

# Mapping the use of electronic health records in the EU and EEA

Fields marked with \* are mandatory.

## Survey participant information sheet

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RAND Europe (a not-for-profit research institute) is conducting an assessment of the use of electronic health records (EHR) for infectious disease surveillance, prevention and control within EU/EEA countries. This work has been commissioned by the European Centre for Disease Prevention and Control (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 EHR 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 survey of key stakeholders across EU/EEA countries. You have been selected to participate because of your knowledge of EHR systems, infectious diseases, policymaking related to the use of electronic health records, or healthcare informatics.

The survey should take no more than 30 minutes to complete. Your participation in this survey is voluntary and you are free to withdraw at any time without giving a reason, without being penalized in any way, or having your legal rights being affected. We do not anticipate any direct benefits or harms to you from your participation in this research. The potential for loss of confidentiality is a risk with any research, including this study. Your responses will be kept confidential and the information you provide will be used solely for the purposes set out in the information sheet provided. The data collected through the survey will be held securely by RAND Europe in accordance with the European General Data Protection Regulation and for up to one year after the end of the research study; and thereafter, be securely erased.

If you have any questions about this research or your rights as a study participant, please contact:

**Dr Katherine Morley**, Project Leader

RAND Europe | Westbrook Centre, Milton Road, Cambridge, CB4 1YG

(email) [kmorley@rand.org](mailto:kmorley@rand.org) | (telephone) +44 1223 353329

\* I confirm that I have read and understood the information sheet and that I want to participate in the survey:

- Yes
- No

## Participants

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About which EU/EEA do you have the most knowledge of EHR systems? Where you have experience with the EHR system of more than one country, please select the country you are most familiar with.

- Austria
- Belgium

- Bulgaria
- Croatia
- Cyprus
- Czechia
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- Iceland
- Ireland
- Italy
- Latvia
- Liechtenstein
- Lithuania
- Luxembourg
- Malta
- Netherlands
- Norway
- Poland
- Portugal
- Romania
- Slovak Republic
- Slovenia
- Spain
- Sweden
- United Kingdom
- Other

Please specify other country

\* Which of the following best describes your *main* area(s) of professional expertise?

Please select all that apply

- Infectious disease
- Medical informatics
- Public health
- Clinical medicine
- Health Economics
- Policy
- Epidemiology
- Other

If other, please specify

## EHR system characteristics

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In your country of expertise:

By sub-national we mean any geographical region of any size below the national level. By unified we mean the same computer system is shared across multiple care providers (e.g. across hospitals)

	Yes	No	Unsure
* Does your country of expertise have a unified electronic health record system at the <b>national level</b> for <b>secondary healthcare</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Does your country of expertise have a unified electronic health record system at the <b>national level</b> for <b>primary healthcare</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Does your country of expertise have a unified electronic health record system at the <b>sub-national level</b> for <b>secondary healthcare</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Does your country of expertise have a unified electronic health record system at the <b>sub-national level</b> for <b>primary healthcare</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Does your country of expertise have <b>national support for regional electronic health record systems</b> ? For example, does your country provide a system through which regional electronic health record systems integrate a portion of their data?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* Are you aware of any specific examples where electronic health records are used to fulfill infectious disease reporting requirements in your country of expertise or elsewhere in the EU/EEA?

By infectious disease reporting, we mean providing routine disease prevalence information or disease outbreak information.

- Yes
- No
- Unsure

Please provide a brief description and/or links to relevant websites of where electronic health records are used to fulfill infectious disease reporting requirements in your country of expertise or elsewhere in the EU /EEA.

The implementation of EHR systems within healthcare systems requires the transition from paper-based systems to a fully electronic system. Please complete the matrix below where **1** represents a **fully paper-based model**, **5** a **hybrid model**, and **10** a **fully electronic model**.

	1	2	3	4	5	6	7	8	9	10
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* Please select the approximate position of the <b>primary care system</b> for your country of expertise in this transition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Please select the approximate position of the <b>secondary care system</b> for your country of expertise in this transition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* To your knowledge, do the public health authorities in your country of expertise provide information about infectious diseases to healthcare providers through electronic health systems to enable them to identify people at high risk of infectious disease exposure?

For example, identifying people for screening, or prompting re-testing for treatment of people at high risk.

- Yes
- No
- Unsure

\* To your knowledge, do the public health authorities in your country have any role in ensuring the quality of EHR data?

For example, do they specify the type or format of data that should be recorded about a particular disease?

- Yes
- No
- Unsure

## Completeness of EHR Data

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Considering your country of expertise: what is your view of the completeness of EHR data within **primary care** for the following types of information?

