnoses and vaccination information from the national archiving system Kanta, to implement the EU Digital COVID-19 certificates. The Institute for Health and Welfare and Kela are also investigating ways to use Kanta as a data source also for public health surveillance, for example COVID-19 laboratory testing efforts by age-group, and case ascertainment of serious adverse events in COVID-19 vaccine safety evaluation.

Lessons learned

Key lessons can be learned from the Finnish EHR case study on the use of EHRs to identify, assess, and communicate regarding current and emerging infectious disease:

- Having a national system in place that uses structured data covering national, regional and local EHR systems (for public healthcare providers at an acute, primary and social care level, as well as private healthcare providers and pharmacies) has been conducive to increase information flow and the interoperability of the EHR system in Finland.
- Interoperability and an integrated EHR system in Finland have been facilitated by putting an obligation on public healthcare providers (and most private healthcare providers) to join the national data system by 2014.
- However, much of the information exchange in the EHR system in Finland still takes place at the regional level, as the regional systems have better integrated work processes and better represent some data, such as medical images.
- There are some challenges with having a decentralised healthcare system in Finland as there are 311 municipalities that have responsibility for providing health and social care services. Some of these challenges might be alleviated by the creation of 18 Sote Areas or integrated social care networks.
- The sharing of EHR data at a European and bilateral level, through the ePrescription pilot with a number of European countries, and Finland's participation in the EU e-health network and the Nordic Ministerial Working Group on e-health, might contribute to Finland's efforts to use EHRs for public health functions.

Estonia

The current status and trends in the use of EHRs in the country

Estonia was the first European country to implement a national EHR database and is generally considered a leader in e-health (and other 'e-state' solutions) throughout Europe. Since September 2008, Estonia has had a functioning national health information system (48) that serves as a central electronic database for the health records of all patients who receive care from any Estonian healthcare provider, covering primary, secondary and tertiary healthcare sectors. This national 'umbrella' system sits alongside the electronic record-keeping systems of individual healthcare providers, which are required to synchronise data to the national system, typically either by automatic overnight synchronisation or by manual order. The data that are uploaded to the national system for each patient are then available to providers in the country, allowing for an effective exchange of EHR data. Nearly all healthcare providers in Estonia have access to data in the national system, with the exception of pharmacists, who are only able to access certain parts of the e-prescription system (48).

All officially recognised healthcare providers are obligated by law to upload patient data to the national health information system according to the Health Services Organisation Act (49) and the Regulation on the Documentation of Provision of Healthcare Services and the Conditions and Arrangements for the Retention of these Documents (50), and face potentially losing their professional license if they fail to do so. Due to the nature of this mandate, the national health information system has achieved wide coverage, with 99% of patients having a national digital health record (51). As of 2017, it was reported that over 25 million health documents have been stored in the health information system (52).

Patients are owners of their health data, and can access their health records within the national health information system through a patient portal (53). They log into this portal using their electronic national ID card, or through a mobile phone-based ID, and are able to provide access to other authorised users (e.g. caregivers, partners) through the portal. Healthcare providers with a valid Estonian activity license and professional license are able to access any patient's record in the national system by logging in with their national ID card. The portal also provides both patients and providers access to online services such as e-prescriptions, digital registration (booking appointments online), digital stamp (online signatures) and digital images (online access to scans and medical images) (48).

The main drivers for implementing this system in Estonia were to increase the speed and accessibility of healthcare services, to assist providers with administrative and medical issues by providing more complete information about patients, and to shift to a paperless system that would help cut costs and increase environmental sustainability (54).

Completeness of EHR data

Data in the national health information system is patient-oriented, meaning that it is structured by epicrises about each patient's interaction with the healthcare system (55). Documents about the following services are required by law to be uploaded to the national system:

- ambulatory epicrisis, along with notice of opening and closing ambulatory medical case;
- stationary epicrisis, along with notice of opening and closing stationary medical case;

- doctor's letter entitling the patient for a medical procedure or appointment with another doctor, and replies to this letter;
- notice on assessment of development;
- notice of immunisation and side effects of immunisation;
- notice of physical examination; and
- notice of counselling.

