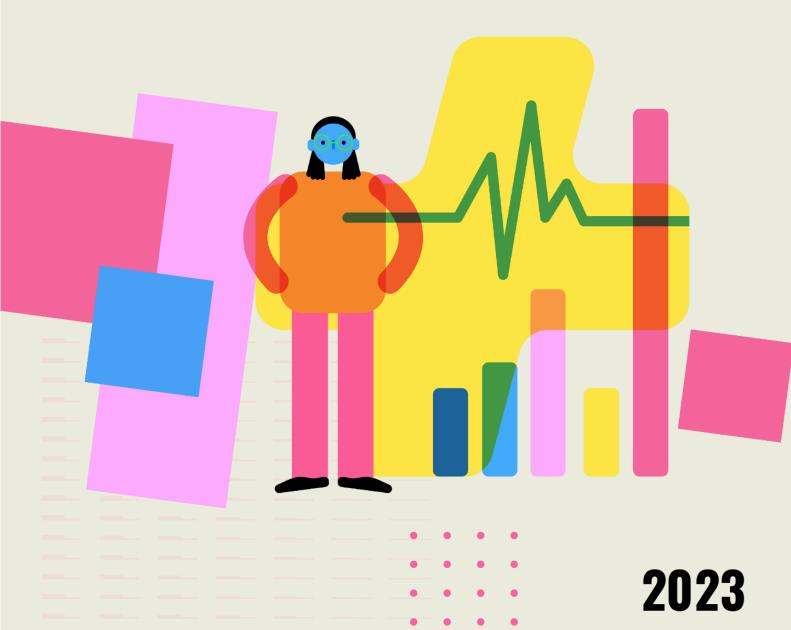


## LITERATURE REVIEW

## Electronic Personal Health Record (ePHR)

Advancing from EMRs, where the ownership is with health service organisations, to E-PHRs, where the ownership is with the patient.



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We are deeply grateful for their expertise and collaboration in shaping the trajectory of this endeavour. Their contributions have been pivotal in advancing our understanding and implementation of Electronic Personal Health Records (E-PHR) within Indonesia's healthcare system.

#### **About Transform Health**

Transform Health is a global coalition of organisations, individuals, and institutions committed to achieving universal health coverage through the use of digital technologies and data. To learn more about Transform Health, visit www.transformhealthcoalition.org.

#### **Glossary**

Access - the availability of telecommunication devices and services for use by any member of the household at any time. In its broadest sense, it considers the economic, sociological and psychological factors that influence persons' opportunities to use technologies (gender, race, age, place of residence, etc.).

Application - a piece of software that can be installed on a device to perform one or more digital health interventions. Mobile applications are add-on software for handheld devices, such as smartphones and personal digital assistants.

Artificial intelligence - Technologies that analyse large amounts of health data to support diagnosis, treatment plans, and personalised medicine.

Connectivity - the various physical means to connect people and machines to the internet or other communication networks. It usually requires either a fixed-line or a wireless solution via a broadband or dial-up service.

**Data -** information, usually in the form of facts or statistics, that can be analysed and used in decision-making.

Data sharing- the practice of making patient health information available across different healthcare systems, providers, and organisations. This allows for more coordinated and efficient care by enabling various healthcare professionals to access and use a patient's health records.

Digital health - the field of knowledge and practice associated with the development and use of digital technologies to improve health.

Digital health expands the concept of e-health to include digital consumers, with a wider range of smart devices and connected equipment.

Digital healthcare - the use of digital technologies to deliver and enhance health services. It encompasses a wide range of tools and platforms designed to improve the quality, efficiency, and accessibility of healthcare services.

**Digital security -** to the protection of patient health information from unauthorised access, breaches, and other

Digital technologies - the application of organised knowledge and skills in the form of electronic, mobile and frontier data-driven technologies to solve health issues and improve quality of life. Digital technologies for health care encompass definitions, components and systems included in digital health, e-health, m-health (and related terminology). Some examples include electronic medical records, telemedicine and health management information systems.

Digital transformation - the multiple processes of integration of digital technology and data into all areas of everyday life and the resulting changes that they bring.

Digital transformation of health - the multiple processes of integration of digital technology and data into all areas that affect individual and collective health and well-being. This includes the necessary changes in the enabling environment, including

legislation, regulation, funding, public awareness, understanding and involvement.

**Digitalisation -** the integration of digital technologies into everyday life.

# electronic Health Record (EHRs) digital versions of patients' paper charts, allowing for easier storage, retrieval, and sharing of medical information among healthcare

providers.

digital versions of the paper charts in a healthcare provider's office. They contain the medical and treatment history of patients within a single practice or health organisation. EMRs are primarily used by healthcare providers to manage patients' clinical information and streamline the workflow within a practice.

#### **Health Information Systems (HIS) -**

Digital systems for managing healthcare data, including patient records, treatment plans, and billing information.

Integration - Connecting different
health information systems to ensure
seamless data sharing between
health facilities, government agencies,
and other stakeholders.

Interoperability - the ability of different applications to access, exchange, integrate and cooperatively use data in a coordinated manner through the use of shared application interfaces and standards, within and across organisational, regional and national boundaries, to provide timely and seamless portability of information and optimise health outcomes.

JKN Mobile - a mobile application developed by the BPJS Kesehatan to facilitate participants in accessing various health services. With this application, participants can check their membership status, find the nearest hospital, and register online.

Mobile Health (mHealth) - health services and information delivered via mobile devices, such as smartphones and tablets. This includes health apps, wearable devices, and SMS-based health information services.

PeduliLindungi - PeduliLindungi is an Indonesian government app developed during the COVID-19 pandemic to support contact tracing, vaccine registration, health status verification, and monitoring individuals' movements for public health. It helps manage the spread of the virus by providing real-time information on vaccination records and COVID-19 test results.

Personal data - any information that relates to an identified or identifiable living individual.

Primary health care - a whole-of-society approach to health and well-being centred on the needs and preferences of individuals, families and communities. It provides whole person care for health needs throughout the lifespan, not just for specific diseases, ranging from promotion and prevention to treatment, rehabilitation and palliative care.

SATUSEHAT - an initiative of the Indonesian government that stands for 'One Health Data'. It is a digital health platform designed to integrate

various health information systems in Indonesia, aiming to create a unified, standardised and interoperable data system across the country.

Telehealth - the use of mobile and telecommunications to deliver health services outside of traditional health care facilities. Telehealth refers to clinical and remote non-clinical services, including providing training and continued medical education for practitioners.

**Telemedicine -** a subset of telehealth that refers solely to remote clinical services.

threats. It involves implementing various measures to ensure that sensitive health data remains confidential, accurate, and accessible only to authorised individuals or systems.

Universal Health Coverage - all individuals and communities receive the health services they need without suffering financial hardship. It includes the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation and palliative care across the life course.

Wearable - electronic devices
designed to be worn on the body,
typically as accessories or embedded
in clothing, that monitor and track
various health and fitness-related
metrics. These devices often connect
to smartphones or other digital
platforms, allowing users to access,
store, and analyse their data.

#### **Summary**

ith the advancement of digital technology, healthcare services in Indonesia have started to implement Electronic Medical Records (EMR) aimed at storing public health data. However, in reality, EMRs have not entirely fulfilled the public's expectations and rights to access their own health data.

EMRs refer to medical records generated through electronic systems specifically developed for managing healthcare documentation. EMRs contain a patient's medical and treatment history, including diagnoses, medications, laboratory results, and treatment plans. However, EMRs typically don't share data outside of the organisation. EMR is still a new policy in Indonesia, so Health Facilities need time to prepare infrastructure and human resources so that EMR can function optimally. The functioning of an EMR containing patient data is essential so people can access their health data via Electronic Personal Health Records (E-PHR). E-PHR serves as a tool to facilitate communication and information sharing between patients and healthcare providers and to maintain the privacy of individual health data.

Globally, E-PHR is used as an integrated personal electronic health record. The use of E-PHR demonstrates that health data is the right of its owner (the patient), and patients have the right to access the information. Furthermore, the E-PHR system promotes the implementation of interoperability standards across diverse healthcare systems, ranging from hospital-based health systems to primary healthcare, clinics, laboratories, and other various healthcare services. The global operation of E-PHR emphasises the importance of protecting personal data and patient health data, employing techniques such as encryption, authentication, and access control in E-PHR operations.

The purpose of this study is to investigate the existing literature on E-PHR, encompassing its design, functions, implementation, results, and advantages for the purpose of providing guidance to the ministry of health on the development of E-PHRs in Indonesia. The research approach used is Scoping Review, and the review procedure adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR). A literature search was conducted spanning from October 2022 to October 2023 across five databases: Proquest, Embase, PubMed, Science

Direct, and Scopus. The study resulted in data extraction from nine articles that met the inclusion and exclusion criteria.

Before the COVID-19 pandemic, generally, large-scale hospitals, clinics, and health centres in Indonesia had implemented an EMR ecosystem. In Indonesia, SatuSehat, an EMR platform and ecosystem that originated during COVID-19 and is now being expanded, is planned to become the forerunner of E-PHR in Indonesia (Ministry of Health, 2023).

As a non-governmental organisation, Transform Health Indonesia will actively advocate for related parties to realise E-PHR in Indonesia. The results of this scoping review are expected to serve as a reference for the development of E-PHR systems in Indonesia, and will be used to inform advocacy with policymakers, especially the Ministry of Health (MoH, RI). The use of E-PHR in healthcare services in Indonesia supports the integration of primary care services, which is expected to enhance the quality of healthcare services and achieve Universal Health Coverage (UHC).

**Keywords:** E-PHR, Digital Health, Medical Record, Mobile Health, Health Service

#### I. Introduction

#### 1.1. Background

ver the past few decades, digital technology has seen rapid development, fundamentally changing how we live our daily lives. This technological advancement has revolutionised how we diagnose, treat, and manage health. Medical innovations such as artificial intelligence, telemedicine, and other digital technologies have transformed the healthcare system (Tavana et al., 2020).

Digital health refers to the use of telecommunications technology to provide information and various healthcare services with the aim of improving public health resources (World Health Organization, 2012). The opportunities for technology in healthcare are vast. In this regard, during the 58th session in Geneva 16 - 25 May 2005 of the World Health Organization (WHO), the World Health Assembly (WHA) 58.28 Resolution was adopted, stating that member countries should begin planning for the development of e-health in their respective countries (World Health Organization, 2005). WHO also launched the Global Observatory for eHealth (GOe) in 2012, an initiative to support the study of eHealth development and its impact in their own countries (World Health Organization, 2012).

