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Why do personal and demographic data matter in healthcare digitalization initiatives?

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Abstract: This study explores the role and usability of personal and demographic data (PDD) in Slovenian healthcare digitalization initiatives, assessing its impact on clinical aspects, operative procedures, public health policymaking, and cross-border health threats. Using a multiple-case study approach, data were collected from expert focus groups and supported by intelligence reports from the Central Register of Patient Data. Data were coded using a content analysis approach and utilized to enhance the understanding of the research subject and refine our inferences. PDD, including identifiers, residence details, education level, employment status, social history, lifestyle behaviors, cultural determinants, and other related information, is vital for effective healthcare delivery, public health surveillance, administrative and financial compliance of the healthcare system's operations, and cross-border actions. The study highlights the pivotal role of PDD in the Slovenian eHealth system through real-world cases and applications. The key findings suggest that leveraging the potential of PDD requires systemic improvements, particularly in national strategy and regulation, data collection and quality, data utilization and integration, and privacy and ethical considerations. Advancing these areas through a coordinated and comprehensive approach can maximize the value of PDD and serve as a model for other countries aiming to strengthen their digital health systems.

Keywords: *Digital health, Healthcare system, Multiple-case study, Personal and demographic data, Slovenia, Usability.*

1. Introduction

Personal and demographic data (PDD), defined as an integrated set of individual-level and demographic attributes, is frequently overlooked in professional and scientific discussions on healthcare digitalization, despite representing an indispensable component of healthcare datasets and documentation [1]. The difference between demographic data and personal data lies in their scope and usage. Demographic data refers to statistical information about a population, and is often applied in market research, public policy, and social studies to examine trends and characteristics of groups. This type of data can be aggregated and presented in a way that does not identify individuals. In contrast, personal data refers to any information that can identify an individual directly or indirectly. It is primarily used for communication and personalized services. Unlike demographic data, personal data is heavily regulated under privacy laws such as the General Data Protection Regulation (GDPR) and other regulatory frameworks due to its potential to uniquely identify individuals [2, 3]. When connecting various information systems and healthcare databases, it is important to ensure a unified system of personal identification [4, 5]. Basic personal data, such as name, surname, address of residence, email address, phone number, social security number, and tax number (or similar identifiers), are essential for the unique identification of individuals and establishing contact with them. However, healthcare data, when supplemented with PDD, such as identifying details, age, gender, next-of-kin, ethnicity, education level, employment status, marital status, social and cultural factors, geographic locations, and habits and lifestyle behaviors, are decisive for contacting individuals and selecting

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appropriate diagnostic, treatment, and rehabilitation procedures. Moreover, big PDD facilitates the categorization, analysis, and planning of necessary measures at the population level, which is instrumental in managing public health and healthcare policymaking[1] [6, 7]. PDD therefore serves an important dual role: on the one hand, they are essential for planning and implementation of individual healthcare treatments; on the other, they provide a crucial foundation for developing health strategies and adopting targeted programs and interventions at the national public health level. Likewise, PDD plays a pivotal role in health insurance reimbursement information systems, serving as a critical factor in the administrative and financial processing of healthcare documentation [8]. To meet the outlined functions and requirements, PDD should preferably be derived from official public reference sources, such as national population or demographic registries [9].

In line with the growing importance of health for the population, control and management of public health have become increasingly demanding, with national healthcare systems expanding in scope, complexity, and cost over recent decades [10]. As healthcare authorities place greater emphasis on understanding the population's health and social status, which is crucial for planning and implementing healthcare policies, the need for the collection and analysis of PDD is of increasing strategic importance [11]. In this context, PDD can be utilized to implement targeted measures that address the diverse needs of various social sub-groups and health conditions [12]. Additionally, there are numerous scenarios where PDD proves valuable, supporting healthcare digitalization efforts and helping to address key public health challenges and priorities [13]. Apart from wide-ranging usability in national healthcare systems, the potential of PDD can also be expanded and applied in cross-border operations.

This article outlines the PDD as one of the fundamental components of the national eHealth system in Slovenia. Practical examples within the article illustrate the sources of PDD, the importance of such data in ensuring the quality of electronic health records (EHRs), and showcase its usefulness in clinical and public health information systems and decision-making processes. In light of these considerations, this article aims to present an in-depth qualitative study of the role and usability of PDD in healthcare digitalization initiatives.

2. Literature Review

The integration of PDD has increasingly become a focal point in healthcare digitalization research, underpinning transformative changes in the delivery, management, and evaluation of health services. Although empirical research in this domain remains limited, a growing body of literature, both directly and indirectly, highlights the rising awareness of PDD's role in driving digital health transformation. Scholars progressively acknowledge the strategic value of PDD in facilitating personalized healthcare, optimizing system performance, and informing public health policy. Modern healthcare technologies, ranging from hospital information systems and EHRs to wearable devices and artificial intelligence (AI), depend heavily on the availability and effective utilization of PDD to support both operational and strategic decision-making [14]. By combining personal and demographic information, PDD enables customized healthcare delivery and comprehensive health system management. These data support not only individual-level interventions but also population-wide planning and response strategies, particularly in domains such as public health surveillance, resource allocation, and policy development [15, 16].

