D9.4

Mid-term public workshop

ABSTRACT

This report summarises the Mid-term public workshop organised by InteropEHRate on 20 and 21 October 2020. It provides details on the presentations of the two sessions, key discussion topics held during the stakeholders' panels and describes the dissemination process and its impact in terms of stakeholders' involvement.

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CONTRIBUTORS

	Name	Partner
Contributors	Tino Marti, Stephan Schug, Diane Whitehouse	EHTEL
	Matteo Melideo, Francesco Torelli, Alessio Graziani	ENG
	Vincent Keunen	A7
	Adrian Bradu	SIMAVI
	Stefano Dalmiani	FTGM
	George Petrescu	SCUBA
	Thanos Kiourtis	UPRC
	Gabor Bella, Simone Bocca	UNITN
Reviewers	Laura Pucci	ENG

LOG TABLE

Version	Date	Change	Author	Partner
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ACRONYMS

Acronym	Term and definition
A7	Andaman7
API	Application Programming Interface
CIO	Chief Information Officer
CPME	Comité Permanent des Médecins Européens
D2D	Device-to-device
DICOM	Digital Imaging and Communications in Medicine
EC	European Commission
ENG	Engineering Ingegneria Informatica S.p.A
EHDS	European Health Data Spaces
EHR	Electronic Health Record
EHRxF	European Electronic Health Record exchange format
EHTEL	European Health Telematics Association
eIDAS	electronic IDentification, Authentication and trust Services
EU	European Union
FAQ	Frequently Asked Questions
FHIR	Fast Healthcare Interoperability Resources
FTGM	Fondazione Toscana Gabriele Monasterio
HCP	Healthcare provider
HL7	Health Level 7
ICD-9, ICD-10	International Classification of Disease version 9 and 10
IPS	International Patient Summary
IRS	InteropEHRate Research Services
IT	Information Technology
KPI	Key Performance Indicators
LOINC	Logical Observation Identifiers Names and Codes
Q&A	Questions and answers
QR	Quick Response
R2D	Remote-to-device
RDS	Research Data Sharing
S-EHR	Smart Electronic Health Record
SDO	Standard Development Organisations
SDPi	Service-oriented Device Point-of-care Interoperability

SNOMED-CT	Systematized Nomenclature of Medicine – Clinical Terms
UK	United Kingdom
UNITN	University of Trento (Italy)
UPRC	University of Piraeus Research Centre (Greece)
UPMC	University of Pittsburgh Medical Center (Italy)
USA	United States of America

TABLE OF CONTENT

LIST OF FIGURES

LIST OF TABLES

1. INTRODUCTION

1.1. Scope of the document

The objective of this deliverable is to report the process and results of the InteropEHRate Mid-term Public Workshop held on 20 and 21 October 2020. It aims to provide a summary of the presentations and main topics discussed during the stakeholders' panels. Results in terms of dissemination, registration, attendance, evaluation, feedback, and other outcomes are also part of its scope.

1.2. Intended audience

As part of the dissemination, communication and collaboration work package, the intended audience of this deliverable ranges from a wider public to specific target groups. This dual logic was projected in the structuring of the Mid-term Public Workshop in two parts. Part 1 oriented to a general audience and end-users (citizens, healthcare professionals, healthcare organisations and health authorities) and Part 2 targeting specific technical stakeholders (eHealth competence centres, Standard Development Organisations, the technology industry, digital health apps developers and other related EU projects).

1.3. Structure of the document

Six chapters structures the document. Chapter 2 describes the background, objectives, outline and target audience of the Mid-term Public Workshop. Chapter 3 and 4 summarise presentations and discussions in Part 1 and 2. Chapter 5 reports the results of the event in terms of registration, attendance, evaluation, feedback, and other outcomes. Finally, Chapter 6 provides the conclusions and next steps elicited from the workshops.

1.4. Updates with respect to previous version (if any)

Not applicable to this deliverable.

2. ABOUT THE MID-TERM PUBLIC WORKSHOP

InteropEHRate Mid-term Public Workshop is a milestone of the dissemination, communication and collaboration activities foreseen in the project. It was originally planned as a face-to-face event in year 2, month 18, just in the middle of the life course of the project as a dissemination steppingstone towards the final conference planned in year 4, month 41. Due to the Covid-19 outbreak, physical meetings were discouraged, and it was decided to organise it virtually in month 22.

Defined as a public workshop, the event was conceived open to different audiences from general public to technical communities. The workshop modality aimed to maximise the interaction between speakers, panellists, and attendees, making use of participation techniques such as live polls and Questions and Answers (Q&A) sessions.

In the design process of the event and considering the modality of an online event, it was decided to divide the workshop into two parts according to intended audiences in two consecutive days:

- Part 1. InteropEHRate Scenarios and Data Flows (20 October 2020)
- Part 2. InteropEHRate Architecture, Protocols and APIs (21 October 2020)

Part 1 targeted a more general audience and especially InteropEHRate end-users including European citizens, nurses and doctors, healthcare organisations and regional, national and European health authorities. Part 2 had a more specific target audience composed of health IT managers, eHealth competence centres, Standard Development Organisations (SDOs), the technology industry, digital health apps developers and related EC-funded projects.