The WHO developed a framework for digital health to assist countries in implementing the integration of digital technology into their healthcare systems. This framework is detailed in the "Global Strategy on Digital Health 2020-2025" document. In this document, WHO provides technical guidance on telemedicine, health data management, and the implementation of action plans, which often require additional resources and capabilities (World Health Organization, 2021).

Digital health encompasses the use of information and communication technology in medicine and other healthcare professions to manage diseases and health risks and to improve overall health. It covers a wide range of applications, including wearable devices, mobile health (mHealth), telehealth, health information technology, and telemedicine. Digital health has become an integral part of contemporary medical practice and continues to evolve. Users, medical providers, healthcare staff, innovators, and companies need to be involved in various stages of digital health design. Patient-designed digital

health tools that focus on the individual can be an alternative way to engage patients in managing their own healthcare (Ronquillo and Zuckerman, 2017). Furthermore, digital health encompasses the provision of healthcare services that leverage cutting-edge technologies like big data analytics, artificial intelligence, the Internet of Things (IoT), and genomics (Krishnan Narayanan and Ajay Bakshi, 2021).

The use of digital health brings numerous benefits. Open exchange of medical information between individuals and healthcare professionals through electronic technology is expected to improve healthcare services and patient health status. Rapid access to quality healthcare providers is also expected to reduce differential diagnoses, complications, and enhance healthcare management (Sunjaya, 2019).

The implementation of digital health is not limited by physical location, so healthcare services, particularly those related to promotion and prevention, can be delivered outside healthcare facilities. Both aspects have the potential to reduce the need for increasing the number of healthcare facilities, which, in turn, can allocate existing resources for improving the quality, facilities, and existing infrastructure (Sunjaya, 2019).

#### Terminology Used in this Study: EMR, EHR, and E-PHR

**Electronic Medical Records (EMRs):** EMRs are digital versions of paper charts in clinician offices, clinics, and hospitals. They contain a patient's medical and treatment history, including diagnoses, medications, laboratory results, and treatment plans in one place. EMRs are primarily used by healthcare providers for diagnosis and treatment. The ownership of EMRs lies with the health service organisations that maintain these records. However, EMRs typically don't share data outside of the organisation.

Electronic Health Records (EHRs): EHRs are more comprehensive than EMRs and are designed to be shared across different healthcare settings. They contain a patient's medical history, diagnoses, medications, treatment plans, immunisation dates, allergies, radiology images, and laboratory test results. EHRs are built to share information with other healthcare providers, such as laboratories and specialists, so they contain information from all clinicians involved in the patient's care. Ownership of EHRs remains with health service organisations, but they provide a broader and more integrative view of patient health.

Electronic Personal Health Records (E-PHRs): E-PHRs are managed and controlled by patients. They are digital representations of health records connected to patient care and centred on the patient, allowing healthcare service consumers to decide which health information to share with healthcare providers. E-PHRs serve to manage and store personal health information throughout one's life for various purposes, ranging from chronic to critical care, medical treatment, and preventive care (Alsahafi and Gay, 2018). They ensure individual health privacy and serve as a means of communication and information sharing between patients and healthcare professionals (Gope and Amin, 2016).

The Ministry of Health of the Republic of Indonesia is undertaking digital healthcare transformation as a leap towards a more advanced and equitable healthcare sector in Indonesia. This digital transformation strategy focuses on the healthcare ecosystem, service efficiency, and data integration for data-driven policies. Digital transformation aims to strengthen efforts in improving healthcare services to the public through digitalisation, standardisation, and system integration in healthcare facilities. The Indonesia Health Services (HIS) is a digital healthcare ecosystem platform that provides data connectivity, analytics, and services to support and integrate various healthcare applications in Indonesia (Ministry of Health, 2021).

Before the COVID-19 pandemic, generally, large-scale hospitals, clinics, and health centres in Indonesia implemented an EMR-based system.

#### The Digital Healthcare Ecosystem in Indonesia

There are currently over 400 health applications in healthcare facilities in Indonesia and limited regulations in data standardisation and exchange, resulting in health data fragmentation and impact on the health system.

In 2017, BPJS (Badan Penyelenggara Jaminan Sosial) or The Indonesian National Health Insurance System launched the Mobile JKN application to improve services to National Health Insurance (JKN) participants. This application makes accessing related information and services more accessible for JKN participants. The features of this application include:

- The participant menu (participant features, participant card, change data, and registration).
- Billing menu (premiums, payment records, virtual accounts, and payments).
- Service menu (service history, service registration, and screening).
- General menus (JKN info, location, complaints and application settings).
- This mobile JKN is the first step in implementing E-PHR.

During the COVID-19 pandemic, the Indonesian Ministry of Communication and Information, in collaboration with PT Telkom, initiated the PeduliLindungi mobile phone application in April 2020. This application aimed to track sufferers, detect the spread of COVID-19, and identify close contacts between individuals to help stop the spread of COVID-19. PeduliLindungi also developed to access vaccine certificates and screening. The Pedulilindungi application was the main requirement for giving public permission when visiting several public facilities. COVID-19 test results from various laboratories and vaccine results were made immediately visible on PeduliLindungi and connected to the EHAC feature, Electronic-Health Alert Card or Electronic Health Alert Card.

PeduliLindungi was crucial in Indonesia's response to the COVID-19 pandemic. This application is widely used by the Indonesian population and is connected to healthcare facilities and public places. Its comprehensive features, including contact tracing, self-assessment, and vaccination registration, have significantly contributed to curbing the spread of COVID-19. As a result, Indonesia saw lower transmission rates compared to neighbouring and even advanced countries. For instance, PeduliLindungi prevented 3,733,067 individuals with a red status (indicating incomplete vaccination) from entering public spaces and prevented 538,659 black-status individuals (infected with COVID-19) from travelling domestically or accessing indoor public spaces (Widyawati, 2022).

After the COVID-19 pandemic, the PeduliLindungi application was transformed into SatuSehat. SatuSehat is a system connectivity platform that integrates personal health data as EHRs between health service organisations and supports health data interoperability through standardisation and digitalisation. It is hoped that the SatuSehat application can develop to become the forerunner of Electronic Personal Health Records (E-PHR) in Indonesia (Ministry of Health, 2023).

During the COVID-19 pandemic, the Indonesian government has also implemented successful protective care as one of the efforts to deal with COVID-19. The successful implementation of Peduli Lindung illustrates that the implementation of E-PHR will be realised.

MoH RI has formulated the 2024 Blueprint for Healthcare Digital Transformation, based on the spirit of collaboratively realising a Healthy Indonesia with all stakeholders in the healthcare industry within SATUSEHAT.

SATUSEHAT is a digital healthcare ecosystem platform that provides data connectivity, analysis, and services to support and integrate various healthcare applications in Indonesia. SATUSEHAT is built on six main principles: service-based platform, architectural and specification standardisation, collaboration with healthcare industry ecosystem players, Open API (Application Programming Interface) based on microservices, compliance through integration, and reciprocal benefits through integrated services and information.

E-PHR serves not only as a means of communication and information sharing between patients and healthcare professionals but also ensures individual health privacy (Gope and Amin, 2016). To create a structured E-PHR system based on a patient-centred approach that allows users to access their personal records from various healthcare points easily, evidence-based narratives are needed to inform advocacy tools with the Indonesian government to adopt the recommended E-PHR model and contribute to legislation regulating E-PHR.

The implementation of E-PHR will greatly aid the Ministry of Health of the Republic of Indonesia (MoH, RI) in its efforts to revitalise promotive and preventive programs, particularly through primary care integration. These efforts are believed to improve public health status in line with the primary pillar of the healthcare system transformation (Ministry of Health of the Republic of Indonesia, 2021).

The study aims to outline the challenges and opportunities in advancing from EMRs, where the ownership is with health service organisations, to E-PHRs, where the ownership is with the patient.

This shift is crucial for enhancing patient engagement, improving health outcomes, and ensuring comprehensive and continuous personal health management.

#### 1.2. Research Objectives

- 1. Mapping paradigms and operationalizing digital health transformation on a global scale, along with some global E-PHR experiences.
- 2. Mapping the digital healthcare system in Indonesia and its disparities related to E-PHR.
- 3. Recommending an E-PHR framework that aligns with the conditions and social and governmental systems in Indonesia.
- 4. Building an evidence base for the adoption of E-PHR in Indonesia.

#### II. Method

The research method used in this study is Scoping Review. This method was chosen to understand the characteristics of E-PHR, map E-PHR, and explore E-PHR implementation (Munn et al., 2018). This research is supported by searching grey literature, workshops with relevant stakeholders, and compiling a report. The research stages are as follows:

#### 2.1. Scoping Review

Before E-PHR development, a Scoping Review was carried out. Based on the narrative review that has been carried out, a systematic and scoping review of E-PHR has previously been carried out. The current scoping review has several differences from the scoping or systematic reviews that have been previously carried out. This scoping review focuses on E-PHR development in a country, not E-PHRs used by individuals.

In the previous scoping or systematic review, E-PHR focused more on individual health services. Previous scoping or systematic reviews were more about E-PHR in individuals, in contrast to the results of this study which focused on countries (Table 3). The results of studies on E-PHR related to individuals are briefly explained in the Appendix (Table A). The detailed activities of the Scoping Review are as follows:

- a. Defining research questions and objectives.
- b. Establishing eligibility criteria (inclusion and exclusion) based on Population, Exposure, Outcome, and Study (PEOS). The determination of eligibility criteria (inclusion and exclusion) in the E-PHR Scoping Review is as follows:

Table 1. Inclusion And Exclusion Eligibility Criteria For E-PHR Scoping
Review

Criteria	Inclusion	Exclusion
Source	PubMed, ProQuest, ScienceDirect, Scopus, Embase	Other database
Dates	October 2012 - October 2023	Review published before or after this period
Language	English and Indonesian	Other languages. Due to limitations in the language mastered by researchers
Population	Government/country	-
Exposure	E-PHR, medical record, electronic health records, national health information infrastructure	-
Comparative	-	-
Outcome	The model, function, and function of E-PHR,	
Study/studies	All studies	-
Type of Publication	Academic Journal and availability of documents and published through the area of public health, policy brief	Other publication

- c. Searching the literature to capture all articles that match the research questions.
- d. Selecting studies to conduct a screening of the captured articles that are relevant to the research questions. The study selection process was carried out manually. The researchers managed bias by establishing clear inclusion and exclusion criteria to ensure consistency, involving multiple reviewers for transparency and accountability.
- e. Performing data extraction to highlight information relevant to the research questions and the PEOS (Population, Exposure, Outcome, and Study Design).

- f. Synthesising the selected studies by making general conclusions from the extracted data from all the chosen articles.
- g. Presenting and reporting Scoping Review data following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) flowchart (Tricco et al., 2018).