In clinical contexts, PDD underpins the creation of personalized care pathways. Digital therapeutics and mobile health (mHealth) applications leverage demographic and behavioral data to deliver targeted interventions that improve patient outcomes while adhering to regulatory standards [17]. Aggregated demographic data facilitate population-level analyses, enabling healthcare systems to identify health disparities, anticipate disease burdens, and design targeted prevention campaigns [18]. Research indicates that large datasets incorporating PDD can accelerate scientific discovery by revealing patterns

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[1] It should be noted that whenever the role and use of PDD are discussed at the population or public health level, the reference is to "big PDD."

and correlations that are not discernible in smaller cohorts, thus advancing medical knowledge and therapeutic innovation [19].

The emergence of advanced technologies, particularly AI and machine learning, offers significant potential to extract deeper insights from PDD. These tools are capable of processing and interpreting vast quantities of complex data, enabling real-time decision support and predictive analytics. However, the technological promise is often constrained by the quality and inclusivity of the underlying data [20]. Incomplete records, inconsistent metadata, and a lack of interoperability standards impede seamless data exchange and reduce analytic reliability. Standards such as HL7 FHIR and SNOMED CT have been proposed to address these issues [21], but widespread implementation remains a persistent challenge.

Privacy, security, and ethical considerations are central to the responsible use of PDD [22]. Regulatory frameworks such as the GDPR and the Health Insurance Portability and Accountability Act (HIPAA) establish critical safeguards but also create barriers to cross-institutional and international data sharing [23]. The risks of identity theft, data breaches, and unauthorized access necessitate robust protections, including encryption and secure authentication protocols. At the same time, digital platforms must balance these security measures with usability. Overly complex privacy settings can reduce user engagement, particularly among vulnerable populations. Designing intuitive, accessible interfaces that maintain user autonomy and trust is essential for encouraging adoption.

Moreover, the literature stresses the importance of addressing bias and promoting equity in digital health systems. Marginalized communities are frequently underrepresented in digital datasets due to barriers such as limited access, digital literacy, or institutional distrust. This underrepresentation can bias AI models and perpetuate existing health disparities [24]. To mitigate these effects, inclusive data governance and culturally sensitive system design are imperative. Adapting digital tools to accommodate linguistic diversity, literacy levels, and cultural norms can substantially enhance user engagement and effectiveness [25].

National and international initiatives demonstrate the strategic application of PDD in health system modernization and public health promotion. In the European Union (EU), the United States, China, and India, research has illustrated the utility of PDD in enhancing personalized healthcare services, improving public health interventions and disease prevention strategies, strengthening epidemiological surveillance, simplifying administrative procedures, and promoting data exchange among stakeholders, offering valuable insights for other nations undergoing similar transitions [26-29]. The World Health Organization's Global Strategy on Digital Health 2020–2025 advocates for person-centered, data-driven approaches to health promotion and healthcare innovation [30].

Overall, the literature review and existing research indicate that the effective integration of PDD into healthcare systems holds significant transformative potential. This study goes a step further by emphasizing that, when managed responsibly and inclusively, PDD can serve as a driver of improvements in individualized care, population health outcomes, and overall systemic efficiency [31]. Moreover, our findings suggest that overcoming persistent challenges in the standardization, collection, and utilization of PDD is critical for unlocking its transformative potential and for ensuring that digital health innovations equitably benefit all stakeholders and diverse population groups within healthcare systems.

3. Methods

3.1. Research Design

This study employs a case study approach to explore the role and usability of PDD in healthcare digitalization initiatives. The primary method of data collection involved thirteen focus group sessions conducted between January and June 2024. The secondary data source for this study included statistical data and business intelligence reports from the Central Register of Patient Data (CRPD). These reports were incorporated to deepen our understanding of the research topic, strengthen our inferences, and support the findings. The applied case study method is classified as a multiple-case study, as it involves analyzing various data sources, including focus group discussions and CRPD reports [32]. Accordingly, the entire research follows the typical phases of the case study: 1) designing the case study, 2) preparing for data collection, 3) collecting data, 4) analyzing data, 5) interpreting the findings, and 6) reporting the results. This methodological framework aligns with Yin's case study methodology and provides a clear roadmap for conducting the research, emphasizing the integration of qualitative data from focus groups and documentary analysis of CRPD reports. The choice of this methodology was influenced by the complex nature of the research problem [33]. Given that the study is largely exploratory, quantitative empirical methods would not have yielded meaningful insights or a reliable assessment of the field. Namely, healthcare digitalization initiatives and eHealth projects in Slovenia and most other countries are in an early developmental stage, far from the desired level of maturity. As a result, obtaining a representative research sample through quantitative methods would have been challenging. For these reasons, focus groups were deemed the most suitable method to provide an in-depth analysis of the role and usability of PDD in these projects [34]. This study aims to promote necessary systemic improvements in the field, which could support the development of more effective digital solutions in the healthcare domain.