Alongside this medical information, data is also included on patients' professions, employers, working conditions, places of residence, educational institutions, health habits, and psychosocial and mental backgrounds and development (48). Local healthcare providers will also maintain their own EHRs, which include additional information about patients' medical histories and treatments that are not uploaded to the national system, although this information will vary between providers as there are no requirements for local EHRs according to Estonian regulation.

Estonia requires information about diseases, symptoms and conditions to be uploaded to the national health information system according to uniform classifications, standards and nomenclatures. Estonia has established their own national standards for socioeconomic information, physical characteristics, clinically relevant behaviours and relevant psychosocial and cultural issues of patients, although they follow external standards for: patient medications (ATC), patient diagnosis (ICD-10); laboratory results (LOINC); imaging results (DICOM); and surgical procedures (NCSP) (43).

The information provided in the national health information system includes diagnoses of each patient, and one could infer that this would include information about infectious diseases. However, the surveillance of communicable diseases is the responsibility of the Health Board through the Communicable Diseases Register, which is discussed below. The Health Board can pull information from the national health information system to complete this duty, and also receive information from providers who are required to report certain information to the register such as data on diagnosis, pathogen and source of infection (described in more detail below). From the literature and sources available, it is unclear to what extent the Health Board uses data from the national information system to report on infectious diseases in practice.

Level of integration within the country and cross-border data sharing

Although Estonia has a national system in place, individual healthcare providers also hold their own databases of health information on patients, which are not required to be interoperable with one another. For example, in practice, most hospitals use the same system (called ESTER), although they are not prohibited from using their own systems. Although providers across primary and secondary care have access to the information that is required to be uploaded to the national health information system, patients must request hard-copy or email versions of their records held in provider-specific databases in order to share more detailed records (including information that is not in the national system) across healthcare providers (48).

In the national system, patients are identified in the national health information system through their national ID number and name (48). Public authorities are able to link information from the national health information system to other public databases, such as birth registers, death registers and insurance records, which occurs through the X-tee data exchange layer described below.

Legislation governing EHRs implemented in Estonia

The Ministry of Social Affairs is the main institution responsible for the national health information system in Estonia. Day to day management of the system was left to the eHealth Foundation in 2005, which was re-organised into the Centre of Health and Welfare Information Systems in 2017. The National Institute for Health Development is also an important stakeholder in the national health information system, and is responsible for collecting and analysing data on health status and helping municipalities within Estonia with their health information needs (56).

The Data Protection Inspectorate is responsible for data security for the national health information system. No specific legislation has been applied to health data, although all sensitive personal data in local and national EHR systems are regulated through the Personal Data Protection Act (57). According to national rules, data in the national health information system is classified as 'high' in terms of security levels to assure the confidentiality and integrity of data, and security levels are independently audited every two years. Consent from patients is not necessary to create an EHR for the purpose of providing healthcare, although patients are able to opt out of sharing their data with the national health information system. Data in the national system is archived indefinitely, according to law (48).

Consent mechanisms for secondary use of data for scientific research or statistics purposes depends on whether the data are anonymised. If data are anonymised, the data are not considered personal data and consent is not needed. If data are not anonymised, the patient can opt out of secondary use of their data by submitting an application to their healthcare provider or to the Ministry of Social Affairs. Using non-anonymised health data

requires a permit from the Data Protection Inspectorate (unless the patients have explicitly consented to the use of their non-anonymised data, in which case data users are only required to submit a notice), which considers if data processing is justified in terms of public interest, whether the goals of data processing could be achieved without access to non-anonymised data, and whether sufficient security measures in place (48). It is expected that by 2021, consent processes will be handled electronically, which will allow for data exchange between the public sector and third parties (58).

EHRs for public health surveillance

The national health information system can be used by bodies that are responsible for different medical registries in Estonia (55), including the communicable disease register. The Health Board is responsible for maintaining this database and reporting information to WHO and ECDC as required. To help with this, providers are required to report on 59 communicable diseases and 91 etiological agents, and to report outbreaks to the Health Board (56). The following information is included in the Communicable Diseases Register:

- name, personal ID, date of birth, and sex of patient;
- education, position, place of work or educational institution, contact details, place of birth, nationality, and socioeconomic information of patient;
- health data, including diagnosis, immunisation, testing material, testing method and result, pathogenic agent and sensitivity of agent, cause of testing, circumstances of becoming infected, assumed way of spreading, hospitalisation, and treatment;
- source of infection (e.g. mother to child infection, sexual infection, belonging to risk group, parenteral infection);
- date and cause of death; and
- data on healthcare provider (59).