By completeness we mean how often types of information are usually recorded in the EHR system

	Always completed	Sometimes completed	Never completed	Unsure
* <b>Patient sociodemographic information</b> (e.g. age, gender, nationality)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Laboratory reports</b> (e.g. diagnostic test used; result of diagnosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Disease diagnoses</b> (diagnosis confirmation and/or codes (e.g. ICD-10))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Disease consequences</b> (e.g. death, complications)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Treatment details</b> (procedures and non-pharmacological treatments)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* <b>Prescription information</b> (drugs prescribed and dispensed)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Patient medical history</b> (comorbid conditions)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Considering your country of expertise: what is your view of the completeness of EHR data within **secondary care** for the following types of information?

By completeness we mean how often types of information are usually recorded in the EHR system

	Always completed	Sometimes completed	Never completed	Unsure
* <b>Patient sociodemographic information</b> (e.g. age, gender, nationality)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Laboratory reports</b> (e.g. diagnostic test used; result of diagnosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Disease diagnoses</b> (diagnosis confirmation and/or codes (e.g. ICD-10))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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* <b>Patient medical history</b> (comorbid conditions)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Recording key timepoints in EHR data sources in your country of expertise:

	Yes - routine for all infectious disease	Yes - but only for some infectious diseases	No	Unsure
* In your view, do EHR data sources in the <b>primary care system</b> in your country of expertise record key timepoints relating to development and course of an infectious disease accurately enough to support disease surveillance? (For example, information on timing of exposure, infection, symptoms, and diagnosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<p>* In your view, do EHR data sources in the <b>secondary care system</b> in your country of expertise record key timepoints relating to development and course of an infectious disease accurately enough to support disease surveillance? (For example, information on timing of exposure, infection, symptoms, and diagnosis)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Please indicate for which diseases data sources in the primary care system record key timepoints:

Please indicate for which diseases data sources in the secondary care system record key timepoints:

## Format of EHR Data

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Considering **primary care** within your country of expertise, to your knowledge, what format(s) are the following types of information recorded in?

'By structured we mean that recording uses an existing coding system such as the International Classification of Disease (ICD-10). By unstructured we mean information is recorded without use of a specific system, such as through written clinical notes.

	Structured	Unstructured	Structured and unstructured	Unsure	Not included
* <b>Patient sociodemographic information</b> (e.g. age, gender, nationality)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Laboratory reports</b> (e.g. diagnostic test used; result of diagnosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Disease diagnoses</b> (diagnosis confirmation and/or codes (e.g. ICD-10))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Disease consequences</b> (e.g. death, complications)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<p><b>* Treatment details</b> (procedures and non-pharmacological treatments)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p><b>* Prescription information</b> (drugs prescribed and dispensed)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p><b>* Patient medical history</b> (comorbid conditions)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Considering **secondary care** within your country of expertise, to your knowledge, what format(s) are the following types of information recorded in?

'By structured we mean that recording uses an existing coding system such as the International Classification of Disease (ICD-10). By unstructured we mean information is recorded without use of a specific system, such as through written clinical notes.

	Structured	Unstructured	Structured and unstructured	Unsure	Not included
* <b>Patient sociodemographic information</b> (e.g. age, gender, nationality)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Laboratory reports</b> (e.g. diagnostic test used; result of diagnosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Disease diagnoses</b> (diagnosis confirmation and/or codes (e.g. ICD-10))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* <b>Disease consequences</b> (e.g. death, complications)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>* Treatment details</b> (procedures and non-pharmacological treatments)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>* Prescription information</b> (drugs prescribed and dispensed)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>* Patient medical history</b> (comorbid conditions)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Sharing and Linkage

Converting EHR data to a common model:

By a **common data model** we mean a standard data format. By **interoperability**, we mean that computer systems are able to exchange and use information.

	Yes	No	Unsure
* Are there existing processes in place to convert <b>primary care</b> EHR data to a common data model to support interoperability?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Are there existing processes in place to convert <b>secondary care</b> EHR data to a common data model to support interoperability?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To your knowledge, in your country of expertise, are the following types of information shared between the **national/sub-national EHR system** and the national public health authority or similar, or organisations external to country:

Please check all that apply

	The national public health authority or similar	Organisations external to the country (e.g. ECDC) directly or via the public health authority	Unsure
* <b>Patient sociodemographic information</b> (e.g. age, gender, nationality)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* <b>Laboratory reports</b> (e.g. diagnostic test used; result of diagnosis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* <b>Disease diagnoses</b> (diagnosis confirmation and/or codes (e.g. ICD-10))	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* <b>Disease consequences</b> (e.g. death, complications)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* <b>Treatment details</b> (procedures and non-pharmacological treatments)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<p><b>* Prescription information</b> (drugs prescribed and dispensed)</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p><b>* Patient medical history</b> (comorbid conditions)</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* Does your country's health or EHR system use unique patient identification numbers?