3.2. Sample

As part of the research planning process, a detailed sampling framework was developed. This framework included definitions and criteria concerning the necessary competences and professional profiles required to conduct credible and well-founded focus groups. Based on these criteria, prominent experts working in the field of healthcare digitalization were identified within the most relevant institutions and companies and were invited to participate in the study. Focus group participants were ultimately selected based on their expertise and experience in eHealth projects and healthcare data, ensuring the credibility of their input. A non-random, stratified sampling method was employed to create a representative sample of information and communication technology (ICT) experts and healthcare professionals. Focus group recruitment continued until saturation was reached [35] with a final sample of 20 experts. The participants were affiliated with various institutions: 11 from the National Institute of Public Health (NIPH), 3 from the Ministry of Health, and 6 from ICT companies. The group consisted of eHealth project managers, experts in engineering and health information systems (including developers, consultants, data scientists, and analysts), as well as public health professionals such as physicians, government officials, policymakers, methodologists, and statisticians.

Given that the research topic is directly related to their current professional responsibilities, and, for most, also to their future project agendas, all invited experts accepted the invitation and confirmed their participation. In this respect, their involvement in the study was aligned with their regular professional duties, and the focus group sessions were conducted during their working hours, which significantly facilitated the overall implementation of the study.

The majority of activities related to expert outreach and recruitment, preparation of materials, coordination of schedules, and meeting organization were carried out by colleagues from the NIPH. Initially, organizing and coordinating focus groups with such a large number of participants proved challenging and time-consuming. Over time, however, the coordination process became more streamlined, as meeting schedules stabilized and sessions were held approximately every two weeks over six months.

3.3. Data Collection and Analysis

The objectives of the focus group sessions were refined with participant input, addressing any conceptual uncertainties. All invited experts participated, resulting in a 100% response rate. Each session lasted approximately 120 minutes and took place at the NIPH. The discussions were structured and directed to cover topics such as the current state, potential, and challenges in the use of PDD; the identification of needs and priorities; and the substantive, technological, and organizational issues related to PDD. The discussions also addressed necessary actions at both the regulatory and implementation levels. The sets of initial focus group questions are presented below (Table 1). The platform for conducting focus groups and formulating pertinent questions was developed based on existing literature and previous research by individual scholars and international organizations. These sources emphasize the importance and value of data, including PDD, in designing comprehensive digital health solutions and business intelligence tools for analytics, simulations, modelling, and policymaking in the healthcare sector [36-39]. On the other hand, the questions were derived from the expressed data needs of various stakeholders and decision-makers in the healthcare system, including the Ministry of Health, the Health Insurance Institute, healthcare providers (both professionals and administrative staff), the NIPH, as well as other financial, statistical, and expert agencies, patient associations, social welfare institutions, and other entities authorized to process such data and information. These frequently identified needs, which should be incorporated into the planning and design of digital solutions, were articulated by focus group participants. The focus group questions combined experiential and theory-based approaches, as the existing literature directly addressing the role and usability of PDD in healthcare digitalization initiatives is quite limited, as mentioned earlier in the article [40, 41]. These questions were designed to address a broad range of issues, exploring the nuances of the topic and encouraging meaningful discussions on the current state, significance, potential, challenges, and necessary actions for the effective collection and use of PDD in healthcare. As the discussion developed among the focus group participants, additional related and interdependent sub-questions and starting points for further exploration emerged during the sessions. In any case, the research aims to include as much information, experience, and knowledge as possible. All responses and discussions were incorporated into the final content analysis. Thus, the research results comprehensively and accurately reflect the opinions, justifications, and conclusions of the focus group participants.

Table 1.
Focus group questions (and sub-questions).

How would you assess the current state of PDD use in digital solutions (eHealth) and the healthcare system in general? What do you think is the untapped potential of PDD in improving healthcare services and public health management? How do you see the role of PDD evolving with the rapid advancement of AI?
What are the key challenges currently facing the collection, processing, and utilization of PDD in healthcare digital solutions? What organizational changes or improvements are needed to effectively collect, manage, and utilize PDD within the healthcare system?
What steps should be taken to ensure that stakeholders comply with strategic guidelines and regulatory acts regarding the collection and processing of PDD? What are the main challenges in ensuring adequate funding and resources for the effective use of PDD in health systems?
How do you view the role of digital solutions in overcoming current challenges in managing PDD? What specific actions or steps do you believe should be prioritized at the implementation level to enhance the collection and use of PDD in the healthcare sector?
What are the most critical factors to ensure the accurate, methodical, and timely collection of PDD in healthcare? How can we improve data completeness and standardization to better serve patient care?
What regulatory actions should be taken at national or international levels to ensure the security and ethical use of PDD in healthcare? What measures should be implemented to protect the privacy and security of sensitive PDD in healthcare? How can ethical concerns be addressed to build trust between patients and healthcare providers?
What are your thoughts on the need for comprehensive norms to regulate the provision and use of PDD in the healthcare system? What are the most significant challenges in implementing policies and strategies related to PDD? How can these be overcome?
How can international or global organizations encourage the coordinated use of PDD in addressing healthcare challenges? How can cross-border health threats influence policies and practices regarding the collection and use of PDD in healthcare?
How can the integration of PDD with other healthcare data (e.g., clinical or behavioral data) improve decision-making, patient care, and overall service efficiency? What are the main barriers to achieving effective data integration and interoperability? What role do real-time access and analytics play in supporting research initiatives in healthcare?