2.1. Objectives

Three were the main objectives of the Mid-term Public Workshop:

- Disseminate the InteropEHRate approach to health data sharing, progress and expected results
- Receive feedback from experts and key stakeholders on InteropEHRate approach and potential impact
- Liaise and develop linkages with relevant eHealth policies, initiatives, and projects

2.2. Outline

Structured in two parts, the outline of the workshops was adapted to accomplish the objectives and fulfil the expectations from the target audiences. Therefore, **Part 1** focused on introducing the project providing a European perspective and update on health data sharing and describing the main goals and vision of the project. This introduction was followed by three presentations addressing the three scenarios (healthcare, emergencies, and research) and using live demos to showcase how the citizen and healthcare provider interfaces connect and exchange health data. A synopsis of the key features and added value of the InteropEHRate approach closed the presentations and opened the discussion. Debate was organised through a panel of stakeholders' representatives to provide feedback on InteropEHRate approach and impact. A live poll was designed to run along the discussion to encourage attendees to express their opinion in a pre-defined set of questions.

Part 2 delved in the technical aspects of the project. It started with a description of the architecture for decentralised health data sharing followed by the presentation of the three open specifications and protocols enabling data sharing in the three scenarios. Device-to-device (D2D), Remote-to-device (R2D) and Research Data Sharing (RDS) protocols were presented by leading partners. A final presentation describing InteropEHRate semantic tools preceded the panel discussion. As in Part 1, a stakeholder panel representing different technological sectors was defined to provide feedback on the approach and impact of InteropEHRate and a live poll was deployed during the discussions.

In Annex 1, the agenda of both parts of the Mid-term Public Workshop is available.

2.3. Dissemination of the workshops

Dissemination of the Mid-term Public Workshop was articulated to reach out intended target audiences, from end-users for Part 1 to technical stakeholders for Part 2. A combination of channels was used to raise the attention to the workshops, including social media spread by partners' networks to website events and tailored invitation letters sent to the InteropEHRate email subscribers and EHTEL multi-stakeholder network.

A registration form was used to collect profile information of participants, track their actual attendance, and develop further the InteropEHRate community for future events and the final conference.

3. PART 1: INTEROPHERATE SCENARIOS AND DATA FLOWS

The first day of the Mid-term Public Workshop aimed to provide an overview of the InteropEHRate project and present the results achieved hitherto to a wider audience representing end-user, from European patients, nurses and doctors to regional, national and European health authorities. This first part was structured around the open specifications used in the three scenarios covered by the project – healthcare access, emergency access and research access –, showcasing live demos of the patient and healthcare reference implementations. A panel debate on stakeholders' feedback on InteropEHRate approach and impact followed the presentations.

3.1. Presentations

Overview of InteropEHRate

Matteo Melideo (ENG), InteropEHRate project coordinator, presented the main facts and figures related to the project. InteropEHRate aims to make health data available - wherever people are - "in their hands", with the data to be installed on people's mobile device. Data does not need to be saved in the cloud and it can be on people's mobile phone. The exchange of data follows the EC Recommendation (2019) on EHRxF exchange format.

InteropEHRate adopts a bottom-up approach where data exchange is centred on the person and not set by a superior authority e.g., EC or Member States.

It makes use of device-to-device (D2D) and remote-to-device (R2D) protocols. D2D connections does not require internet connection and it is based on Bluetooth. R2D enables communication with cloud storage. Other key aspects include conformance levels, a FHIR profile, a standard reference implementation based on new trends in interoperability trialled in three different use cases (regular healthcare, emergencies, and research) and in four countries (Belgium, Greece, Italy and Romania). Finally, a well-defined InteropEHRate governance model will ensure technological updates and sustainability beyond the project.

Access to patient at point of care (live demo)

Vincent Keunen (Andaman7) and Adrian Bradu (SIVAMI) acknowledged the work of a very large team on security, standards, authentication, and translation. Together they provided a presentation of the first use case (regular healthcare) where a patient obtains and share personal health data with a healthcare provider (HCP) in a local context without internet connection. A Smart EHR (S-EHR) on the patient smart phone and an HCP app connected in a live demo to exchange data through the D2D protocol.

Concerns about credibility and trusted sources of health data were raised as an important aspect to gain acceptability from both sides. Some studies have shown that about 30 per cent of health information entered in hospitals is wrong. Providing access to patients may contribute to correct it.

Decentralised data-sharing for research

Stefano Dalmiani (FTGM) described different types of research studies (retrospective and prospective cohort studies) that can be undertaken if more health data is collected by research centres. The preferred model is the "Open Research" platform protocol that follows accountability principles.

In the third InteropEHRate scenario (research access), the starting point is the patient or the healthy person who gives his/her authorisation to join the research protocol. Using InteropEHRate Research Services (IRS),

data is published in a public repository that allows transmission along with data protection policy (e.g., pseudonymisation or anonymisation).
Each country or region can have a reference research centre responsible of multi-centre protocols. These centres will aggregate health data with given consent from patients to be in the clinical trial and therefore become candidates for the research project.
Before signing consent, patients should receive communications encouraging their participation to the research project. They would be informed about the purpose of the research, the research centre, the local research centre (where the patient dwells), and anonymisation process. Therefore, patients would be informed to make the decision of participating in the research and sign consent. The patient can withdraw his/her involvement at any time.

In the Q&A session, the discussion turned around the compliance of researchers with the research protocol. Information about the protocol must reach both researchers and the IT departments supporting research who are often not aware of the research protocols. Involving data scientists is today associated with many research protocols and might help to improve the management of the research.