#### 2.2. Conducting A Literature Review Through Grey Literature

Searching for grey literature is the process of seeking, collecting, and analysing sources of information that are not available in official academic publications or conventional literature. In this research, the search for grey literature involves looking for literature that doesn't fit the PICOS framework but is essential for discussing E-PHR.

#### 2.3. Organising A Workshop With Relevant Stakeholders

The E-PHR development workshop for Indonesia serves to refine the research findings and serves as a means of disseminating the research results. In this study, the workshop involves stakeholders, namely, the Badan Penyelenggara Jaminan Sosial (BPJS) and the Digital Transformation Office (DTO) of the Ministry of Health.

#### 2.4. Preparation of The Final E-PHR Research Report

The preparation of the final report is a process for presenting the findings, methodology, and research results, as well as providing recommendations based on the research conducted.

#### 2.5. Assignment of Research Personnel's Roles

**Table 2. Assignment of Research Personnel's Roles** 

Assignment	Principal	Team						
, isolgimient	Investigator	1	2	3	4	5	6	
1. Research Preparation	√	√						
2. Preparation of Inception report	√		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\sqrt{}$	
3. Scoping Review:		$\checkmark$					$\sqrt{}$	
a. Defining Scoping Review Questions and Objectives								
<ul> <li>b. Establishing Eligibility Criteria         (Inclusion and Exclusion) based on         PEOS (Population, Exposure,         Outcome, Study design)</li> </ul>	√	√	√	√	√	√	√	
c. Literature Search		<b>V</b>	$\sqrt{}$	$\checkmark$	$\checkmark$	$\checkmark$	$\sqrt{}$	
d. Study Selection		$\checkmark$	$\checkmark$	$\checkmark$			$\sqrt{}$	
e. Data Extraction		$\checkmark$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	
f. Study Synthesis		$\checkmark$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	
g. Presentation of Scoping Review Data following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)	√	√	√	√	√	√	√	
4. Workshop on the Development of E- PHR in Indonesia	√	√	√	√	√	√	<b>√</b>	
5. Preparation of the E-PHR Research Report	√	√	√	√	√	√	√	

#### 2.6. Activity Schedule

No	Activities	Time
1	Signing of TOR (Terms of Reference) and SPK	5 – 12 Dec 2022
	(Work Order)	3 – 12 Dec 2022
2	Research Team Preparation Meeting	5 – 12 Dec 2023
3	Inception Report Drafting	5 – 12 Dec 2023
4	Finalisation of Inception Report	19 – 24 Dec 2023
5	Data Collection (Literature Search)	2 Jan – 4 March 2023
6	Ethical Review	6 February – 4 March
7	Study Selection	6 March – 4 June 2023
8	Synthesis	5 June – 31 July 2023
9	Report Preparation-PHR Workshop	1 August – 2 Sep 2023
10	Interim Report	4 – 30 September
	miceriii Keport	2023
11	Final Report	16-30 October 3023

## **III. Scoping Review Results**

## 3.1. Preferred Reporting Items For Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR)

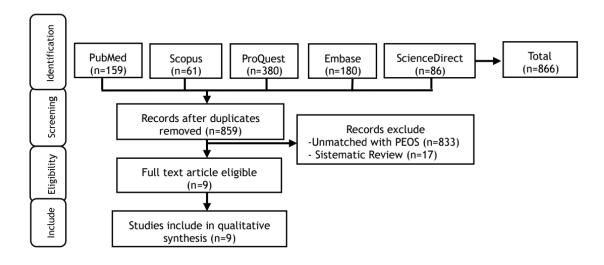


Figure 3.1 Diagram PRISMA Scoping Review

**Table 3. Articles Selection: Result of Soping Review** 

No	Title of the Article	Author	Year of	Country	Research	Results
			Data		Design	
			Collection			
	Digitising health services by implementing a personal electronic health record in Germany: Qualitative analysis of fundamental prerequisites from the perspective of selected experts	Matthies LM, Grundstein F, Szecsenyi J, Ose D, & Wensing M. (2020).	2015	Germany	Qualitative Analysis	Integration between the healthcare system and technology is a fundamental prerequisite. The importance of data privacy and security, patient and stakeholder transparency, as well as adequate support and training for healthcare staff cannot be overstated.  To make E-PHR (Electronic Personal Health Records) successful, existing healthcare practices must first be rationalised, simplified, and redesigned. According to experts, the appropriate approach is to structure the digital environment. Paper forms and templates with four carbon copies should not be electronically duplicated. Experts suggest that anyone mentally entrenched in the paper-based world will struggle to realise the advantages of the digital realm.
						The initial phases of digitalisation in healthcare services primarily focused on collecting and
						digital data storage, while the digitalisation of
						relevant care processes was not considered.
						Before E-PHR implantation can occur, the
						uncontrolled growth of different standard

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
						operating procedures in file systems must be halted.
						In addition to interoperability as a critical prerequisite for the digitalisation of healthcare in general and E-PHR implementation in particular, clear political will, laws, procedures, and appropriate incentive structures are emphasised.
						From the expert perspective, E-PHR is generally seen as desirable and inevitable. At the same time, several implementation challenges in Germany have been outlined. Three key themes emerge: (1) documentation standards - the processes that apply in the world of analog bureaucracy, (2) interoperability - the plurality of actors and electronic systems, and (3) political structure - the lack of clear political regulations and political incentive structures.
						In conclusion, regarding the implementation of E-PHR, a crucial prerequisite for digitalisation success is the precedent of system reform to be digitised. Whether the recently enacted Act for Faster Appointments and Better Care will be a step in the right direction remains to be seen.

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
2	E-Health in Belgium, a new "secure" federal network: Role of patients, health professions and social security services	Francis Roger France	2010	Belgium		<ul> <li>The health platform complies with the regulations applicable in Belgium, in accordance with the Law of August 21, 2008.</li> <li>Main objectives: (1) to optimise the quality and continuity of healthcare services and patient safety; (2) to simplify administrative tasks; and (3) to contribute to public health policies.</li> </ul>
						<ul> <li>Technical security aspects: by using Identification Numbers in the form of chip cards (identity and social security cards), eHealth provides software that allows reading the contents of the chip card through specific readers. Institutions can access eHealth through a "certificate" made up of 2 keys for authentication and signature for specific web access.</li> </ul>
						• Basic services of the platform (BSP): integrated management of user and author access, logging, end-to-end encryption, anonymization, and portals.
3	TreC platform. An integrated and evolving care model	Claudio Ecchera,* Lorenzo	2020	Italy		<ul> <li>TreC (Trentino Citizens Clinical Record) is an Integrated Care Model for patient empowerment and data storage, through</li> </ul>

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
	data repository	Giosb Alberto Zanuttoa Giancarlo Bizzarric Diego Confortid Stefano Fortia				<ul> <li>the Personal Health Record (PHR) platform used in Italy.</li> <li>TreC comes with a mobile application ecosystem (apps) and a web-based platform as well as a dashboard for patients and medical doctors/healthcare staff.</li> <li>Benefits: <ol> <li>Access to and management of services provided by healthcare providers (e.g., access to medical reports, payments)</li> <li>Collection and management of personal data (e.g., lifestyle, parameters measured with personal devices)</li> <li>Data sharing with healthcare staff for prevention and/or treatment purposes, including medical records, laboratory results, socio-demographic data, medical history, service utilisation.</li> </ol> </li> <li>TreC is designed for: <ol> <li>Prescription and self-care monitoring</li> <li>Telemonitoring of patients with chronic conditions</li> <li>Lifestyle promotion for chronic disease prevention.</li> </ol> </li> </ul>

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
						<ul> <li>Key actions in the Platform: <ol> <li>Management and delivery of online services for citizens (e.g., online medical records and reports)</li> <li>Management of remote healthcare assistance programs, including personalised and integrated programs.</li> <li>Launching online/application-based prevention campaigns (e.g., screening campaigns).</li> </ol> </li> <li>Planning and implementation of healthcare research using available data generated by new technology and Patient-Generated Health Data (PGHD) (e.g., data from wearable devices).</li> </ul>
						• TreC adopts the classical three-tier architecture, where the application logic, computer data storage, and user interface (presentation) are developed and maintained as independent modules on a separate platform. The main innovation lies in the multifaceted approach adopted for the TreC platform, using various elements and strategically embedding them within the e-government framework supported by the Trento Province, with the goal of

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
						ensuring adaptability and interoperability of the platform.
4	The development and deployment of electronic personal health records A strategic positioning perspective	Lewis, M Baxter, R Pouder, R	In-depth Longitudina I Case Study Methodolog y A two-year timeframe, but the starting date is not specified.	USA	In-depth Longitudinal Case Study Methodology A longitudinal case study that tracks the development and implementation of E-PHR over two years.	<ol> <li>Findings: Three strategic positions</li> <li>Targeting self-insured entrepreneurs.         Trade-off for Position 1 (data accessibility)</li> <li>Targeting Third-Party Administrators         (TPAs). Trade-off for Position 2 (innovation capacity and customer accessibility).</li> <li>Targeting corporate benefits and disease management. Trade-off for Position 3         (technical and relational scalability).</li> </ol>
5	Usability of WebbasedPersonal Health Records:An Analysis of Consumers Perspectives	Tiankai Wang,PhD, and Diane Dolezel, EdD, MSCS, RHIA	2013 – 2014	USA	Mixed methods	PHR (Personal Health Record) helps patients make decisions based on their health and wellbeing information, allowing healthcare providers to access patient health information to provide optimal and safe care. Web-based applications enable users to access information anytime and from anywhere. Therefore, web-based PHRs can be a future trend in PHR development. Researchers studied the usefulness of web-based PHRs by comparing retrospective USE survey data on two PHRs and concluded that Microsoft HealthVault received higher user evaluations in most categories.

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
						Other developers of web-based PHRs may refer to Microsoft HealthVault for better usability development. Future research may explore additional web-based PHRs and provide a more comprehensive evaluation.
6	The health literacy demands of electronic personal health records (E- PHRs): An integrative review to inform future inclusive research Science direct	Hemsley B, Rollo M, Georgiou A et al	2015		Integrative Review	Results: E-PHR generates various demands for health literacy, both for patients and healthcare providers. Patient participation in E-PHR depends not only on the level of education and computer literacy but also on attitudes towards sharing health information, executive function, verbal expression, and understanding of oral and written language.
						Demands related to health conditions: The study mentions very little information on how the health condition itself (i.e., signs, symptoms, features, or disorders related to the health condition) directly impacts someone's health literacy or the use or benefits of E-PHR.  Demands on activities and the E-PHR environment: The use of E-PHR inherently involves various activities and the use of technology in the environment (i.e., tools and equipment) and support from other

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
						providers supporting E-PHR usage and assistance from others in using technology), so these findings are reported together.  Findings related to knowledge and education indicate that everyone, regardless of their educational level, will require instruction and information support regarding medical jargon and terms used in E-PHR because this can be challenging to understand. Information about E-PHR needs to be communicated at an educational level suitable for those with reading
7	Adoption of Electronic Personal Health Records in Canada: Perceptions of Stakeholders	Marie-Pierre Gagnon, Julie PayneGagno n, Erik Breton, Jean- Paul Fortin, Lara Khoury, Lisa Dolovich,	2013-	Canada	Qualitative Analysis	Imitations.  There is no agreed-upon definition of E-PHR in Canada. Factors that can influence the implementation of E-PHR are related to knowledge (confusion with other Electronic Medical Records [EMR] and lack of awareness), system design (usability and relevance), user capacity and attitude (health literacy, patient education, and interest, support for professionals), environmental factors (government commitment, target population), and legal and ethical issues (information control and storage, confidentiality, privacy, and security).