Participants played an active role in all phases of the study. Their tasks were twofold: first, following the pertinent literature and the CRPD reports, they were required to engage in a comprehensive analysis of the role and usability of PDD in the current eHealth settings, identifying areas where such data plays a critical role and describing its value for stakeholders in the healthcare system and public health at the national level. Second, based on their expertise, they were asked to envision how PDD could further drive the development of digital healthcare solutions, improve healthcare processes, and inform policymaking and management in the healthcare system. All discussions and responses of the participants were recorded in written form.

The collected data were analyzed using conventional content analysis [42, 43]. Conventional content analysis is a systematic approach used to interpret textual data by identifying patterns, themes, and meanings within the content. In the context of examining the role and usability of PDD in healthcare digitalization initiatives, this method enables researchers to delve into qualitative insights provided by the focus group participants. Thus, the overall findings on the role and usability of PDD in healthcare digitalization initiatives reflect a triangulated synthesis of evidence from relevant literature, CRPD reports, and qualitative insights gathered from focus group discussions. The content analysis was conducted using MAXQDA Analytics Pro 2022 (version 2022.4.1). MAXQDA is a software package designed for qualitative and mixed-methods research. In MAXQDA-based content analysis, focus group participants' statements are systematically coded and categorized according to the identified areas of relevance. The coding process involved several stages, beginning with the initial reading of transcripts to familiarize researchers with the data. Subsequently, an inductive coding approach was applied, yielding a set of the most significant codes derived from the focus group transcripts. A total of 15 primary codes were identified, encompassing various aspects of the role and usability of PDD in healthcare digitalization initiatives. Using MAXQDA, the identified codes were systematically analyzed and grouped into four main thematic categories [44] (Figure 1). These categories reflect the central topics that emerged from the focus group discussions and offer a foundation for interpreting participants' insights on the role and usability of PDD in healthcare digitalization initiatives. They may also serve as a conceptual framework for future research and development in this field:

3.3.1. National Strategy and Regulation

Respondents emphasized the need for the development of a national strategy and the updating of the legal framework in the field. Compliance with strategic guidelines and adherence to regulatory acts would enable stakeholders to act consistently in collecting and processing PDD. This would contribute to more efficient healthcare policies, technological development, and budgeting.

Key codes**:** Compliance, healthcare policies, technological initiatives, and resource allocation.

3.3.2. Data Collection and Quality

Participants highlighted the significance of methodical, accurate, and timely collection of PDD as foundational to effective healthcare delivery. Proper data quality is crucial for patient identification, treatment planning, and organization of clinical work.

Key codes: Methodology, accuracy, completeness, standardization.

3.3.3. Data Utilization and Integration

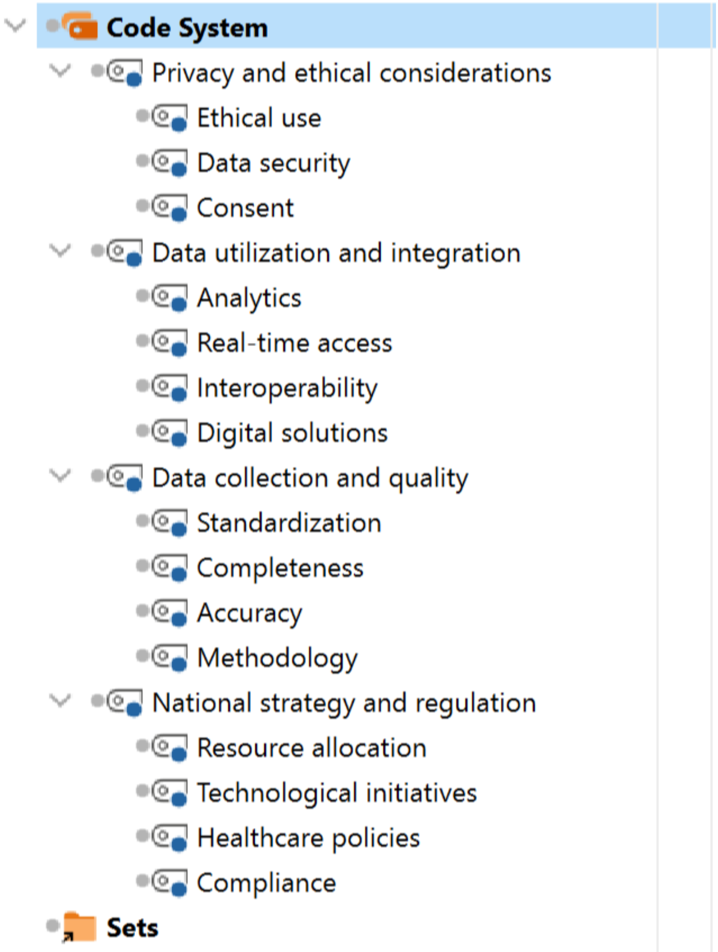
Participants underscored how PDD is used to improve patient care and data flow, enhance service delivery, and support research initiatives. Integration of PDD with clinical data in effective digital solutions was seen as vital for holistic patient insights.

Key codes: Digital solutions, interoperability, real-time access, analytics.