Access to patient data in emergency situations

George Petrescu (SCUBA) presented the third scenario where the patient requires urgent care and healthcare professionals can retrieve personal health data from the S-EHR cloud. A spoken description was offered following the demo portrayed in the following visual. Access to health data in emergency situations through this mechanism is verified, secured and fast. The data is sent is in an encrypted format and the cloud provider cannot access the patient's data. Only the patient and the patient's trusted provider can access the data.

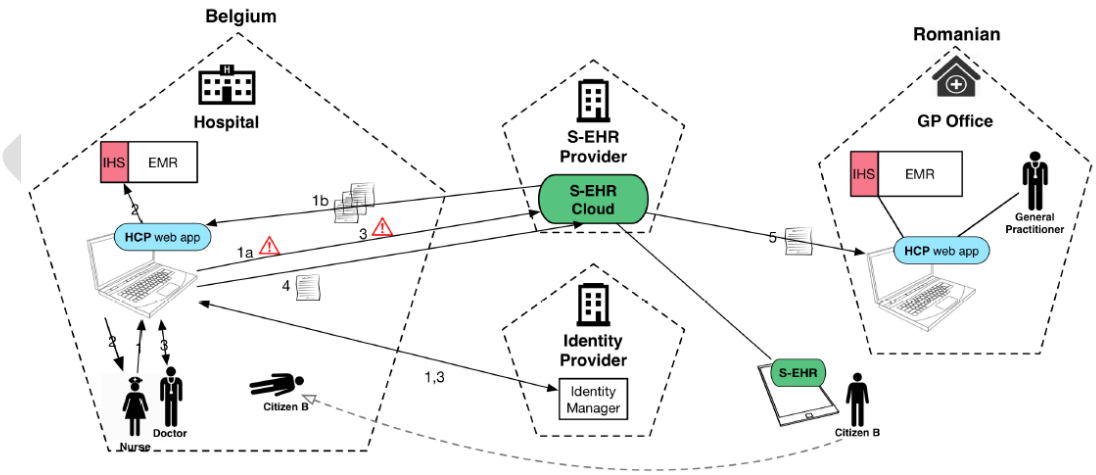


Figure 1. Data sharing in emergency situations

Synopsis: Key features and added value of the InteropEHRate approach

Francesco Torelli (ENG), InteropEHRate technical coordinator, summarised the open specifications and protocols in the three scenarios and highlighted the complimentary at European level of the healthcare centred approach with the citizen-centred InteropEHRate approach. In the former, data are governed by healthcare providers while in the latter data are governed by citizens. Limitations and advantages of both

approaches were described. The combination of both approaches is synergetic and considers citizens, healthcare organisations and research centres as peers.
In the citizen-centred approach, exploited more by the InteropEHRate project, the patient controls the management of the data. Protocols can be exploited without Internet connection and citizens can directly connect to research studies. There is, however, a duplication of data (saved both in the healthcare institution and in the device of the citizen). Medical image files are difficult to store on a mobile device, but through a pointer system this can be solved. Researchers can therefore contact potentially more people which is a big advantage for secondary use or re-use of data.
Open specifications, not tied to a specific vendor, easiness to move the data from different sources to different destinations, compliance with eIDAS to apply the same credentials, semantic tools to convert data in different languages, and the exploitation of digital signatures in different protocols are the key advantages of InteropEHRate. From an end-user point of view, citizens can be more aware of their health and the user of their data, protecting privacy in cloud storage. Researchers benefit from receiving richer and larger data and can enlarge their geographical scope.
Ultimately, the goal of the InteropEHRate project is to make an integration between these two approaches.

3.2. Panel discussion

The panel "Stakeholders' feedback on InteropEHRate approach and impact" was moderated by Stephan Schug (EHTEL) and composed by the following panellists:

- Eva Turk (University of Oslo, Norway) in representation of European citizens
- Asija Délalic (NHS England, UK) in representation of European nurses
- Sara Roda (CPME, Belgium) in representation of European physicians
- Andrea Belardinelli (Tuscany Region, Italy) in representation of health authorities
- Ceri Thompson (DG CONNECT) in representation of the European Commission

A first round of feedback proceeded highlighting the role of citizens in data collection and curation and the importance of digital literacy and empowerment. The panel welcomed the project approach to European nurses and underlined the importance of citizens' access to health data. Several challenges related to standardisation, translation of documents, technical capabilities of mobile devices, and financing aspects of cloud data storage were pointed out. Concerns about privacy and security in case of stolen or blocked mobile phone, about encryption of data, and the use of meta-data were raised. Attention was also drawn to the longstanding goals of the EC on cross-border healthcare, trusted access, and quality of data. Chronic disease patients are envisaged as the leaders in this front and therefore digital and health literacy and empowerment in relation to data management remain fundamental. An EC survey conducted this autumn on these matters is about to bring new insights. Largely in this complex landscape, the InteropEHRate project has a place as a very important nexus in the whole debate.

InteropEHRate presenters responded to this first round of feedback differentiating between mobile app and the cloud storage. Both require encrypted data and meta-data. It was recalled the focus of the project as mainly on the protocol and the communication specifications. Additionally, the project has also released a set of rules that must be followed by the mobile application(s) and the [fair] cloud. This could become the basis of a future certification service, where both are certified. It has been assured that the provider cannot access the data and hide the identity of the citizen to send data anonymously.