Despite the existence of the national health information system and the inclusion of disease diagnoses within this system, it is unclear to what extent the national system is used to fulfil the Health Board's duties in collating information on and reporting on infectious diseases. The Estonian government has identified a weakness in using and analysing health information across Estonia, in particular in comparison with Nordic countries that have implemented more systematic analysis into public health activities.

In their national plan, the country has the goal of increasing the capability of healthcare providers to use standardised and structured data entry to be able to automatically analyse machine-readable data (60), which may potentially include public health monitoring of infectious diseases. Although standards have been developed, there are still issues in terms of national capability in using them. This weakness has not only been identified by the Estonian government, but also in external sources. Although Estonia has high operational and technical readiness to use their EHRs system to fulfil national health information needs and research objectives, they have low readiness in terms of data governance because of their lack of resources and technical ability to extract information from the system and analyse it in a systematic way for secondary uses (43).

Facilitators to the implementation of EHR systems

Estonia's extensive 'e-state' infrastructure has facilitated the implementation of the national health information system, along with the implementation of EHRs across the country. All Estonian residents have an electronic identity to access e-services, including e-health services, which is carried on national ID cards (held by 98% of all citizens and permanent residents), mobile ID cards and smart ID cards. Data sharing across e-services is facilitated through X-tee, a data exchange layer established in 2001 for information sharing that establishes a unified protocol to exchange information securely. X-tee has been referred to by the Information Systems Authority as the 'blood vessels of the e-state' (58), and uses blockchain technology (61). X-Road, the English version of X-tee which was developed jointly by Estonia and Finland, allows for the exchange of information across national borders, and has been used to exchange information between the two countries since 2015 (58).

It was also reported that since Estonia is a country with a relatively small population, the implementation of the national health information system was easier than it may be in countries with a larger population (48).

Barriers to implementation of EHR systems

Estonia faced challenges when implementing the national health information system, because there was no national system for them to copy or borrow from. The implementation of this system had high development costs in terms of hardware, software and training, particularly with respect to the implementation of standardised and harmonised definitions across the system (55). Since providers were either not or minimally compensated for the additional work required to upload mandatory data to the national health information systems, there were challenges associated with lack of financing from the state, combined with existing financial challenges in the Estonian healthcare system (54).

The decentralised nature of how data is inputed into the system is also a challenge in terms of interoperability and compatibility, as data input relies on individual healthcare providers (56). National standards around data conventions have been identified as a national eHealth priority, and it was acknowledged that this would be a long and resource-intensive process despite the establishment and publication of national standards by the Estonian eHealth Foundation (60).

Although the Estonian national health information system is considered advanced, several challenges remain. Firstly, since only certain data items are required to be uploaded to the national system, there are issues with a lack of data being available across healthcare providers to be able to provide all information necessary in providing care to patients. There are also issues with sharing records internationally for patients that have received care in Estonia, since providers are required to have a valid Estonian activity and professional license to access the national health information system. Records must be shared on an individual basis because of this limitation (48). In Estonia's eHealth Strategic Development Plan 2020 (published in 2015), the government also identified issues with data quality and technical errors in the national health information system, including incorrect completion of some data fields and delays to (or in some cases, failure in) uploading required data to the system. They also address issues with international sharing of data and the need to make data more useful in terms of research and development activities, including for the secondary use of data in health policy in this plan (60).

What are the implications, if any, for public health functions?

Estonia is a leader in the implementation of a national EHR system and has implemented a national system alongside the EHRs and paper-based health records that are held by individual healthcare providers. They have taken steps towards standardising the use of terminology within this system in terms of establishing definitions and training providers, although there are still challenges associated with this. Estonia is moving towards having machine-readable data that can automatically be analysed, which will assist in using data from the national health information system to complete public health functions including infectious disease surveillance.