3.3.4. Privacy And Ethical Considerations

Respondents expressed concerns about patient privacy and data security, stressing the need for robust protocols to protect sensitive PDD. Ethical considerations were deemed paramount in building trust between patients and healthcare providers.

Key codes: Consent, data security, ethical use.



Code System
- Privacy and ethical considerations
  - Ethical use
  - Data security
  - Consent
- Data utilization and integration
  - Analytics
  - Real-time access
  - Interoperability
  - Digital solutions
- Data collection and quality
  - Standardization
  - Completeness
  - Accuracy
  - Methodology
- National strategy and regulation
  - Resource allocation
  - Technological initiatives
  - Healthcare policies
  - Compliance

Sets

Figure 1.
Snapshot of the coding process in MAXQDA Analytics Pro 2022 (version 2022.4.1).

To ensure objectivity and credibility, multiple coders (the authors) conducted the final content analysis independently [45]. Additionally, statistical data and business intelligence reports from the CRPD were incorporated to support and validate the findings. These sources helped enhance the interpretation of the research results and strengthen the conclusions [46]. The applied case study framework, utilizing focus group insights and CRPD reports, provided a comprehensive and robust tool for evaluating the role and usability of PDD within the eHealth system.

4. Results

Figure 2 presents the frequency distribution of all identified primary codes across the 13 focus group discussions. The visual representation highlights the prominence of specific thematic categories, with codes related to data utilization and integration (*digital solutions*) and national strategy and regulation (*healthcare policies*) appearing most frequently. This pattern underscores participants' shared concerns about the dual importance of ensuring the effectiveness of digital solutions, facilitating data utilization and integration, while simultaneously establishing coherent healthcare policies that support the development of national strategies and regulatory frameworks in the field of PDD.

Meanwhile, codes associated with the thematic categories of Privacy and Ethical Considerations and Data Collection and Quality, such as *data security* and *methodology*, also appeared consistently, reflecting a strong stakeholder emphasis on the security-related and methodological aspects of collecting and using PDD within healthcare digitalization initiatives. The frequency of these codes helps illuminate the most pressing issues and priorities identified by participants concerning the role and usability of PDD in healthcare digitalization initiatives.

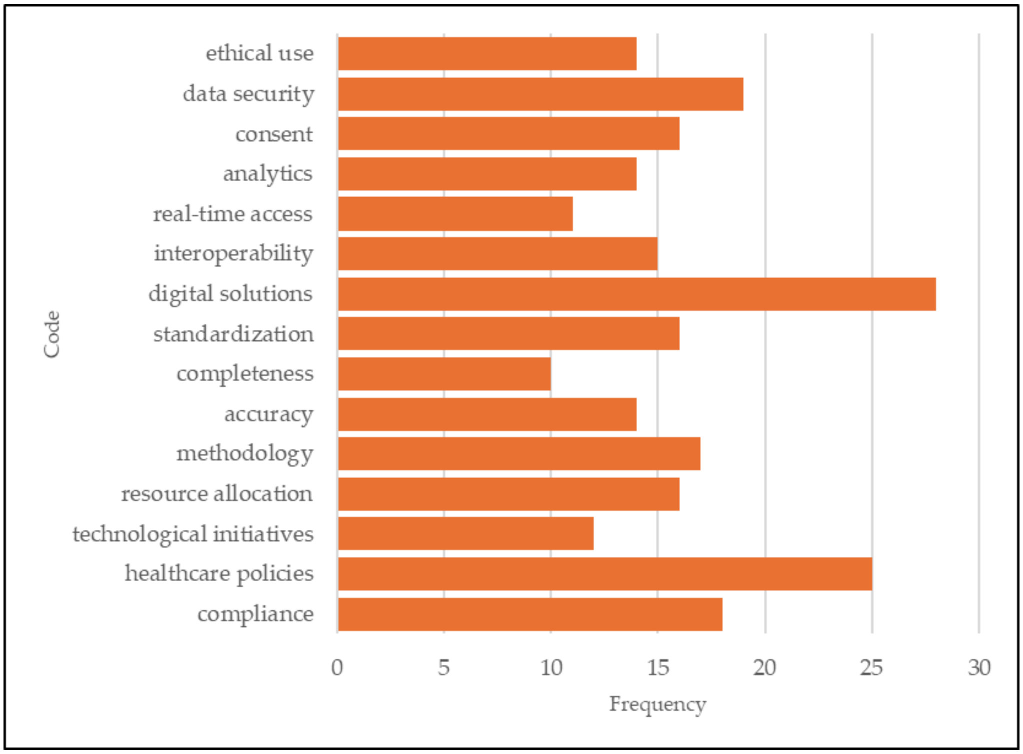


Figure 2.
Frequency of codes across all focus group discussions (MAXQDA Analytics Pro 2022).