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
8	Factors Affecting Usage of a Personal Health Record (PHR) to Manage Health	Jessica Taha	2013	Miami, USA		<ul> <li>Participants in both age groups experienced significant difficulties in using PHRs to complete routine health management tasks.</li> <li>Elderly individuals, especially those with lower numeracy and technology skills, faced greater challenges in using the PHR system.</li> <li>Cognitive ability in predicting individual task performance varied with task complexity.</li> <li>Recommendations: It is essential to consider crucial factors in PHR design to meet the needs of middle-aged and elderly adults.</li> </ul>
9	Design Guidelines for Effective Occupation-Based Personal	Mahesh Fernando, Colin Fidge, Tony Sahama	2020	Australia	Data Collection through Qualitative and Quantitative Methods.	<ul> <li>Features that can make the PHR system user-friendly and motivate users to use it:</li> <li>1. Connection between Health and Work: The importance of linking individual health information to their work-related aspects. This is beneficial for understanding the impact of work on health and providing relevant support.</li> <li>2. Interaction Design Guidelines: Detailed guidelines for effective interface design. This includes how to display structured</li> </ul>

No	Title of the Article	Author	Year of Data Collection	Country	Research Design	Results
						health information, how to enable users to link health issues to specific work tasks, and how to make the system intuitive and user-friendly.  3. Security and Privacy: Ensuring the security and privacy of sensitive health data is crucial. The guidelines also discuss ways to protect this information from unauthorised access.  4. Interoperability: The importance of systems that can integrate with other systems, such as electronic medical records or workplace health management systems.  5. Effective Data Management: These guidelines emphasise how to manage data properly, including secure storage, proper maintenance, and allowing appropriate access.  6. User Engagement: It's important to involve users in the design process. By understanding user needs and preferences, the system can be more relevant and useful.

## 3.2. The Results of The Literature Search Beyond The Scoping Review On E-PHR

The scoping review identified several articles that did not meet the established criteria. However, these articles are related to E-PHR in a specific country, which serves as the basis for further investigation into the development of E-PHR in each country (Table 4).

Table 4. Literature Search Beyond The Scoping Review On E-PHR

No	Articles	Authors	Year	Country	Name of E-PHR	
1	My [Electronic] Health Record" – Cui Bono (For Whose Benefit)?	Mendelson D, Wolf G	2016	Australia	My Health record	
2	The use of regional platforms for managing electronic health records for the production of regional public health indicators in France	Metzger MH, Durand T, Lallich S, Salamon R, Castets P	2012	France	medical record/ dossier medical partage (DMP) French personal	
3	Ten years of structural reforms in Danish healthcare	Christiansen T	2012	Denmark	The Danish National eHealth Portal/sundhed.dk	

This scoping review found out how E-PHR operated and the characteristics of the features developed in each country. A more detailed explanation was as follows.

#### 3.2.1 The Operationalisation of E-PHR At The Global Level

In its implementation, there are three types of E-PHR (Nøhr *et al.*, 2017; Alsahafi and Gay, 2018):

1) **Standalone E-PHRs:** Users are responsible for creating and maintaining their own health information. This type of E-PHR is stored on personal

- computers or on the internet and is used to monitor and track various health-related aspects, such as physical exercise and food consumption.
- 2) **Tethered E-PHRs:** Consumers are allowed to access information stored by healthcare providers.
- 3) **Integrated or unified E-PHRs:** The collection and display of health information comes from various sources, including multiple healthcare providers, and can be used regionally or nationally. This system allows healthcare consumers to control information, add or modify some information, or even restrict who can access specific information in their E-PHR.

Based on their functions, E-PHRs can include the following (Pagliari, Detmer, and Singleton, 2007; Nøhr et al., 2017):

- 1) Access to electronic clinical records from providers (summary or detail), such as medical history, diagnoses, medications, test results, immunizations, outpatient and inpatient summaries, and referral letters.
- 2) Personal health diaries or journals, including clinic visits, doctors, tests, dates, non-prescription treatments, and scanned documents.
- 3) Self-management support, such as treatment plans, symptom tracking, passive biofeedback, instructive or motivational feedback, decision support tools, or reminders.
- 4) Secure patient-provider communication for scheduling appointments, prescription refills, or seeking advice (e.g., patient-doctor emails).
- 5) Links to static or interactive information about diseases, treatments, or selfcare.
- 6) Links to support sources, such as patient organisations or virtual peer networks. Data collection of symptoms or health behaviours through self-reporting or objective monitoring via electronic devices (fixed or portable).

From the results of the scoping review, it was found that the E-PHR has been in use for a long time in various countries, starting in 2010 in France. The implementation of the E-PHR starts with national planning in each country, with support from policymakers who establish laws and regulations related to the E-PHR. The development of the E-PHR involves various stakeholders,

including government entities, private organisations, and health insurance providers.

The E-PHR platforms established and developed in various countries are primarily web-based, and some are equipped with mobile applications. In its implementation, multiple parties are involved in data entry and usage, including government bodies, service providers, academics, and even individuals who have the right to access and manage their own clinical data.

Implementing E-PHRs is necessary not only for documentation but also to optimise the quality and continuity of healthcare services. E-PHRs are integrated with service provider information systems to combine personal record storage, access to electronic health records, and various information and communication functions. Technology readiness, human resources, and interoperability are required for system integration into E-PHR.

# 3.2.2 Features of E-PHR In The Literature Review

Table 5. Usage/ Features In E-PHR

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
My Health Record	Australia	Launched in 2012, in 2019 it was allocated for all Australian residents.	90,1%	Website	There are two users:  a. Healthcare providers access information about consumers, including vaccination, allergies, medical conditions, medications, advanced care documents (health summary based on advice and guidance, treatment plans, specialist letters), and they can test or scan results. In Queensland, Health Care Providers can view My Health Record using The Viewer application (available in all Queensland Health facilities) and the integrated Electronic Medical Record (ieMR).  b. Consumers control the information in their "My Health Record," including the ability to permanently delete "My Health Record" at any time.  c. Consumers can choose whether they have a "My Health Record"	My [Electronic] Health Record" – Cui Bono (For Whose Benefit)?  Nationwide citizen access to their health data: analysing and comparing experiences in Denmark, Estonia and Australia  https://www.digitalhealth.go v.au/ https://www.health.qld.gov. au/

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features Source of Reference
					or not, who can access it, delete or restrict documents from viewers, receive notifications when their records are accessed via text or email, decide what information is sent to "My Health Record," and provide imaging for withdrawal approval. They can also nominate someone to access/manage their records on their behalf.  d. Queensland: My Health Record data is sourced from authorised parties such as Phillips,  BreastScreen Queensland for medical data, AUSLAB for pathology, CIMHA for mental health, eLMS for medication records, and ieMR for debit summaries.
dossier médical partagé (DMP)	France	The idea was conceived in 2004, and the design process began in 2007. The DMP blueprint was established in		Website	DMP (Dossier Médical Partagé) is a centralised patient-controlled record, created according to an optin consent model, which contains documents that healthcare practitioners voluntarily push from their EHRs. It is designed to track key elements of a patient's clinical path

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
		nine locations			to enable better coordination among	
		in 2017, and it			healthcare professionals involved in	
		was fully			patient care management. Some key	
		implemented			elements to be included in the DMP	
		on September			are hospital reports, laboratory	
		27.			results, X-ray results, prescribed	
					medications, primary care	
					summaries, and other relevant	
					information that doctors find useful	
					for coordinating patient care.	
					Patients can also copy or upload	
					data to specific sections of the DMP.	
					The most important decision is to	
					entrust the DMP project to the	
					national public health insurance	
					system (Caisse Nationale	
					d'Assurance Maladie des Travailleurs	
					Salariés, or CNAMTS), which is a	
					powerful institution with significant	
					autonomy.	
The Danish	Denmark	Starting in	In the first	Website	Sundhed.dk is an integrated part of	Nationwide citizen access to
National		2003, in 2009, a	quarter of		the national economic negotiations	their health
eHealth		new technical	2019, there		and national eHealth strategy in	data: analysing and
Portal /		platform was	was an		Denmark, operating at three levels of	comparing experiences
sundhed.dk		launched.	average of 3.9		governance: state, region, and	in Denmark, Estonia and
			million total		municipality, and is organised within	Australia
			visits per		two structures: the 'primary	
			month (from		healthcare sector' (general	https://www.sundhed.dk/

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
			both citizens and healthcare professionals)		practitioners, home care, pharmacies) and the 'secondary healthcare sector' (hospitals). Sundhed.dk is structured in two spaces: the 'open space' and the 'closed space.' Sundhed.dk offers 24/7 access to personal health data and general information on health prevention and diseases for citizens and healthcare professionals, free of	European Observatory on Health Systems and Policies & Petersen, Morten E. (2019).  Achieving better health and well-being via the Danish e-Health portal sundhed.dk. Eurohealth, 25 (2), 20 - 23.  World Health Organization. Regional Office for Europe.
					The 'open space' offers evidence-based information for free (free from commercial influence), such as medical handbooks, to improve health literacy and explain terminology that may appear in Electronic Health Records (EHRs) or other medical literature, and health promotion.  The 'closed space' can only be accessed with secure login and provides access to personal health	Regional Office for Europe.
					data. Citizens enter "My Health," which provides oversight of individual prescribed medications, self-monitoring of medication	

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
					compliance, EHR, hospital visit notes,	
					X-ray and scanning descriptions, and	
					vaccination summaries. Additionally,	
					all laboratory test results and	
					consultations (video consultations)	
					with hospitals and other primary	
					healthcare professionals, including	
					dentists, are available. They can also	
					register as organ donors and gain	
					access to the local disease	
					management system at outpatient	
					clinics, the shortest waiting lists for	
					surgery, and hospital quality ratings.	
					A new feature is the ability to grant	
					authorization to relatives or trusted	
					individuals to access one's personal	
					health records, allowing family	
					members and informal caregivers to	
					provide necessary support when	
					needed.	
					The Danish eHealth Portal also	
					provides free access to a directory of	
					healthcare institutions in Denmark	
					and several health-related	
					encyclopaedias, facilitating	
					communication among stakeholders	
					in the Danish Healthcare Services.	