However, Estonia's national health information system was built with the goal of providing efficient and effective healthcare in mind, rather than necessarily to facilitate the secondary use of EHR data for public health functions. The country keeps a separate database, the Communicable Disease Register, despite some of the necessary information (diagnoses, for instance), also being available in the national health information system. As Estonia implements additional training and resources to analyse data more proactively, it has the opportunity to consider how these factors could contribute to infectious disease surveillance.

The Netherlands

The current status and trends in the use of EHRs in the country

In 2014, the Dutch Ministry of Health, Welfare and Sport set out an agenda for the implementation of national Electronic Health Records for all residents in the Netherlands, with the aim of improving the effectiveness and quality of care. The agenda set the following objectives to be achieved by 2019 (62): (1) 80% of the chronically ill population and a minimum of 40% of the overall population should have direct access to their health and medical data; (2) 75% of chronically ill patients and older patients should be able to perform certain kinds of self-examinations (e.g. measuring blood pressure, blood sugar levels or weight); and (3) patients who receive care and support at home should be able to communicate with medical professionals at any time via a screen (63).

By 2019, the availability of patient portals offered by hospitals was more than 80% (objective 1) (64), and approximately 75% of people with a chronic condition who are willing and able to conduct self-monitoring were able to do so (objective 2) (65).

In order to achieve these objectives, the Dutch government used both a top-down and a bottom-up approach to implementation of EHRs (62). They established a countrywide infrastructure for the exchange of data between healthcare providers (called AORTA), which includes elements such as an electronic healthcare provider card, a countrywide patient registry, security standards and legislation for one unique countrywide patient ID (66). In addition, there were local and regional initiatives that resulted in bespoke implementations of solutions, such as electronic medication services, web-based referral services, and integrated solutions for disease management (62).

EHRs for public health surveillance

In the Netherlands, several sources of information are being used for the surveillance of infectious diseases, ranging from self-reported symptoms of respiratory infections to mandatory disease notifications by physicians and laboratories (27). EHRs kept by GPs are one such source of information, as they provide an overview of the population's health.

In the Netherlands, there is the Netherlands Institute for Health Services Research ('NIVEL') primary care database, which comprises a weekly collection of longitudinal data from EHRs of a large sample (approximately 500) of general practices and other primary healthcare providers (27). Although these practices neither actively report patients nor take laboratory samples for surveillance purposes, around 300 participating practices use an information system that allows automatic pseudonymised weekly data extraction from medical records. In addition, a subset (n = 38) of practices, known as sentinel practices, actively report on patients who consult them for an acute influenza-like illness (ILI). In these sentinel practices, GPs are asked to take a nose and throat swab from two ILI patients per week, which get tested for influenza and a selection of other respiratory viruses by the National Institute for Public Health and the Environment (RIVM) Infectious Diseases Diagnostics and Screening Laboratory (27).

Data from the EHRs are extracted on a weekly basis and results are published in the weekly 'NIVEL Surveillance Bulletin'. Deviations from normal disease patterns, (i.e. signals) are reported to the RIVM Early Warning Committee and regional signals are notified to the municipal health services (27). The data that is reported for notifiable infectious diseases includes diagnosis, post code, year of birth or age, deceased status, how diagnosis was made, was this an isolated case, was infection acquired abroad, and vaccination status for vaccine-preventable diseases (67). However, the extent to which all EHRs in the Netherlands provide information to the National Institute for Public Health and the Environment (RIVM) for all these fields is unknown.

Weekly numbers on acute respiratory infections collected from the EHRs and cases of ILI collected from sentinel practices are submitted to the database hosted by the European Surveillance System (TESSy), jointly coordinated by ECDC and the WHO Regional Office for Europe, for the European influenza surveillance (67).