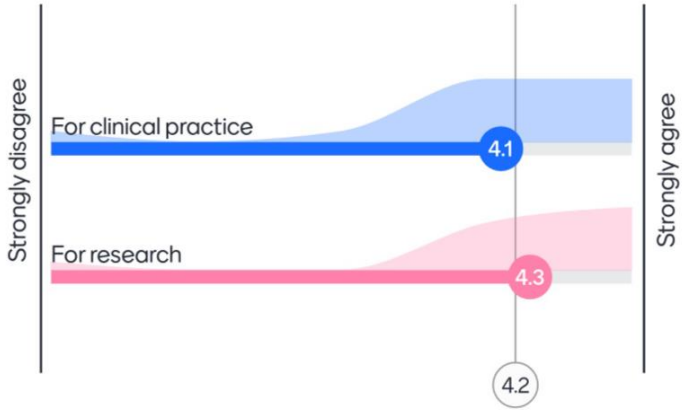
The moderator opened a second round of feedback around the question of having an EHR interfacing with a wellness app (e.g.: fitness tracker). Panellists expressed support but pointed out the mindset challenge, especially in some Member States, considering the vast use of wellness apps (step counters, sleep monitors). Cultural differences and levels of digital literacy must be contextualised with patient groups on how the data will serve them the best. The combination of health and wellness data can enrich research. It was also stressed the need of integrating health data sharing in health care pathways to allow doctors adoption and enabling them to spend more time with the patient.

A live poll was conducted during the panel discussion and 22 participants from the audience provided feedback to two couples of questions.

Figure 2. Part 1 live poll results to Questions 1 and 2

Participants largely agreed on the willingness to collect, manage and transport health data in mobile devices for data sharing. By scenarios, regular and emergency healthcare access had a higher score than for research use. Security, privacy, and data protection were the most used words that need to be carefully taken of.

As health professional or researcher, are you willing to take these data into account for your clinical practice or research?



What word comes to your mind first to explain your answer?

Figure 3. Part 1 live poll results to Questions 3 and 4

From a professional point of view, participants expressed higher willingness to accept health data shared by patients for research than for clinical practice. However, the differences were minor and in average respondents scored high. Availability and globality were the most used words to explain the answer.

The results did not surprise the panellists but contrasted them with the low expectations and different levels of trust about such a system from different kinds of people. An increased focus on these tools anticipates an explosion in the market and a fast uptake of early adopters. A very exciting phase but clearly not yet there. A concluding remark express this sentiment: “if we crack all the security challenges, we are in for a very exciting time.”

4. PART 2: INTEROPHERATE OPEN SPECIFICATIONS, PROTOCOLS AND APIs

The second day of the Mid-term Public Workshop focused on technical elements of the project: open specifications, protocols, and APIs. It was tailored to reach a more technical audience including the technology industry, eHealth competence centres, SDOs and digital health apps developers. A panel debate on stakeholders' feedback on InteropEHRate approach and impact followed suit.

4.1. Presentations

Matteo Melideo (ENG), InteropEHRate project coordinator, welcomed attendees and provided the background of the project underlining the value proposition of empowering citizens as the vehicle to share data more easily among health care stakeholders, and providing them with the possibility to hold data in their hands via EHRs on their own devices. Through specifications, guidelines, protocols made available to the community, InteropEHRate is in a position to provide an interesting contribution to the European Union.

Architecture for decentralised health data sharing

Francesco Torelli (ENG), InteropEHRate technical coordinator, outlined the main objectives of the project: exchange between European citizens and healthcare providers using three different protocols (D2D, R2D, RDS) in three different use cases respectively (healthcare, emergency and research access). The main results of the project are the open specification, protocols with rules, reference implementations. Every open specification satisfies a protocol. For instance, the D2D protocol does not require the use of Internet and uses Bluetooth instead to ensure privacy. The InteropEHRate Framework includes reference implementations with examples for e.g., libraries, research, other services such as translation into other languages.

InteropEHRate D2D protocol

Thanos Kiourtis (UPRC) presented the D2D protocol used to securely exchange health data via Bluetooth. He defined the users' problem related to health information exchange and its consequences in terms of efficiency, errors, and value of care. Under the healthcare visit scenario, InteropEHRate enables citizens to travel with, store and exchange their health data with their smart phones, using the Bluetooth protocol.

The D2D protocol proposition is a ten-steps scheme that employs a secure and easy-to-use data exchange process with minimum user interactions and fast response times. Exchange of demographic data is first activated through a QR code scan. Once connection is established, the HCP app gets the content decision from the side of the S-EHR app and health data exchange (International Patient Summary - IPS) starts until is disconnected from either side. Next steps include the citizen option of sending partial information, exchange other kind of health data (medical images) and test with other short-range communication technologies such as Wi-Fi direct.

In the Q&A session, it was suggested aligning roadmaps with the community working on Device Interoperability using Service-oriented Device Point-of-care Interoperability (SDPi) and FHIR.[1] It was noted

[1] Device Interoperability using SDPi and FHIR community engagement: https://confluence.hl7.org/display/GP/Community+Engagement

that InteropEHRate exchange of data is bi-directional and physicians must have capacity to read and to share. Finally, it was clarified that in the D2D protocol the consent is stored on the citizen mobile.

InteropEHRate R2D Access | Cloud | Emergency protocols

Alessio Graziani (ENG) presented the R2D protocols to access data from national or foreign healthcare providers, generate an automatic and secure backup on citizens' preferred cloud and share data in case of emergency. R2D Access basic principles include a read-only protocol completely based on FHIR (data model on specific FHIR profiles and FHIR RESTful APIs query language), eIDAS authentication and encrypted data exchange.