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
The Central	Estonia	Started from			The central system of the Electronic	Nationwide citizen access to
Health		2008			Health Record (EHR) is a patient-	their health data: analysing
Information		maintained by			oriented system (based on a	and comparing experiences
System/		The			personal ID code, for every individual;	•
Personal		Estonian			doctors and patients). All records	Australia
Digital		Ehealth			should be linked using commonly	
History		Foundation.			accepted keys: personal code for	https://www.digilugu.ee/logi
www.digilug					citizens, institution code, and	<u>n?locale=en</u>
u .ee -as EHR					standard address representation.	
The Patient						Estonian Central Health
Portal					An epicrisis for each case (a brief	Information System and
					overview of the visit, medical history,	Patient Portal European
					diagnosis, treatment, examinations,	Commission –
					and recommendations) has been	https://ec.europa.eu/digital-
					collected and linked to the Medical	buildingblocks/wikis/display
					Image Bank, Prescription Centre,	/BLOG/2019/07/26/Estonian+
					and the healthcare service provider	Central+Health+Information
					system via X-road. Data in the	+System+and+Patient+Port
					central database can be viewed by	al
					all doctors treating the patient. All	
					access will be logged and only	
					allowed for licensed healthcare	
					providers.	
					A specialised service portal for	
					patients is called the Patient Portal.	

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
					Everyone can view their own	
					personal data. A patient can also	
					search for information about their	
					children (up to 18 years old) or others	
					if specifically allowed. There are	
					several services available for patients:	
					Contributions, distribution of rights	
					for family members to open or close	
					data, data closure for doctors) across	
					Estonia. Patients can appoint	
					representatives for themselves, and	
					for those representing others, they	
					can act on behalf of those who have	
					appointed them as their	
					representatives. Patients can view	
					treatment invoices, prescriptions,	
					and who has accessed their data.	
					The Patient Portal also includes	
					information about one's general	
					practitioner and health insurance. It	
					is possible to add and modify	
					existing information, but not to	
					change information elsewhere	
					except in the Patient Portal.	
					Features found in the Patient Portal	
					include a coronavirus analysis tool	
					developed by scientists at the	
					University of Tartu (Tartu Ülikool), a	
					health information system (including	

Application	Country	Year of	Participation	Platform	Description of Usage/Features	Source of Reference
		Development	Rate			
					medical data submitted by	
					healthcare providers about patients),	
					patient rights and data protection,	
					important topics (web pages where	
					consumers can find systemic	
					information related to health	
					management and healthcare), the	
					National e-Booking System, package	
					leaflets, and the Health and Welfare	
					Information Systems Center (TEHIK).	
NHS digital	United				<ul> <li>Your Health and Lifestyle</li> </ul>	https://web.archive.org/web
	Kingdom				Track your weight over time, set	/201110 08052216/https://
					your own goals, and then create a	<u>www.healthspace.</u>
					graph or print the results. You can	nhs.uk/visitor/visi
					also keep important notes about	<u>tor_diary.aspx</u>
					your health and record any	
					allergies you may have.	https://www.nhs.uk/
					<ul> <li>Lifestyle Details</li> </ul>	
					Record your alcohol consumption,	
					smoking habits, and calorie	
					intake. You can also set targets	
					and create graphs to show your	
					intake over time.	
					<ul> <li>Medications</li> </ul>	
					Find your medications in our	
					medical dictionary, then add	
					dosage details, frequency, start	
					dates, and other important notes	

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
					<ul> <li>to HealthSpace.</li> <li>Blood Monitor your blood pressure, blood sugar, cholesterol, and save your blood type.</li> <li>General Fitness You can keep track of your fitness measurements by recording resting heart rate and maximum heart rate or lung capacity.</li> <li>Calendar and Address Book Use the calendar to track appointments and events, or the address book to store your NHS contacts, such as your general practitioner, dentist, or local pharmacy.</li> <li>Summary Care Record (SCR) Contains important information taken from the electronic medical records stored by the NHS for you. This information can assist those caring for you, especially in emergency situations.</li> </ul>	
Depends on	United				Citizens can access their medical	https://www.healt hit.gov/ -
citizens. The Office of the	states				records from online patient portals provided by healthcare institutions	The Guide to Getting & Using
National					such as USAHealth (University of	Your Health Records
Coordinator					South Alabama) based on the	

Application	Country	Year of	Participation	Platform	Description of Usage/Features	Source of Reference
		Development	Rate			
for Health					location where the patient received	https://www.myh
Information					care; MyChat Patient Portal (Hospital	<u>ealth.va.gov/</u>
Technology					for Special Surgery, New York);	
(ONC)					TRICARE Online (for active duty	https://www.healt hit.gov/ -
mentioned					members); MyHealtheVet (for	The
some digital					veterans); and My Medicare Gov (for	Guide to Getting & Using
tools					individuals with Medicare coverage).	Your Health Records
including The						
Patient					An individual may have several	
Portal,					patient portals from all the places	https://www.medi
The Personal					where they receive care, including	<u>care.gov/</u>
Health					their primary care physician,	
Record					hospitals, specialists, pharmacies,	https://www.usah
(PHR) and					laboratories, and their insurance	<u>ealthsystem.com/</u>
The Health					providers. Each of these portals	
Арр					requires a username and password.	
					Many Personal Health Records	
					(PHRs) give individuals the option to	
					add information they deem relevant	
					but may not be in possession of by	
					their doctors, such as over-the-	
					counter medication information,	
					exercise habits, or sleep schedules.	
					Generally, these PHRs are not	
					connected to employers, healthcare	
					systems, or insurance companies.	
					These systems are usually web-	

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
					based and available for free or with a minimal subscription fee.	
Healthhub	Singapor e			Website and mobile apps	minimal subscription fee.  For instance, features in MyHealtheVet include pharmacy information, appointment scheduling, messaging, and health records.  Mobilising family physicians to provide preventive care to citizens; developing health plans that include lifestyle adjustments, routine health checkups, and appropriate vaccinations to be discussed by doctors with citizens; engaging community partners to support citizens in adopting a healthy lifestyle; launching a national registration program for citizens to commit to seeing one family doctor and implementing a health plan; preparing the necessary supporting factors like IT infrastructure, workforce development plans, and financing policies for the Healthier Singapore to function for individuals, children, and designated family members.	https://www.healthhub.sg/HealtheServices

Application	Country	Year of Development	Participation Rate	Platform	Description of Usage/Features	Source of Reference
					<ul> <li>Personal appointment</li> <li>Notes</li> <li>Healthier SG</li> <li>Immunisation</li> <li>Lab Test Results</li> <li>Medical Alerts &amp; Adverse Drug Reactions/Drug Allergies</li> <li>Screenings</li> </ul>	
					Disposal Information     Track Health Vital Signs     Medical Reports/Certificate Requests	
					Health Risk Assessment	
					Medications  • Medications  • Medication Refills	
					Billing  • Financial Consent  • Payment  • Admission	

The patient portal is a core feature in each of the E-PHR systems reviewed above. One of the core features of the patient portal is the summary of in- and outpatient visits that healthcare providers must submit to a central platform. Based on the research results of Nohr, et al (2017), the functionality of each patient portal has three characteristics and types of communication levels that support each function. The three levels of communication types are (Table 6).

- a. Level 1 One-way Communication The public can read information produced by health authorities or individual health care providers.
- b. Level 2 Two-way Communication Citizens can change existing information, receive reminders, make appointments, and renew prescriptions.
- c. Level 3 Communications currently under development.

Table 6. Functionalities of Patient Portals In The Countries of Australia, Denmark, And Estonia

Functionality available	Denmark	Estonia	Australia
Permissions for access	Opt-out	Opt-out	Opt-in
Non-medical information	Read and modify (Level 1)	Read and modify (Level 1)	Read and modify (Level 1)
Permissions and requests <sup>a</sup>	Read and modify (Level 1)	Read and modify (Level 1)	Read and modify (Level 1)
Immunization	Read and modify (Level 1)	Read (Level 2)	Read (Level 2)
Prescriptions	Read and renew (Level 1)	Read (Level 2)	Read (Level 2)
Outpatient Care summaries	Read (Level 2)	Read (Level 2)	Read (Level 2)
Referral letters (if applicable)	N/A	Read (Level 2)	Can be uploaded (Level 2)
Inpatient Care summaries	Read (Level 2)	Read (Level 2)	Read (Level 2)
Diagnostic laboratory tests	Read (Level 2)	Under development (Level 3)	Read (Level 3)
Diagnostic images	Not available to citizens (Level 3)	Read (Level 3)	Read (Level 3)
Appointments to primary care, secondary care physicians.	Read and book (Level 1)	Under development (Level 3)	
Log data on access	Read (Level 2)	Read (Level 2)	Read (Level 2)

<sup>&</sup>lt;sup>a</sup>Read and modify one's official representative(s). He or she has the right to read, modify data and/or fill in prescriptions depending on the extent of the rights given. Read and alter one's volition or declination to donate organs, receive blood transfusion and donate one's body to medical research. A Person has the right to take back the volition at any time, the volition in compulsory for physicians to abide by

Data security in e-PHR is critical. Countries that already have e-PHR have security procedures using two-factor authentication or personally generated passwords. The two primary users who use e-PHR are citizens and health workers

with their respective powers and rights. Every citizen with an e-PHR must also protect personal data by reporting suspicious behaviour from their e-PHR account (Table 7) (Nohr, 2017).

**Table 7. Security Log-in Procedures In E-PHR** 

Log in and security issues	Denmark	Estonia	Australia
What is the log-in procedure	Two factor authentication	2 factor PKI combined with an electronic identity	MYGOV generated Number; Personally Generated Password; Security Name or Number (via Mobile Phone)
Who has access?	The citizens can access own data. Health professional can access data of patients they treat	The citizens can access own data. Health professional can access data of patients they treat	The citizens can access own data. Health professional can access data of patients they treat
How is security controlled?	Letter send in case of suspected abuse. Citizens control own log. Bi-annual audits of log files	Citizens are expected to report suspicious behaviour to the E-Health Foundation	Citizens are expected to report suspicious behaviour to the E-Health Foundation
User support	Only technical and navigation questions.	Only technical and navigation questions.	Only technical and navigation questions.

Adapted from Nohr, et al (2017)

Each country has designed a different E-PHR architecture.