Completeness of EHR data

A 2013 survey from the National IT Institute for Healthcare in the Netherlands ('NICTIZ') and NIVEL found that 93% of GPs and 66% of medical specialists update their records primarily or exclusively electronically. The study found that 83 to 90% of GPs exchange patient data electronically with public pharmacies, emergency GP services and hospitals, and that 46% of medical specialists exchange patient data electronically with GPs (68). [xiv]

There are several EHR solutions in place in the Netherlands, as well as multiple systems in place for the electronic exchange of patient data inserted in EHRs. For example, at the local/regional level there are systems that connect the information systems of GPs, GPs' out-of-hours surgeries, and pharmacists (e.g. 'OZIS-ring'). Other regional solutions include Zorgdomein (exchange of patient data between GPs and hospitals in case of referral to a specialist); POINT (exchange of information between the hospitals and the institutions for care and homecare); and EDIFACT (exchange of patient data between GPs, hospitals, and pharmacists used for the exchange of prescriptions and results of the laboratories). There are also systems connecting medical specialists or other healthcare providers that work together in management for a specific disease (e.g. cancer). However, these systems are not accessible for healthcare providers outside a specific region (as described below in 'Level of integration within the country and cross-border data sharing') or outside the chain or specialism.

The information contained in EHRs in the Netherlands depends on the type of treatment and the practitioner's profession. In general, records contain information regarding findings of an examination, diagnosis, treatment, test results, medical scans, reports, and referrals (69).

When a patient gives permission (as described under 'mechanisms for consent to EHR data sharing'), their data will become available for the National Switch Point (LSP, for *Landelijk Schakelpunt)* and can be requested using the patient's citizen service number [xv] (BSN, for *Burgerservicenummer*). Once a request is received, the concerned GP discloses part of the patient's file known as the professional summary or General Practitioner data, which includes: a list of episodes; consultations of the last four months or the last five consultations (i.e. the journal list); prescribed medication for the last four months; measurements and results within the period of the delivered journal; contraindications; and current transfer data (70). In addition, a pharmacist provides an overview of the medication provided to the patient, which includes: medication provided to the patient in the last six months; and data on intolerances, contraindications and allergies (70).

Level of integration within the country and cross-border data sharing

In the Netherlands, healthcare providers can only exchange medical data within their region, with the exception of hospitals that can request data throughout the whole country. At a regional level, there are Regional Cooperation Organisations (RSO), which promote data exchange within a region. RSOs are independent and manage the

[xiv] Respondents to our survey reported that the Netherlands had fully transitioned from a paper-based to an electronic record keeping system in primary and secondary care (see Figure 4).

[xv] In the Netherlands, residents and non-residents who stay up to four months receive a citizen service number.

infrastructure for data exchange themselves, using their own regional manager. Therefore, RSOs can implement bespoke communication solutions in a region (70).

Within the RSOs, patient data such as GP data, medication data, data from the youth healthcare system and data from the mental healthcare system are exchanged.

RSO Nederland is the umbrella association of all RSOs in the Netherlands, that guarantees the quality and interests of the RSOs and promotes standardisation in healthcare communication across the Netherlands. To prevent all RSOs from exchanging information with each other and creating their own exchange paths, an ongoing project seeks to centralise communication via the LSP, which belongs to the Association of Healthcare Providers for Healthcare Communication (VZVZ)(71).

The LSP is a healthcare infrastructure that connects the majority of public and outpatient pharmacies, General Practitioner, GP practices, and hospitals in the Netherlands, enabling different actors in the healthcare system to consult medical data of patients (70). The LSP provides a reference index for routing, identification, authentication, authorisation and logging (72). The LSP is not a database as no medical data is stored but rather it is transported. Data is only available through LSP if patients have given their permission. There are only two healthcare providers who can make the medical data available to a patient to be shared with other healthcare providers through the LSP: the GP and the pharmacist.

Legislation governing EHRs implemented in the Netherlands

There are no specific laws or action plans to regulate EHRs in the Netherlands, rather they rely on general health and data protection laws for the use of EHRs, such as the Medical Treatment Contracts Act (WGBO for *Wet geneeskundige behandelingsovereenkomst*), Personal Data Protection Act (WBP, for *Wet bescherming persoonsgegevens*), the Proposal Patient's Rights, and the 2013 General administrative regulation with regard to the electronic exchange of data between healthcare providers (*Besluit elektronische gegevensuitwisseling tussen zorgaanbieders*).