Figure 3 presents the aggregated frequency of all codes grouped under their respective thematic categories. The distribution reveals that National strategy and regulation, and Data utilization and integration were the most frequently referenced themes across the focus group discussions. This reflects a strong emphasis among participants on the development of modern strategic and regulatory frameworks, as well as on leveraging PDD for digital and data-driven improvements in healthcare planning and delivery. Notably, the categories Data collection and quality and Privacy and ethical considerations were also consistently represented, highlighting stakeholder concerns regarding data processing and quality, as well as ethical issues and the potential for misuse. The figure illustrates the multidimensional nature of the discourse and underscores the need for balanced attention across strategic, regulatory, technological, user-centered, procedural, and ethical domains in the implementation of PDD.

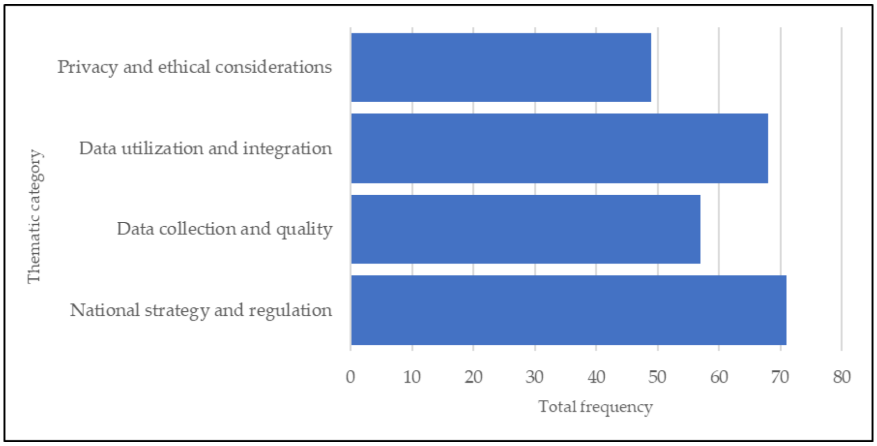


Figure 3.
Total code frequencies by thematic category (MAXQDA Analytics Pro 2022).

Table 2 presents a selection of notable statements and opinions expressed by focus group participants, along with their classification within the main thematic categories and their pairing with corresponding key codes. The table also includes relevant stakeholders who should take responsibility for removing barriers and supporting the implementation of the objectives identified in the participants' statements. These excerpts were obtained through qualitative analysis using MAXQDA and provide insight into participants' perspectives on the role and practical usability of PDD within healthcare digitalization initiatives. The statements reflect diverse experiences and viewpoints that correspond to all the main thematic categories identified, highlighting both the opportunities and challenges related to the integration of PDD into digital health systems and their effective utilization.

Table 2.
Some of the points highlighted by the focus group participants and thematic categories.

Notable observations	Thematic categories and key codes
"The area of providing and using PDD in the health system should be comprehensively regulated by norms and legislation. This should be followed by thoughtful development and integration of all national ICT infrastructures for the collection and use of PDD."	1. National strategy and regulation Key Codes: Compliance, healthcare policies, technological initiatives, and resource allocation. 2. Data collection and quality Key Codes: Methodology, accuracy, completeness, standardization. 3. Data utilization and integration Key Codes: Digital solutions, interoperability, real-time access, analytics. Stakeholders involved: Government authorities and agencies, healthcare providers, and ICT service providers.
"For a more in-depth utilization of the value of PDD, it is necessary to initially develop strategic and policy documents and subsequently adopt appropriate legal foundations while ensuring material and human resources. In this sense, this area is critically marginalized and underfunded."	3. Data utilization and integration Key Codes: Digital solutions, interoperability, real-time access, analytics. 1. National strategy and regulation Key Codes: Compliance, healthcare policies, technological initiatives, and resource allocation. Stakeholders involved: Government authorities and agencies.
"The EU lacks guidelines or recommendations that encourage Member States to accurately monitor and utilize PDD in public health management. Clearly, there is still insufficient awareness within international or supranational organizations regarding the importance of this area."	1. National strategy and regulation Key Codes: Compliance, healthcare policies, technological initiatives, and resource allocation. 3. Data utilization and integration Key Codes: Digital solutions, interoperability, real-time access, analytics. Stakeholders involved: Supranational and international

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	institutions.
"The methods and scope of collecting, monitoring, maintaining, and processing PDD in health information systems should be precisely defined in terms of content and methodology."	2. Data collection and quality Key Codes: Methodology, accuracy, completeness, standardization. Stakeholders involved: Government authorities and agencies, healthcare providers, professional associations, and ICT service providers.
"In the currently operating information systems and application solutions, it is evident that the use of structured and high-quality PDD holds significant practical value. With the development of AI, predictive analytics systems, and decision support, it is expected that the importance of PDD will only increase."	3. Data utilization and integration Key Codes: Digital solutions, interoperability, real-time access, analytics. Stakeholders involved: Government authorities and agencies, healthcare providers, and ICT service providers.
"The added value of collecting PDD can only be realized if we have clear, well-defined objectives and effective, user-friendly digital solutions. These solutions must be widely accepted and utilized by the broadest possible range of users."	2. Data collection and quality Key Codes: Methodology, accuracy, completeness, standardization. 3. Data utilization and integration Key Codes: Digital solutions, interoperability, real-time access, analytics. Stakeholders involved: Government authorities and agencies, healthcare providers, patients, and ICT service providers.
"Cross-border health threats, which we have increasingly witnessed recently, necessitate a comprehensive approach and coordinated policies both within the EU and likely on a global scale concerning the importance and use of PDD in the health sector."	1. National strategy and regulation Key Codes: Compliance, healthcare policies, technological initiatives, and resource allocation. 3. Data utilization and integration Key Codes: Digital solutions, interoperability, real-time access, analytics. Stakeholders involved: Government authorities and agencies, healthcare providers, supranational and international institutions, patients, and ICT service providers.
"The effective collection of PDD relies on the trust of citizens, making it essential to incorporate robust security mechanisms for the protection of personal data. These mechanisms must ensure controlled access, limited to authorized personnel only."	2. Data collection and quality Key Codes: Methodology, accuracy, completeness, standardization. 4. Privacy and ethical considerations Key Codes: Consent, data security, ethical use. Stakeholders involved: Government authorities and agencies, healthcare providers, professional associations, patients, and ICT service providers.