From the citizen point of view, R2D Access has four steps: initialization, authentication, downloading and storage. A schematic view of the transactions from the developer's viewpoint was presented showing concrete operations. The development roadmap ahead will clarify the similarities and differences between definitions (e.g., Mobile Health Device by IHE and International Patient Access by HL7).

R2D back-up protocol completely hide everything from the cloud provider. It is aimed that the cloud provider does not know about what data is stored on his cloud and does not rely on encryption mechanisms provided by the cloud provider.

In an emergency, the healthcare provider can access health records from private clouds using a QR code, printed on a specific Emergency card owned by the Citizen, and downloading this information 'temporarily'.

Discussion with the audience focused on the privacy of data and transfer of large amounts of data using services such as DICOM API. It was clarified that medical images can be transferred through a pointer system.

InteropEHRate RDS [Research Data Sharing] scenarios

Gabor Bella (UNITN) framed the RDS protocol around two problems: data heterogeneity (languages, standards, laws, etc) and data collection. The InteropEHRate solution addresses these problems through security and access, following explicit consent, an 'interoperability profile' based on FHIR and citizens' capacity of giving and revoking consent on a per-study basis, element primed by the Innovation Radar 2020. Through the Research Data Sharing Protocol and demonstrator implementations, InteropEHRate informs citizens of research studies, checks silently them for eligibility, and aids to share health data anonymously. Each citizen is 'attached' to just one of the research centres, 'local centres'. Consent is digitally signed. Phone regularly retrieves health data, pseudonymises or anonymises it. Any withdrawal is also handled through the same mechanism.

InteropEHRate semantic tools

Simone Bocca (UNITN) presented the semantic tools developed to address the problem of translation and conversion of data into healthcare providers' own language. The InteropEHRate mapping tools, and services, are based on a set of multilingual knowledge resources, containing FHIR health record definition, medical standards codes definitions (such as ICD-9, ICD-10, SNOMED-CT, LOINC) and medical terminology.

A demo of the Knowledge Explorer was projected showing how data scientists can map, extract, and explore health data. The advantages of this system include the automatic re-apply of mappings already generated, the automatic mapping procedure on a large number of health records and the exploitation of new standards, terminology and languages only updating the Knowledge Base. High-quality knowledge definition leads to high-quality mappings and high-quality conversions and translations. The Hospital Data

Scientist is in charge to keep the Knowledge Base updated, through periodic operations of new knowledge collection and mappings generation.

4.2. Panel discussion

The panel "Stakeholders' feedback on InteropEHRate approach and impact" was moderated by Vincent Keunen (A7) and was composed by the following panellists:

- Maria Marques (Smart4Health, Portugal) in representation of a related EU project
- Marta Calvano (UPMC, Italy) in representation of European hospitals
- Christof Geßner (Gematik, Germany) in representation of eHealth Competence Centres
- Ernest Sarrias (Cerner, Spain) in representation of the technology industry
- Frédéric Lambrechts (Osimis, Belgium) in representation of app developers
- Giorgio Cangioli (HL7, Italy) in representation of Standard Development Organisations

A first round addressed the first impressions from panellists. Panellists reassured that the project is moving on the right direction and in line with what companies like Cerner is doing in terms of interoperability in the last years. HL7 believe open standards are the future for more openness and initiatives like InteropEHRate will contribute and thrust cross-institutional interoperability. Synergies between Smart4Health and InteropEHRate were commented as they follow complementary approaches related to health data access from citizens. Compliance with the General Data Protection Regulation and suggesting focusing on rare chronic diseases were the concerns from the hospital perspective.

A second round of specific questions were formulated by the moderator. Regarding the mechanisms to enforce InteropEHRate from a European approach, it was pointed out that healthcare jurisdiction is under Member States and relies on country autonomy. Therefore, creating consensus among people and institutions who can adopt such a solution is the way forward. For instance, including the adoption of InteropEHRate in the specifications of public procurement (tenders) or approaching institutions that can really create standards. Comparing Europe and USA, the Obama administration did not impose interoperability standards to US hospitals. Rather they asked the companies to agree on a standard. As a result, the industry agreed on FHIR, and hospitals worked to be interoperable to keep contracts with the government. The key message is thinking big and allowing the companies to do their job. From the small and medium companies' perspective, two trends were underlined. First, moving from a very static ways of looking at things (pictures > data) to a more predictive model (taking other information than just medical imaging info). Second, access to a lot of key performance indicators (KPIs) to know whether your solutions are influencing outcomes. The discussion rounds ended inviting InteropEHRate to join the IPS and X-eHealth community in quality of a European IPA standard to promote this kind of standardisation.

A live poll was conducted during the panel discussion and 29 participants from the audience provided feedback to two couples of questions.