Here are examples of **E-PHR architectures in Denmark, Estonia, and Australia** (Nohr, 2017).

#### a. Denmark

Data is generated in primary care and specialty practices, hospital patient administration systems (PAS), and hospital EHR systems. Most GP data is sent to the Danish General Clinic Quality Department (DAK-E) and made available to patients through Sundhed.dk.

Data from the hospital's PAS and EHR systems will be transferred to a repository database (E-Record database) and made available to the public, family physicians, and other hospitals.

Patient data is delayed by two weeks for ethical reasons, and healthcare providers can only access data for the patients they treat.

The nation and its general practitioners access data via his Sundhed.dk, and hospitals access electronic records browsers via his secure National Health Data Network.

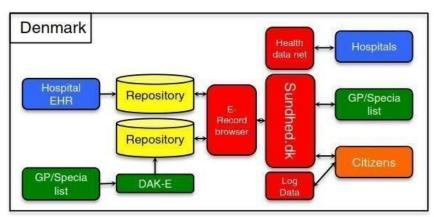


Figure 3.2. E-PHR Architecture In Denmark

# b. Estonia

Data is created in the hospital or GP/ specialist information system and stored in the country's EHR. Prescription data is stored at the Prescription Centre. Additional information about the citizen is collected from other state registries and can be accessed by both health care providers and the citizen through her PP (such as contact details and existing health insurance).

Data collected from various sources is made available to the public, general practitioners, hospitals and clinics through the patient portal (digilugu.ee).

However, most hospital information systems and some primary care physician information systems integrate with PP, so physicians do not need access to a web-based solution.

Information will be presented without delay. Additionally, a specialist who is unable to set up his own information system can access his e-health data through the government-provided doctor portal.

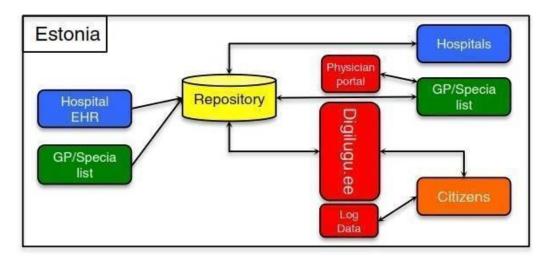


Figure 3.3. E-PHR Architecture In Estonia

#### c. Australia

Clinical data is generated and stored in primary care, specialist, and hospital systems, and summary data is transferred to the MyHR system. A variety of data sources, both public and private, are used to provide a comprehensive overview data set. A central MyHR infrastructure manages the location and transfer of data from distributed systems.

There are a number of repositories set up to collect and store this clinical data, and while there are also links to other organisational repositories, there is no way to directly query an individual organisation's EHR, only his aggregated EHR.

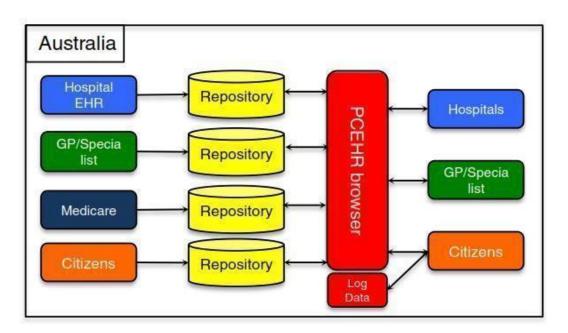


Figure 3.2. E-PHR Architecture In Australia

Handling and exchanging data in E-PHR involves many parties. Table 8 provides an example of e-PHR data handling and exchange in Estonia. Citizens as consumers have a role in health data, health documents are facilitated by health care providers (hospitals, doctors, etc), registries are controlled by the National Health Information Systems, and processors are held by Health and Welfare Information Systems Centre (former Estonian eHealth Foundation; (https://ec.europa.eu/).

Table 8. Handling and Data Exchange In E-PHR

Stakeholder name	Stakeholder type	Stakeholder role	Kind of data
Health Information System (TEHIK)	Government	Database owner	Health data
Population Register	Government	Database provider	Personal data
Business Register	Government	Database provider	Business
Universities, Scientists	Citizen	Data consumer	Health data
Address Data System	Government	Database provider	Address data
Health Care providers (GP, Hospital, Emergency service, Dentists IS)	Business	Data recorder	Health data
Medicines Coding Centre (State Agency of Medicine)	Government	Database provider	Semantic data
Registre of Handlers of medicines – Licences of	Government	Database provider	Licences data
Pharmacies and pharmacists (State Agency of Medicine)			
Health Insurance Status Register (Health Insurance Foundation)	Government	Database provider	Insurance data
Health care providers Register (Health care Board)	Government	Database provider	Providers data
Health professionals Register (Health care Board)	Government	Data consumer	Data about professionals
Statistics Portal	Government	Data consumer	Statistics data
HIS X-Road MISP – Portal for GP	Business	Data recorder	Health data
HIS X-Road MISP – portal for Emergency Mobile Stations	Government	Data consumer	Health data
Prescription Centre (Health Insurance Foundation)	Government	Database owner	Health data

Stakeholder name	Stakeholder type	Stakeholder role	Kind of data
Medical Images Repository	Government	Database provider	Health data
Patient Portal	Citizen	Data consumer	Health data
Road Administration Board	Government	Data consumer	Health data
Social Security Board	Government	Data consumer	Health data
Health Insurance Foundation	Government	Data consumer	Health data
Medical Registries (Cancer Register) – National Health Development Institute	Government	Data consumer	Health data
Medical Registries (Infection Diseases register) – Health Care Board	Government	Data consumer	Health data
State Information Board (X-road, eID, Mobile-ID, ID-card)	Government	Data supervisor	Governance data
Citizen as Patient (via <u>www.eesti.ee</u> or <u>www.digilugu.ee</u> )	Citizen	Data consumer	Health data

# 3.3. Key Learnings From The Scoping Review for E-PHR Implementation In Indonesia

Some key learnings that emerged from scoping review relevant to planning and implementation of an E-PHR system in Indonesia:

- Infrastructure Challenges: Indonesia should have an E-PHR architecture that will be built and ensure internet connectivity in urban and rural areas. In Indonesia, the building of the SatuSehat architecture is handled by the Ministry of Health's digital transformation office (DTO) team. SatuSehat is expected to become an E-PHR in the future. Currently, SatuSehat is built as EHRs
- Regulatory framework: Understanding the legislative context governing health data privacy, security, and interoperability is critical to E-PHR

- deployment. Compliance with Indonesia's data privacy laws and standards is critical for establishing trust among users.
- User acceptance and engagement: Usability, perceived utility, and trust in the system all have an impact on adoption rates among both healthcare providers and patients. User acceptability and involvement are essential for a successful E-PHR implementation.
- Interoperability with existing Systems: E-PHR systems must be integrated with existing healthcare IT infrastructure, such as electronic medical records (EMRs) and hospital information systems (HIS), to ensure smooth data exchange and continuity of service.
- Sustainability and Scalability: Creating a sustainable business model and scalable infrastructure for E-PHR implementation supports the system's long-term viability and expansion to meet a growing population and changing healthcare demands.

# IV. Discussion

# 4.1. Medical Record And Health Information Policies In Indonesia

The healthcare information system in Indonesia is organised through a single health data in the healthcare field, which is a part of Indonesia's Single Data (Ministry of Health, 2022). Effective and efficient healthcare efforts are carried out through a healthcare information system organised by the central government, local governments, healthcare facilities, and individual or group communities. Health information system requirements must ensure reliability, including availability, security, maintenance, and integration by testing system fitness, maintaining data confidentiality, determining data access rights policies, obtaining system reliability certifications, and conducting periodic audits (Law No 17 of 2023 on Heath, 2023).

Several aspects have been improved in the Health Law, including the transition from a fragmented information system to an integrated one. The government agrees with the Indonesian People's Consultative Assembly (DPR RI) that various healthcare information systems need to be integrated into a national healthcare information system, making it easier for everyone to access their health data without compromising individual data protection. General and specific personal data protection, including health data and information, are regulated under Law No 27 of 2022 on Personal Data Protection. This law aims to protect personal data and the rights of personal data subjects, which refer to individual persons or corporations that possess personal data or, in other words, individuals who own personal data. Personal data is information about individual persons that is identified or can be identified, either directly or indirectly, through electronic or non-electronic systems (Law No 27 of 2022 on Personal Data Protection, 2022).

This is also stipulated in healthcare legislation. As a security measure, healthcare information system providers are obligated to ensure data and information protection. Therefore, when processing individual healthcare data, consent must be obtained from the data owner and/or compliance with other regulations. A patient's personal healthcare information is anything related to the findings of medical professionals and healthcare workers in the context of treatment and is documented in the patient's medical record. It is confidential,

and patients have the right to access the information contained in their medical records (Law No 17 of 2023 on Health, 2023).

Medical records are the foundation of medical services. They contain patient identification data, examination results, treatments, procedures, and other services provided to patients. Based on the Minister of Health Regulation (PMK) number 24 of 2022 regarding Medical Records, patient medical records are transitioning to electronic-based systems. Through this policy, healthcare facilities are required to implement electronic medical record-keeping for patient medical histories. The transition process planned by the Digital Transformation Office (DTO) should be completed no later than December 31, 2023. However, until now, the digital transformation of health in Indonesia is still ongoing and the research team does not know when this transition process is targeted to be completed.

The transition from the previous regulation, Minister of Health of the Republic of Indonesia Regulation No. 269/Menkes/PER/2008 concerning Medical Records, to the current Minister of Health of the Republic of Indonesia Regulation No. 24 of 2022 concerning Medical Records is based on healthcare needs, advances in science and technology, as well as legal service requirements. This regulatory change has resulted in the digital transformation of healthcare services, which must develop digital technology for the public and provide electronic medical records that prioritise data security and confidentiality (Ministry of Health, 2022). Medical record documents are owned by healthcare facilities, while the content of medical records belongs to patients. The content of medical records must be kept confidential by all parties involved in healthcare at healthcare facilities, even after the patient's death. The disclosure of medical records to other parties is done with the patient's consent (Law No 17 of 2023 on Health, 2023).

All healthcare facilities must integrate EHRs as part of the regulations supporting the implementation of Health Technology Transformation, constituting the 6th Pillar of Health Transformation. The goals of the medical record regulation are for all healthcare facilities to adapt and enhance their capabilities in providing healthcare services. In this context, healthcare facilities are also required to connect and integrate with the SATUSEHAT platform developed by the Ministry of Health. The steps to achieve this goal include facilitating healthcare facilities (especially Puskesmas) that lack sufficient resources to implement digitization.