For the exchange of electronic health data, two main legislations are particularly relevant: the Code of Conduct for Electronic Data Exchange in Healthcare (Gedragscode EGiZ) and the Netherlands Standardization Institute (NEN) standards. The Code of Conduct for Electronic Data Exchange in Healthcare is a form of self-regulation by several umbrella healthcare organisations that applies to information systems that are used for exchanging personal data between healthcare providers. It lays down requirements specific to the Personal Data Protection Act as well as technical requirements with regard to (i) the rights of the data subject, (ii) informed consent, (iii) authorisation of healthcare providers and patients with regard to health data and (iv) information security and logging (72).

The NEN standards comprise of voluntary agreements between market parties on the quality and safety of their products, services and processes. The general administrative regulation with regard to the electronic exchange of data between healthcare providers describes functional, technical and organisational measures with respect to the electronic exchange of health data and explicitly prescribes that electronic exchange systems, network connections, and logging of the system must comply with NEN standards (72).

In the Netherlands, patients must provide explicit consent to enable healthcare practitioners to share data with third parties, unless there is a 'treatment relation' with the third party (72). A proposed Patient's Rights law provides for the prohibition of access of healthcare insurance companies, company medical doctors, insurance companies' medical advisors and medical examiners (72).

Facilitators to the implementation of EHR systems

The approach of the Netherlands to the implementation of EHRs with its support for local/regional solutions connected by data sharing infrastructure supports the introduction of new technologies alongside existing healthcare information technology (HCIT) solutions. Based on early troubled efforts to take a more 'top-down' approach with the development of AORTA (described below), the Netherlands actively embraced the involvement of local companies and providers in the development of future initiatives (62). There is some evidence that the involvement of local companies and healthcare providers in the development of later regional eHealth initiatives contributed to their success (62).

Allowing for regional variation and the involvement of local providers and companies has also arguably facilitated the inclusion of up-to-date technologies within the EHR systems in the Netherlands. The use of an open competition model is argued to encourage HCIT providers to offer competitive e-health solutions, while not requiring healthcare service providers to be locked-in to specific vendors (62). At the same time, the flexible nature of the Dutch system allows for new systems to co-exist with older systems, enabling the system as a whole to transition to a higher level of technological development without substantial disruptions.

Barriers to implementation of EHR systems

One of the main barriers to implementation of EHRs in the Netherlands was the lack of a uniform e-health strategy within a fragmented system. Until 2002, the Netherlands lacked a stable framework or a national e-health strategy, and therefore various authorities worked relatively independently without coordination on the development of HCIT (73). The lack of policies and standards created a situation where patients with multiple conditions typically faced different EHR solutions provided by different clinics (74). In addition, variability in both the degree of accessibility provided by technological solutions, and in the use of EHRs within and across organisations may lead to inequality in patient access based on the specific service used.

In 2002, the Ministry of Health, Welfare and Sport founded the National ICT Institute for Healthcare (Nictiz) to establish a nationwide digital infrastructure (AORTA) that would foster secure and reliable exchange of medical data between various service providers. The infrastructure required was completed in 2011 and included nearly half of all Dutch patients' data records (73). However, following issues with draft legislation (described below), AORTA was disbanded and Nictiz, was required to destroy the eight million patient data records it had collected so far for AORTA.

The draft legislation contained the second barrier to the implementation of EHRs in the Netherlands in that when AORTA was set-up, it used an opt-out solution for patients, meaning that patients would have to explicitly declare that they reject registering for AORTA and the use of EHRs. This went against the self-governance principle under which the Dutch healthcare system is based, creating a barrier to its use by healthcare providers (73). Therefore, the draft legislation was rejected by the Dutch Senate who denied the Ministry of Health, Welfare and Sport any authority over ICT infrastructure developments and rejected an opt-out solution for patients, leading to the creation of the decentralised data exchange infrastructure currently in use.

What are the implications, if any, for public health functions?

Electronic health records are widely used in the Netherlands, including for infectious disease surveillance, mainly focused on influenza. The automatic extraction and reporting system for ILI, enables rapid outbreak detection at a national and European level. This system could potentially be expanded to cover all notifiable communicable diseases as well as to collect information from all primary care services in the Netherlands. The Dutch system serves as an example of how EHRs could be leveraged for public health functions.

European Centre for Disease Prevention and Control (ECDC)

Gustav III:s Boulevard 40, 16973 Solna, Sweden

Tel. +46 858601000
Fax +46 858601001
www.ecdc.europa.eu

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