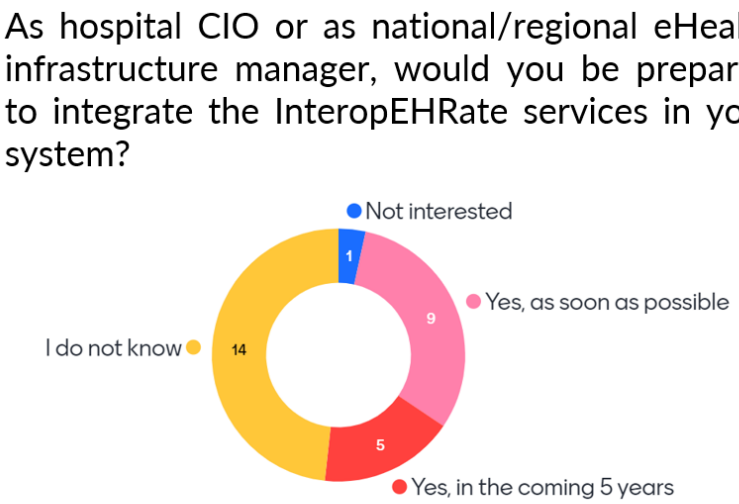
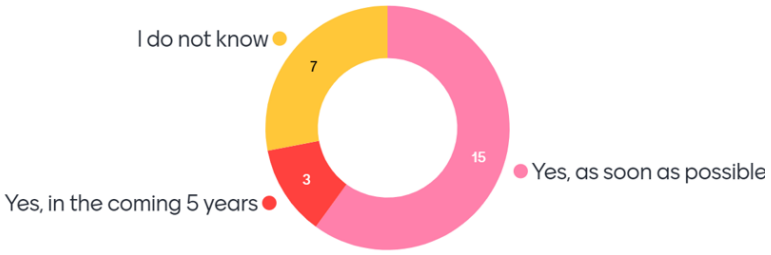


Figure 4. Part 2 live poll results to Questions 1 and 2

As the first set of questions was addressed to hospital CIOs and national/regional eHealth infrastructure managers, most participants replied to do not know. However, among those with the background to provide a response, the most voted one was "Yes, as soon as possible". Interoperability, funding and policy were the most cited words to explain their position.

The second set of questions inquired to health professionals and researchers and their willingness to accept data shared by patients into their clinical and research practices. A majority of respondents agreed that they would accept it as soon as possible. Funding stood out as the first word to describe their opinions.

As health professional or researcher, are you willing to take these data into account for your clinical practice or research?



What word comes to your mind first to explain what would you need to do so?

Figure 5. Part 2 live poll results to Questions 3 and 4

4.3. Workshop wrap up

Dr Ceri Thompson (European Commission) and Matteo Melideo provided the concluding remarks for the second day of the Mid-term Public Workshop. Dr Ceri Thompson underlined the sense of the project and the community that is developing around the project, reaching out to the health data ecosystem. She announced the participation of InteropEHRate in the eHealth Network meeting that oversees digital health activities in the EU, presenting the project approach and results to Member States.

Along the discussion facing off the European Union versus the USA approach, she pointed out that the relationship between the EU and the Member States is far different from the USA and their states. The Member States are the key decision-makers in terms of priorities and policies for their own health and care systems. In the EU, the health and care systems are based on joint risk-sharing, public funding, clear equity, and access. In the USA, it is a largely private system and they have set up the systems largely for billing. In the EU, there is not a billing mechanism – always free at the point of delivery. Now we are trying to make these systems broader e.g., including the patient experience(s) or combined with other parts of the health system, enlarging databases to health data ecosystems.

In going back to the discussions about FHIR, the Member States have discussed it among themselves, making the right decision for their own countries and systems. It is also very regionally organised. The European Union has no role to play in this. In the EU, the Member States can set legislation and they can

incentivise via funds. Once the decision has been made, the Member States' have lots of tools to make it happen.

Multi-annual financial framework (MAFF) is kicking off next year. The picture in terms of funding for digital health for the Member States will indeed become very large due to the COVID-19 crisis and it will comprise the Digital Europe deployment programme as well as EU4Health, and the Resilience Programme. This recovery programme is guided by digital and green drivers, propelling Europe into the future. Around 20 per cent of the budget is reserved for digital (approximately 20 billion euros) over the next 5-6 years. All going to rely on the new technologies, and new proofs-of-concepts.

Regulatory review of eIDAS, and whether it is still 'fit for purpose'. The EC intends to come forward on this, with proposals on how to strengthen it. A 'digital governance act' is foreseen and what Member States need to do next to handle the strengthening of national data spaces. In 2021, we will see more about the European Health Data Space (EHDS), legislation on health data sharing and secondary use of data.

Matteo Melideo thanked attendees, organisers, and the European Commission for participating in this milestone event and giving inspiration for the months ahead. A positive balance of two days of intensive work with lots of interesting questions and comments, new professional contacts, and new challenges for the upcoming months.

5. ATTENDANCE, EVALUATION AND OTHER OUTCOMES

This chapter reports outputs and outcomes of the Mid-term Public Workshop. Registration and attendance are taken as outputs of the dissemination event as proxies of the interest raised towards the project. Evaluation and feedback is reported as a primary outcome of the event. Other outcomes include the content of the discussions held through the Q&A segments, the two panel discussions reported before and the compilation of questions received through the chat box.

5.1. Registration and attendance

In total, 115 participants registered to attend the Mid-term Public Workshop. 60% of them were externals to the project (69 participants) while 40% belonged to the Consortium partners (46 participants). By sessions, 101 expressed willingness to participate to Part 1 and 99 to Part 2. The geographical distribution of participants covered 22 Member States of the European Union (Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Poland, Portugal, Romania, Slovenia, Spain, Sweden and the United Kingdom), 2 Non-EU European countries (Norway and North Macedonia) and 2 from other continents (Algeria, Panama).