According to the Ministry of Health, adopting EHR aims to improve healthcare management processes and patient safety at an affordable cost. Adopting EHR and technology for a country's healthcare priorities should ensure that the system's coverage extends to all citizens. e-Health/Health Informatics should become a public commodity that enables universal healthcare access and coverage. To achieve this, it is recommended that EHR implementation should be modular and/or incremental, starting with core components that represent the Ministry of Health's EHR Adoption Stages (Figure 4). This includes patient administration systems with demographics, structured diagnoses, procedural data, admission-discharge-transfer (ADT), and support systems for laboratory, pharmacy, and radiology services. More advanced components, such as clinical decision support (error checking and clinical protocols) and structured templates for physician documentation, should be implemented in subsequent stages when EHR is more mature.

# Figure 4: Indonesian Ministry of Health's EHR Definitions and Adoption Stages

EMR focuses on patient records within a single healthcare organisation, EHR encompasses a broader health history across multiple providers, and E-PHR is a personal health record controlled by the individual patient.

# **EHR includes:**

- 1) A longitudinal collection of electronic health information for and about individuals.
- 2) Direct electronic access to individual and population-level information by authorised users and only those authorised.
- 3) Provision of knowledge and decision support that enhances the quality, safety, and efficiency of patient care.
- 4) Support for efficient healthcare service delivery processes.

# EHR capabilities include:

- 1) Storage and retrieval of health information and data.
- 2) Result management.
- 3) Order management.
- 4) Clinical decision support.
- 5) Electronic communication and connectivity.
- 6) Patient support.
- 7) Administrative processes.
- 8) Reporting and population health.

# EHR in surveillance:

Countries should leverage EHR in routine disease and syndromic surveillance to improve timely, complete, and efficient reporting. Benefits may include the use of large-scale data aggregation, increased reporting completeness, improved public health response, and better contact tracing. The process should be tailored to each country's specific needs and requires resources, including staff.

# **EHR Stages:**

The Ministry of Health, through the Satu Sehat Technical Working Group (TWG), classifies EHR based on its functionality. This model has eight stages that increase in complexity, with each stage containing cumulative capabilities from the previous stages. The required capabilities for each stage are as follows:

- Stage 7: Basic Clinical Decision Support, Clinical Data Analytics
- Stage 6: Patient EHR Portal, Electronic Signatures
- Stage 5: Basic Clinical Decision Support, Medication Administration
- Stage 4: Clinical Instructions, Integration into Support Information Systems, Interoperability
- Stage 3: Discharge Planning, Care Plan, Progress Notes, Procedure
   Orders, Medication Dispensing, Standard Terminology

- Stage 2: Assessment, Results Management, Medication Prescription, Medical Summary
- Stage 1: Patient Registration, Encounters, Diagnoses
- Stage 0: EHR Not Yet Implemented

# 4.2. Data Security In Indonesia

The most crucial aspect of the healthcare information system, especially E-PHR, is data security. Legal provisions related to the protection of users' personal data are included in the Minister of Communication and Information Regulation No. 171 and 257, which regulates personal data. This refers to Government Regulation No. 71 of 2019 regarding the Implementation of Electronic Transactions Systems. Data security is also governed by Law No. 27 of 2022 on Personal Data Protection (MOCI, 2021), (UU No 27 of 2022).

One government effort to protect personal data is the use of One Time Password (OTP) in the PeduliLindungi application for the surveillance of Coronavirus Disease and vaccination. This application, launched in 2021, includes features such as Certificate Pinning, Security Information Event Management, anti-DDoS, which is monitored 24/7 (Kominfo, 2021). The PeduliLindungi app has since been renamed to the Satusehat app and is registered as a "strategic" electronic system provider (PSE) by the Ministry of Communication and Information, which ensures data protection and prevents personal data abuse. According to the Personal Data Protection Act (UU tentang PDP), PSE, which refers to application, portal, and website providers, are obliged to ensure data protection and prevent the abuse of personal data. To ensure data security, the Satusehat mobile app uses masking and data encryption (Antara, 2023).

# 4.3. Implementation of Electronic Medical Records In Indonesia

The digitization of medical records is expected to simplify patients' ability to complete and access their medical records. Likewise, healthcare facilities can access the electronic medical records of individuals, subject to the patient's consent. Patient data protection is ensured, not only within the systems

implemented by the Ministry of Health but also within healthcare service facilities.

Currently, the implementation of EMR in Indonesia faces several challenges. Among them are the availability of facilities, including systems and equipment, and inadequate human resources. The available devices need to meet the standards for implementing EMR based on their number and capacity. The internet network needs to be improved. There are still areas with poor signal and even areas where the internet still needs to reach. Human resources, not all health facilities have IT experts, and the digital literacy of health workers is also low. HR management needs to be maximised to be implemented and utilised accurately, so it requires the support of competent personnel in the technology field.

Indonesia also needs to address other challenges in EMR implementation, such as internet access or provider coverage, especially in remote areas far from urban centres. Many healthcare and non-healthcare professionals still complain about poor service from vendors, including inadequate follow-up on technical issues and insufficient training and support related to electronic human resources (ESDM) (Neng Sari Rubiyanti, 2023).

Apart from human resources and facilities, a significant consideration in implementing EMRs is the budget for implementation. Hospitals transitioning to electronic systems must be prepared to establish and operationalize the necessary infrastructure. To accomplish this, specific funding or budget allocation is needed for the sustainability of EMRs. In order to achieve this TH Indonesia in their Phase 2 strategy have defined an Objective where they aim to have an increase of 20% by the end of 2026 in investments for digital health transformation towards priority areas such as infrastructure, workforce training and technology development.

Currently, not all healthcare facilities are prepared to meet this requirement (basis for Health Informatics Research Cluster (HIRC) to conduct an E-PHR readiness study in Indonesia). Additionally, operational costs and the recruitment of expert human resources to support electronic system implementation pose additional expenses for hospitals. Hence, readiness and budget planning are of utmost importance.

# 4.4. Implementation of Electronic Health Records In Indonesia

Support for healthcare data and application development needs to be accompanied by a collective spirit to realise a healthy Indonesia collaboratively, enhance an integrated and sustainable healthcare system from the early stages of life in the womb to comprehensive healthcare services for the elderly. In developing an EHR or E-PHR system, challenges such as data protection and security must be considered. In this regard, advanced security and data protection systems, collaboration, and innovation from various stakeholders are needed to develop an electronic health record system that meets user needs to improve the quality of healthcare services for patients.

In EHRs implementation in Indonesia, concerns persist about the need for human resources with the capability to design, develop, and maintain applications, as well as analyse the requirements for the initial development of an information system. Additionally, the implementation of EHR requires the capability and willingness of human resources to use applications to aid in their work processes (Sudirahayu & Harjoko, 2016).

Furthermore, organisational alignment is still required, encompassing cultural values, decision-making, characteristics, leadership commitment, and strategies, including vision, mission, strategic plans, internal and external communication. Organisational capacity should include information management, clinical and administrative staff, training, workflow processes, accountability, finance, budgeting, patient involvement, IT management support, and IT infrastructure, all of which need attention (Khasanah, 2021).

# 4.5. Challenges In The Implementation of E-PHR In Indonesia

The challenge faced by Indonesia in implementing E-PHR is that human resources and infrastructure still need to be prepared.

In human resources, only some health facilities have IT personnel, and the digital literacy of health workers and the public still needs to improve. There needs to be more human resources available in each health facility based on their number and capabilities, both in primary and tertiary services. At the same time, the low digital literacy of most people, including patients as well as healthcare providers, remains a challenge.

In terms of infrastructure, only some health facilities have a good internet network or availability of devices; constrained by transmitters and geography, several areas in Indonesia still need to be improved. A large population with diverse geographical conditions is a challenge in completing infrastructure.

Further, no policy currently regulates the implementation of E-PHR, which means there are no incentives nor guardrails for implementing E-PHR in Indonesia.

# V. Conclusion

# 5.1 Paradigm and Operationalisation of Global E-PHR

At the global level, E-PHR represents the shift from physical personal health records to integrated electronic personal health records. Globally, E-PHR emphasises that health data is the right of its owner (the patient), and patients have the right to access their health data.

The operationalization of global E-PHR also highlights the importance of protecting personal data and patient health data through techniques like encryption, authentication, and access control.

E-PHR systems also support interoperability standards between various healthcare systems, such as hospital systems, primary health care, clinics, laboratories, and other healthcare services. In its implementation, global E-PHR ensures easy and secure access to health data, for example, through web portals or mobile applications that easily connect patients to their E-PHR.

# 5.2 Development of E-PHR In Indonesia

Indonesia is currently undergoing a National Healthcare System Transformation that adopts technology to improve healthcare services for the public, including enhancing public access to their own health data. The Indonesian Ministry of Health (MoH, RI) has formulated a Blueprint for the 2021-2024 Health Digital Transformation Strategy, with the collaborative aim of achieving a healthy Indonesia together with all stakeholders in the healthcare industry within the Indonesia Health Services (IHS) Platform.

The development of E-PHR in Indonesia will build on the initial implementation of the EMR system, which helps store and manage public health data, marking the first step toward E-PHR. Indonesia also has applications that allow the public to access their health data, such as Mobile JKN, which provides easy access to information and services, although it is currently limited to members of the National Health Insurance (JKN). Indonesia is currently working on integrating healthcare information and services into a single application called SATUSEHAT. SATUSEHAT is being developed to integrate health data, improve healthcare service efficiency, and enhance patient access to their personal

health data; it is envisaged to be the precursor to a future E-PHR ecosystem in Indonesia.

In support of growing Indonesia's digital healthcare ecosystem from one of primarily EMRs to E-PHRs, electronic medical records still need to be strengthened with supporting regulations, including regulations for telemedicine, biotechnology applications, and other technologies. Further, the development of policies and regulations governing E-PHR will be needed to both incentivize further development of platforms into E-PHRs centred on the patient as well as to ensure appropriate guardrails, data privacy, and security in the sharing of data.