To illustrate the current significance and value of structured, high-quality PDD, focus group participants shared information on infrastructural components – such as the PDD server – as well as various datasets already in use within the Slovenian healthcare system (see Sections 4.1 to 4.11). In these sections, they also referenced real-world examples in which PDD plays a critical and often indispensable role. These examples are aligned with all four main thematic categories, underscoring their relevance in both current conditions and future development trends. They highlight clinical, organizational, and managerial contexts in which the availability and integration of PDD have a direct impact on patient care, service planning, and evidence-based decision-making. The insights were systematically summarized using MAXQDA, and they are further examined and discussed in detail in the following sections.

4.1. PDD Server and Data Sources

The Slovenian PDD server is integrated into the CRPD, which represents the core information system of Slovenian eHealth (Figure 4). The CRPD enables the collection, storage, and exchange of EHRs and is accessible to all healthcare providers [47]. The Central Population Registry is the source of basic PDD, such as identifiers (unique citizen number, tax number), name, surname, gender, date of birth, and residence. Addresses of permanent and temporary residence are structured and include precise location data obtained from the information system of the Surveying and Mapping Authority of the Republic of Slovenia. The Central Population Registry also provides data on next-of-kin (spouse, child) and legal guardians.

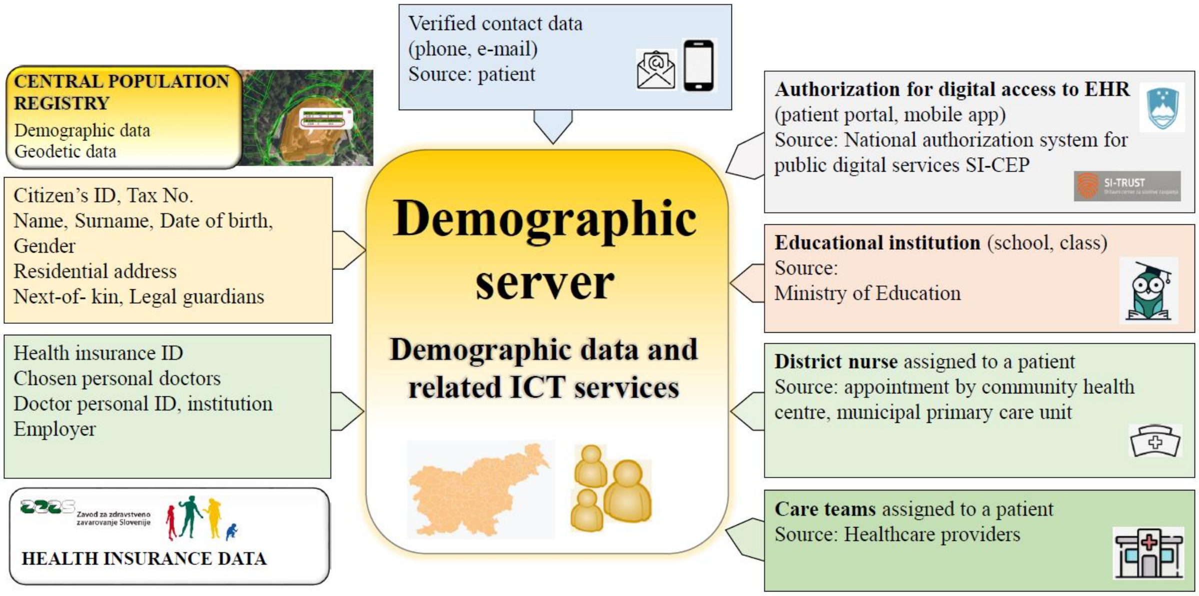

Figure 4.
PDD server and data sources.

Data on health insurance (insurance number, chosen personal physician) are obtained from the records of the Health Insurance Institute of Slovenia. For employed individuals, data on employers is also available. The Ministry of Education is the source of data on pupils and students (school and class). Contact details are entered by the patients via the zVEM Patient Portal or mobile application zVEM [48], or healthcare providers can enter them on behalf of the patient through their information systems. Automatic verification is triggered upon entry (for example, the patient confirms a notification message by clicking a link and confirming a phone number or an email address). Data on authorized health professionals and healthcare teams are administered by the supervisors of healthcare institutions via a web application.