- Yes
- No
- Unsure

\* If yes, do the unique identifiers apply to both primary and secondary care? Or is it the same identifier across both the primary and secondary care systems?

- Primary care only
- Secondary care only
- Same identifier across both primary and secondary care
- Different identifiers for primary and secondary care

In your country of expertise:

Please check all that apply

	Laboratory information systems	Pathology information systems (e.g. anatomic pathology laboratory information system (APLIS), or digital pathology system)	Pharmacy information systems (e.g. national ePrescription system)	Automatic vaccination alerting system	Disease or vaccination registries	None	Other	Unsure
* What other systems do <b>primary care</b> EHR systems link to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* What other systems do <b>secondary care</b> EHR systems link to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please specify the other systems that the primary care EHR systems link to:

Please specify the other systems that the secondary care EHR systems link to:

## Legislation and Governance

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\* Does your country of expertise have specific legislation governing access to EHR data or the national support structure for EHR in addition to GDPR?

- Yes
- No
- Unsure

In your country of expertise:

	No access for secondary use	Indirect access through the owner or a third party	Direct access restricted to specific data sets	Direct access to full data set	Unsure
* To what extent are <b>primary care</b> EHR data available for secondary use, such as by public health authorities for disease surveillance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* To what extent are <b>secondary care</b> EHR data available for secondary use, such as by public health authorities for disease surveillance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* To your knowledge, what mechanisms to permit sharing of EHR data for public health purposes are in place in your country?

Please select all that apply

- Point-of-care consent mechanisms (opt-in consent process)
- The law allows patients to opt-out of having their data included in shared data sets
- Consent is only required for non-anonymised secondary use of health data/EHR data National legislation
- National data guardian (or similar)
- Other consent models
- No specific legislation regarding patient consent for data reuse

Unsure

Please specify the other consent models that are in place to permit sharing of EHR data for public health purposes:

\* Are you aware of any examples of particular legislation around the use of EHR in your country of expertise?

- Yes
- No
- Unsure

Please provide examples of particular legislation around the use of EHR in your country of expertise

If you do not have all the details for a particular example, that is fine. We are also happy to receive partial information and/or links to websites or documents.

## Barriers to use of EHR systems

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The below table contains potential barriers to using EHR systems to **record data**. Please select all that apply as they relate to the following:

	Lack of financial resources	Lack of training for staff in how to use systems	Difficult to use or does not meet clinical needs	Lack of time	Not viewed as a priority by staff	Not viewed as a priority by organisation	None	Unsure
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<p>* When considering <b>primary care</b>: In your opinion, which of the following do you view as barriers to the use of EHR systems in your country /region of expertise by <b>healthcare staff</b>, particularly for infectious diseases?</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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<p>* When considering <b>secondary care</b>: In your opinion, which of the following do you view as barriers to the use of EHR systems in your country /region of expertise by <b>healthcare staff</b>, particularly for infectious diseases?</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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The below table contains potential barriers to **data stored** in EHR systems. Please select all that apply as they relate to the following:

Please select all that apply

	Lack of data sharing between organisations	Patient data are incomplete	Information important to infectious disease surveillance is not captured by the system.	Patients have concerns about privacy	Reporting /provision of information is not timely	Lack of framework (regulatory, legislative, ethical) on confidentiality and privacy issues	Unsure	None
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<p>* When considering <b>primary care</b>: In your opinion, which of the following do you view as barriers to the use of EHR systems in your country of expertise by <b>public health authorities</b>, particularly for infectious diseases?</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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<p>* When considering <b>secondary care</b>: In your opinion, which of the following do you view as barriers to the use of EHR systems in your country of expertise by <b>public health authorities</b>, particularly for infectious diseases?</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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## Closing Questions

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\* Are you aware of any examples where EHR has been used for communicable or non-communicable diseases for surveillance, prevention or control?

- Yes
- No
- Unsure

Please provide any examples where EHR has been used for communicable or non-communicable diseases.

If you do not have all the details for a particular example, that is fine. We are also happy to receive partial information and/or links to websites or documents.

Is there anything else that you think we should be aware of related to EHR use for infectious disease surveillance?

When you click through to the next page, please press "Submit." EU Survey will then confirm that all questions have been answered, and will re-direct you to any questions that are outstanding.