Actual final participation was of 95 attendees in total, being 73 in Part 1 and 63 in Part 2. This resulted in a total show-up rate of 83% of registered participants that can be considered very successful given the concurrence of online events.

From a stakeholders' perspective, 38 different institutions external to the project were present in either sessions. They represented health authorities, eHealth Competence centres, healthcare organisations, technology companies, and academic and research centres. The following table lists the name of the participant institutions classified by stakeholders' groups.

Stakeholders' groups	Participant institutions
Health authorities	European Commission, Ministry of Health of the Czech Republic, Tuscany Region Government (Italy)
eHealth Competence centres	TicSalutSocial (Spain), SPMS (Portugal), Finnish Institute for Health and Welfare (Finland), Nictiz (Netherlands), Swedish eHealth Agency (Sweden), Gematik GmbH (Germany)
Health care organisations	Uniklinik RWTH Aachen (Germany), Health Services Executive (Ireland), Athens Naval and Veterans Hospital (Greece)
Technology industry	Cerner (Spain), Kelyon (Italy), 3fs (Slovenia), Datawizard srl (Italy), MCS Datalabs (Germany), EXUS (UK), SORSIX (North Macedonia), Docplanner Group (Spain), Medondo (Germany), Psyma (Germany), DHN (Luxembourg), Suite 5 (Cyprus), Osimis (Belgium), OncoDNA (Belgium), Onecube (France), Informatica Alto Adige (Italy), Siemens Healthineers (Germany), Deloitte (UK)

Academic and research centres	University of Bologna (Italy), Tallinn University of Technology (Estonia), Edinburgh Napier University (Scotland, UK), Università degli Studi di Milano Bicocca (Italy), University of Oslo (Norway), Onorach (UK), École Supérieure en Informatique (Algeria), Eindhoven University of Technology (Netherlands)
Associations and networks	COCIR, ECHAlliance, CPME, IHE Europe, aNewGovernance

Table 1. Participant institutions by stakeholders' group

5.2. Evaluation and feedback

After the workshops, an evaluation and feedback survey was distributed among the participants to gauge the quality of contents and explore further engagement in upcoming events, especially in view of the final conference planned for 2022.

A total 22 responses were collected, 6 participated only in Part 1, 5 in Part 2 and 11 attended both sessions. Three questions aimed to explore usefulness of contents, time for participation and willingness to participate in the final conference.

	Only Part 1	Only Part 2	Part 1 and 2	Total
How useful was the workshops' content for your work?	8.2	8.6	8.3	**8.3**
Did you find enough time for questions and comments?	6.0	6.6	8.0	**7.1**
How likely will you join the InteropEHRate final conference in 2022?	9.5	8.0	9.2	**9.0**

Table 2. Evaluation results in 1 (lowest) – 10 (highest) scale

Attendees rated the usefulness of contents for their work as high (8.3 out of 10). Despite minor different between sessions, Part 2 participants scored the highest mark (8.6). Time of questions and comments was slightly lower but satisfactory (7.1 out of 10). Those that participated in only one session found time for discussion lower (6.0 for Part 1 and 6.6 for Part 2). Willingness to join the InteropEHRate final conference in 2022 was the highest mark (9.0 out 10) demonstrating high expectations from the audience. Part 1 participants were the most inclined to attend (9.5) compared with Part 2 (8.0).

A final open question sought to capture more qualitative feedback. Respondent expressed gratitude for having had the opportunity to participate and praised the quality and clarity of the presentations, highlighting the opening presentation from the European Commission and the panel discussions. More detailed and technical information on the three use cases was claimed which encourages further dissemination effort.

6. CONCLUSIONS AND NEXT STEPS

The Mid-term Public Workshop has been extremely useful for the InteropEHRate project and consortium to strengthening and confirming the value of its approach to health data sharing in the three scenarios. It has brought new questions to reflect on and has provided the opportunity to reach new target audiences and people.

Dividing the workshop into two specific sessions has helped to deep dive into fruitful discussions, engagement, and feedback. Questions that arose during the panel debates, Q&A sessions and the chat are an unexpected asset that will be exploited further to develop a live FAQ section on the website and to organise dedicated External Stakeholders Board sessions.

The compilation of questions raised during the Q&A sessions after some presentations, the discussions held by the panellists of the stakeholders' feedback on InteropEHRate approach and feedback, and the questions posed through the chat box system are a rich source to be exploited. It makes explicit the main doubts and concerns about the project functional and technical approach, and it is largely valuable as the basis to develop a Frequently Asked Questions (FAQ) section on the website.

The recording of both sessions together with the presentations are also valuable contents that are made available through the website under the Resources and News section.

New connections established with a myriad of stakeholders will serve to increase the outreach of dissemination activities and ultimately maximise the impact of the project.

ANNEX 1. PROVISIONAL PROGRAMME

Part 1. InteropEHRate Scenarios and Data Flows (20 October 2020)

Welcome and Introduction

Workshop Facilitators: Tino Marti, Stephan Schug, EHTEL

10:05 – 10:15
Health data sharing in Europe – strategies and implementation
Dr Ceri Thompson, Dep. Head of Unit H3 eHealth, Well-Being and Ageing, DG CONNECT, European Commission

10:15 – 10:25
Overview of InteropEHRate
Matteo Melideo, InteropEHRate Project Coordinator, Engineering, Italy
InteropEHRate prepares an open health data sharing process for European citizens and patients. The self-managed EHR exchange supports national and cross-border settings.