Figure 5. Development of Medical Records In Indonesia

# 5.3 Recommendations For The E-PHR Framework For Indonesia

In our review of the literature, moving to E-PHR requires a shift in the features, regulations, facilities, infrastructure, standards and data security. The features built can accommodate the needs of providers and the community and guarantee the continuity and improvement of the quality of health services. For this reason, researchers recommend the following features:

**Table 9. Recommended Features For Indonesia's E-PHR** 

Feature	Definition and Function		Types of Information
Security	Using one identity number and a password	•	ID number using National ID number (NIK) currently on Satusehat platform
		•	Requires a password for access currently on Satusehat platform  Restricts individuals/parties who can access the data
Identity and Demographic Data	Information that encompasses an individual's characteristics, which serves to identify the patient, personalise care, and ensure that the stored health data accurately corresponds to the individual.	•	Name Date of Birth Age Occupation Residential Address Marital Status
Screening	A feature used to track and manage the results of individual health screenings. The stored screening results can be used as a basis for health monitoring, screening for various diseases, recording symptoms, and disease tendencies. This tool or feature can also serve as a reference when consulting healthcare service providers.	•	Infectious disease screening Non-infectious disease screening, including degenerative and mental diseases Minimum screening as per transformation
Health Records	Health records, including the medical history recording menu, function as the	•	Health history: allergies, immunizations, family history, lifestyle, genetics

	management of individual health information. This feature helps individuals	(blood type, Rh factor), visit data
	manage and monitor their health, making it easier to diagnose and plan treatment when consulting with medical or healthcare professionals.	<ul> <li>List of complaints, examinations (physical, supporting), diagnoses, treatments, procedures/operations</li> <li>Healthcare facility history: location, profession/specialisation, staff names</li> <li>Personal monitoring: blood pressure, random blood sugar, BMI (graphical representation)</li> </ul>
Education	to provide health	<ul> <li>Reminders: medication reminders, check-up schedules, healthy behaviours</li> <li>Teleconsultation</li> <li>Telemonitoring</li> <li>Remote programs</li> </ul> Articles on prevention and health promotion, as well as health news in the form of infographics in multimedia

Realising E-PHR must start by preparing regulations, facilities and infrastructure according to standards, including data security.

# Table 10. Recommended Enabling Environment Factors (Policies, Regulations, Standards, Infrastructure, and Human Resources) For Indonesia's E-PHR

Category	Recommended Features or Policy Actions	Exemplar Countries <sup>1</sup>
Regulations	Establish clear legal frameworks for data protection and privacy	Estonia, Australia, Denmark
	Localise data protection regulations like GDPR and HIPAA	
	Mandate regular audits and compliance checks for E-PHR systems	Australia, France
Standards	Establish standards for data formats and interoperability	Australia, Denmark
	Ensure compliance with international standards for health data exchange. Adopt international interoperability standards (e.g., HL7, FHIR) where feasible	Estonia, Australia
Data Security	Implement robust encryption and secure authentication protocols	Estonia, Denmark
	Define strict access controls and authentication mechanisms	Australia, France
	Ensure regular data backups and disaster recovery plans	

<sup>&</sup>lt;sup>1</sup> These recommendations are based on various studies and reviews on E-PHRs reflected in this scoping study, including Alsahafi and Gay (2018), Krishnan Narayanan and Bakshi (2021), Neng Sari Rubiyanti (2023), Nohr et al. (2017), and Pagliari et al. (2007).

Category	Recommended Features or Policy Actions	Exemplar Countries <sup>1</sup>
Infrastructure	Develop robust and secure infrastructure for data storage and transmission	Denmark, Estonia
	Implement high-speed internet connectivity for widespread access	
	Invest in scalable and secure cloud infrastructure for E-PHR	Estonia, UK
Human Resources	Provide training for healthcare professionals on E-PHR use and data management and privacy practices	Australia, Denmark, UK, France
	Recruit IT specialists for ongoing system maintenance and security	Estonia, Denmark
	Ensure adequate staffing and resources for E-PHR support and maintenance	
Patient Digital Literacy	Offer patient education and support for E-PHR use and management	Australia, Denmark
	Ensure patient literacy and digital skills are considered in E-PHR design	
Data Sharing	Establish clear guidelines for data sharing and access control	Estonia, Denmark
	Ensure patient consent and authorization for data sharing	

Literature Review on Electronic Personal Health Record (ePHR)

Category	Recommended Features or Policy Actions	Exemplar Countries <sup>1</sup>
Monitoring and Evaluation	Regularly monitor and evaluate E-PHR systems for effectiveness and patient satisfaction	Australia, Denmark
	Conduct periodic security audits and risk assessments	

# 5.4 Next Steps For Transform Health Indonesia Feb - December 2024

To help realise E-PHR in Indonesia, THI and HIRC will prepare a policy brief and advocate for related parties, especially policymakers. This will include presenting the policy brief to the Ministry of Health and conducting knowledge sharing sessions. Additionally, the advocacy campaign will focus on creating E-PHR policy framework, which should be highlighted throughout the advocacy efforts. The objective is to raise awareness and support among local parliamentarians and the public, using direct contact and social media engagement to build a strong coalition that influences policymakers and drives the adoption of the E-PHR policy.

# February - April 2024

- Policy Brief Preparation and Advocacy:
  - Research and Evidence Gathering
  - Drafting the Policy Brief
  - Stakeholder Mapping
  - o Review and Finalization of the Policy Brief
  - Finalise the Policy Brief

# **May - June 2024**

- Engagement with the Ministry of Health through regular meetings to present and discuss the policy brief and the E-PHR initiative in order to advocate for the creation of an E-PHR framework which would guide the process of developing E-PHR's for Indonesia.
- Policy Dialogue Sessions with key stakeholders such as the Ministry of Health, Parliament, BPJS, etc to build consensus and support for the E-PHR policy. By involving these stakeholders, we aim to ensure that the proposed E-PHR framework receives the endorsement and collaboration needed for its successful development and implementation across Indonesia.
- Advocacy Campaign to raise awareness and garner support for the E-PHR policy among policymakers and the public. To achieve this, the campaign will involve parliamentarians through

discussion/meetings and use social media to engage the public with informative posts and hashtags. The goal is to mobilise public support through petitions and awareness events, encouraging individuals to contact their representatives and seek endorsements from influential figures. This multifaceted approach is designed to build a strong coalition that can influence policy makers to support and adopt the E-PHR policy

# July - August 2024

- Technical Assistance and expert consultations with the Ministry of Health and other relevant bodies to support the development of the E-PHR policy framework.
- Capacity Building Workshops: Conduct workshops for policymakers and healthcare providers on the implementation and benefits of E-PHR in order to ensure their support for the implementation of the framework. These workshops will provide detailed training on the technical aspects and advantages of E-PHR, enabling participants to better advocate for and implement the policy. Support can be demonstrated through endorsement of the E-PHR framework in their professional roles, and by integrating E-PHR practices into their organisational strategies. Additionally, they can use the knowledge to influence policy decisions, advocate for resource allocation, and promote the adoption of E-PHR within their networks. These would include Government bodies such as the Ministry of Health, Ministry of ICT, Local health departments, Health care providers, Professional and Industry associations, educational institutions, NGOs International partners. Through the following forums Indonesian Health Congress, Regional Health Forums, Joint workshops with ministries, Policy Advocacy Forums, National Health System Policy Review, National Health Information System Forum Innovation and Health Technology Expos. The different stakeholders can show support by publicly endorsing the E-PHR framework and integrating into their operational strategies. Using their knowledge from workshops to secure funding and resources required for E-PHR implementation from partners in the private

and public sector and professional bodies incorporating E-PHR training into ongoing professional development programs.

# September 2024

 Knowledge-sharing sessions among coalition partners to exchange best practices and lessons learned with the goal of influencing decision-making on E-PHR at key forums, these sessions will facilitate the sharing of valuable insights and experiences, enhancing the collective understanding of E-PHR implementation. By highlighting successful strategies and addressing challenges, the coalition aims to provide evidence based recommendations and drive informed policy decisions. The information and recommendations gathered will be presented at key meetings and discussions to ensure that they effectively shape the development and adoption of the E-PHR framework in order to formulate policy recommendations that are practical and achievable within Indonesia's context and ensure that the E-PHR policies developed adopt a people centred approach and align with National priorities.

# October - November 2024

- Evidence Packaging based on the study into user-friendly formats, such as infographics, policy briefs, and presentations. This would be in order to package complex information for distribution across different platforms including digital media which can easily reach a wide audience including remote areas and can easily be translated into multiple languages. This plays a big role in advocacy and communication by empowering community-based organisations, NGO's and healthcare advocates communicate effectively with the public building broader support and ensuring uptake by demystifying myths and misconceptions that might exist due to lack of understanding the benefits.
- Presentation to Stakeholders: Present the packaged evidence to stakeholders, including the Ministry of Health, BPJS, healthcare providers, and patient advocacy groups. In order to ensure that these stakeholders who often come from diverse backgrounds

with limited knowledge and technical expertise on digital technologies can easily interpret complex data through policy briefs and infographics to grasp essential information quickly and make informed decisions.

# December 2024

- Monitor and evaluate the progress of the advocacy efforts and the development of the E-PHR policy.
- o Developing a plan for the next phase of advocacy and implementation efforts for 2025 is crucial to sustain momentum, adapt to evolving contexts, and ensure the long-term success of E-PHR in Indonesia. It enables strategic resource allocation, stakeholder engagement, and policy alignment while allowing for continuous monitoring, learning, and adaptation. By setting new milestones and addressing emerging challenges, the plan ensures that E-PHR becomes a sustainable and integral part of the national health system, building public trust and positioning Indonesia as a leader in digital health innovation.

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# **Appendix**

**Table A. Previous Scoping Studies on E-PHR In Individuals:** 

No	Author	Year	Method	Result
	Salmi, L, et all	2020	Qualitative (six individuals from six nations)	Perspectives from individuals: Sweden: "As patients, we take prime responsibility for managing our own health. From healthcare records, we collected them all on paper and placed them in binder. Chile: I can get some exam results from the clinic website, but only with a special code for a one-time download.  Japan: I think medicine in Japan is profiting from listening carefully to patients.  Canada: Patients want visibility and transparency into all their health data, but they face a large cultural divide: health information custodians and care providers in our country currently control what, when and whether patients can access their own data.  Australia: Our hopes remain unreleased: to uncover information that could help dad change his behaviour or reveal errors (if he would dare point them out to his doctors). For now, I am left with a question that gnaws at me: 'If they're denied access to their own health information, how can patients have agency over their own health?"  USA: In the USA, we have had the right by law for more than 20 years to request and receive copies of our full medical records—including our doctors' notes.

No	Author	Year	Method	Result
2	Harahap, N.,C, et all	2021	Systematic review	Seven function categories were identified in this review, which is grouped into basic and advanced functions. Health records and administrative records were grouped into basic functions. Medication management, communication, appointment management, education, and self-health monitoring were grouped into advanced functions. The issues found in this study include interoperability, security and privacy, usability, data quality, and personalization
3	Ekeland, A.G., et all	2020	Qualitative Systematic review	The basis of the 11 papers, we constructed four governance models to categorise and conceptualise the findings. The models are political governance, normally depicting top-down processes; medical governance, which normally depicts bottom-up processes; the internet and global model, emphasising international business strategies coupled with the internet; self-governance, which builds upon the development of the internet and Internet of Things, which has paved the way for personal governance and communication of one's own health data.