10:25 – 10:45
Access to patient data at the point of care – LIVE DEMO
Vincent Keunen (Andaman7, Liège, Belgium), Adrian Bradu (SIMAVI, Romania)

How a European patient may easily receive electronic health records during a medical visit everywhere in Europe.
How Health Professionals can access the health history of European patients without the involvement of national Electronic Health Records (EHR) and without the Internet.

How healthcare providers can share healthcare encounter results and updates to patient summaries with their patients at distance or in a delayed way, without a need for national EHRs or other intermediaries.
Q&A

10:45 – 11:00
Decentralised data sharing for research
Stefano Dalmiani, Fondazione Toscana Gabriele Monasterio, Pisa, Italy

How European citizens can control if and when to share some health data with specific research initiatives they approve. How researchers can invite European citizens to participate to research studies and receive trustable health data directly from them.

Q&A

11:00 – 11:15
Access to patient data in emergency situations
George Petrescu, SCUBA – Clinical Emergency Hospital of Bucharest, Romania

How European patients can securely store their health data for exclusive access by healthcare providers in emergency situations.

Q&A

11:15 – 11:25
Synopsis: key features and added value of the InteropEHRate approach Francesco Torelli, Technical coordinator, Engineering, Italy

11:25 – 11:55
Panel: Stakeholders' feedback on InteropEHRate approach and impact Facilitator: Stephan Schug, EHTEL

Moderated debate with stakeholders:

[Representatives of European patients]
[Healthcare professionals – Eur. Nurses] Asija Delalic, Infection Control Nurse, NHS England, UK
[Healthcare professionals – Eur. Physicians] Sara Roda, Standing Committee of European Doctors (CPME), Brussels
[Health Authorities] Andrea Belardinelli, Head of eHealth Systems and Innovation of Tuscany Region Government, Italy
[European Commission] Dr Ceri Thompson, DG CONNECT, European Commission

11:55
Closing and invitation for Mid-term workshop part 2 (21 October) Matteo Melideo, Engineering, Italy

Part 2. InteropEHRate Architecture, Protocols and APIs (21 October 2020)

Welcome and Introduction

Workshop Facilitators: Tino Marti, Stephan Schug, EHTEL

10:05 – 10:10
Welcome from the Project Coordinator
Matteo Melideo, InteropEHRate Project Coordinator, Engineering

10:10 – 10:20
Architecture for decentral health data sharing
Francesco Torelli, InteropEHRate Technical coordinator, Engineering
InteropEHRate prepares an open health data sharing process for European citizens and patients. The self-managed EHR exchange supports national and cross-border settings

10:20 – 10:35
InteropEHRate D2D Protocol
Thanos Kiourtis, UPRC Piraeus, Greece

D2D enables secure peer to peer exchange of structured health records among Patients and HCPs by means of Bluetooth.
How a European patient may easily receive electronic health records during a medical visit everywhere in Europe.

How Health Professionals can access the health history of European patients without the involvement of national Electronic Health Records (EHR) and without the Internet.
How healthcare providers can share healthcare encounter results and updates to patient summaries

with their patients at distance or in a delayed way, without a need for national EHRs or other intermediaries.

Q&A

10:35 – 10:50
InteropEHRate R2D Access | Cloud | Emergency Protocols Alessio Graziani, Engineering, Italy

Patient's secure access to structured health records across EU exploiting eIDAS and FHIR. Encrypted backup for patients and controlled access to health records in emergency for HCPs.
How healthcare providers can share healthcare encounter results and updates to patient summaries with their patients at distance or in a delayed way, without a need for national EHRs or other intermediaries.

How patients can securely store their health data on the cloud without disclosing them to the cloud provider or any third party.
How authorised HCPs may access to health records stored on private clouds in emergency situations.

Q&A

10:50 – 11:05
InteropEHRate RDS [Research Data Sharing] Protocol Gabor Bella, University Trento, Italy

Cross-border sharing of FHIR based health records with research under citizens' control.
How citizens can control if and when to share some health data with specific research initiatives they approve.
How researchers can invite any citizen to participate to cross-border research studies and receive trustable health records directly from them.

Q&A

11:05 – 11:20
InteropEHRate Semantic Mapping Tools Simone Bocca, University Trento, Italy

How citizens and health care professionals can consult health records translated in their own languages, and how Researchers can query those records, thanks to:

A knowledge driven approach.
Tools used by Data Scientists to map local data schemas to international medical terminologies and common data formats based on HL7-FHIR standards.
Q&A

11:20 – 11:55
Panel: Stakeholders' feedback on InteropEHRate approach and impact
Facilitator: Vincent Keunen Andaman7, Liège, Belgium
Panellists:

[eHealth Competence Centres] Christof Geßner, Gematik, Germany
[Standard Development Organisations] Giorgio Cangioli, HL7 Italy, [Technology Industry], Ernest Sarrias Ramis, Cerner, Spain
[App and Service Provider] Frédéric Lambrechts, OSIMIS S.A., Liège, Belgium [Hospitals] Marta

Calvano, IT Clinical Application Manager, UPMC, Italy [related EU Project] Maria Marques, Smart4Health, UNINOVA, Lisbon, Portugal

11:55
Wrap-up / Next steps
Dr Ceri Thompson, Deputy Head of Unit H3 eHealth, Well-Being and Ageing, DG CONNECT, European Commission
Matteo Melideo, Project Coordinator, Engineering, Italy