In addition to data storage and management, the PDD server also provides associated interfaces and services for reading and editing data, connecting eHealth applications, clinical information systems at healthcare providers, and other information systems supporting public health activities. The first version of the PDD server was established in 2017. In 2023, a major upgrade was carried out, bringing technological improvements and an extension of content with data on students, patients' contact details, data on health teams, and district nursing areas. At the time of writing this article, the data set on district nursing was still in development, while all other extended data sets had already been implemented in the production environment.

Access to PDD in Slovenia is regulated by a stringent legal framework and security policies established within the national health system. Such data can be accessed exclusively by authorized health professionals, who must first be registered and authenticated using an electronic identity. A system of granular access rights has been implemented to ensure that users are granted access solely to the minimum necessary data required for their professional tasks. By default, all registered physicians and nurses have access to basic PDD of patients. However, access to more sensitive information is restricted. For instance, data on care teams is accessible only to authorized administrators within a specific healthcare provider (e.g., the person responsible for managing care team administration in a hospital). Similarly, population data on mortality is made available solely to explicitly authorized public health specialists. Further levels of granularity and specialization are applied at the level of programming interfaces for certain applications. An example of this is the extended access rights implemented in the epidemiological surveillance system, which provides specialized functionality for monitoring public health trends.

4.2. Unique Identifiers and Linking to Digital Identity

In the past, traditional healthcare information systems commonly used a combination of name, surname, and date of birth as the patient's identifier, which is not a reliable method for determining identity and is not suitable for data exchange. In Slovenia, the unique identifier widely used in healthcare is the health insurance number, originating from the information system of the Health Insurance Institute of Slovenia. The health insurance number is recorded electronically on the health insurance card and is obtained by health service providers via electronic readers. Alternatively, the Personal Identification Number (EMŠO) is used. This identifier is received by every individual registered in Slovenia with permanent or temporary residence and recorded in the Central Population Registry. Verifying the consistency of identifiers during the entry of EHRs significantly reduces errors in person identification and allows the use of electronic access based on modern digital authentication means [49, 50].

The zVEM Patient Portal and mobile application for patients enable access to their data based on login with a digital identity [48]. The connection of digital identity to identifiers in healthcare documentation is crucial for such applications. Digital certificates are linked to users based on their tax number. The tax number is the baseline identifier for digital identity means, such as digital certificates and an electronic identity card. A special challenge is the unified identification of foreigners who do not have a registered residence in Slovenia. A common practice in such cases is to use local identifiers, which are assigned by local health information systems upon treatment. Although this allows a person's EHR to be recorded, it does not ensure that the EHR can be linked across different medical institutions, particularly when the individual receives treatment at multiple facilities. To solve this problem, the PDD server will establish a register of foreigners, allowing the entry of personal data and the assignment of a unique identifier that can be used across all healthcare institutions and healthcare databases in Slovenia.

4.3. Residence Address and Contact Information

Contact information provides a communication channel during healthcare treatment. The permanent residence address enables healthcare providers to send messages by mail. The actual place of residence may be different; in this case, the temporary residence address is relevant. The location of residence is important for responding to health threats and public health measures, including the prevention of the spread of infectious diseases or response to location-specific threats originating from the physical environment (e.g., chemical contamination). Residence is also useful as a socio-economic indicator in public health analyses [51]. In addition to traditional telecommunication (voice calls and SMS messages), modern electronic communications via mobile applications (push notifications) are gaining popularity. In electronic communications, the credibility of contact information is crucial. According to extensive operational experience with the use of unverified mobile phone numbers entered by healthcare service providers (e.g., in eReferrals or COVID-19 screening test results), mistakes are relatively common and are caused either by erroneous data entry or by patients providing incorrect data. Consequently, SMS messages are sent to the wrong recipients, causing dissatisfaction and complaints to supervisory authorities for violations of personal data protection. To prevent such errors, a verification function is triggered during the entry of contact information, with feedback based on the positive outcome of the verification of the respective contact details (mobile phone number, email address). Contact information also has significant potential in supporting epidemiological surveillance and other measures taken as a response to public health threats (e.g., contacting individuals at risk, contact tracing), and for obtaining feedback for quality analyses (e.g., questionnaires about treatment outcomes).

4.4. Age (Date of Birth)

Date of birth or age is a constitutive element of a patient's electronic health record (EHR) and is essential for clinical evaluation. It is also indispensable for organization and planning in healthcare, such as primary pediatric care, preventive medicine like vaccination and cancer screening, and public health policy measures, including the promotion of healthy lifestyles tailored to specific age groups [52, 53]. Additionally, it plays a role in reimbursement models, such as determining eligibility for certain healthcare services.

4.5. Vital Status and Date of Death

If a patient dies, it is necessary to conclude ongoing treatment processes (e.g., cancel referrals and appointments for healthcare services). The PDD server obtains information about the time of death from the Central Population Registry, which is further used in the eAppointment system for the automatic cancellation of referrals, thus improving support for business processes and the quality of data on waiting lists. At the population level, the date of death is a key public health indicator [54]. As this data was available before the outbreak of the COVID-19 epidemic, the NIPH had daily data on mortality for the entire population. In combination with other PDD and health data, mortality data contributed to real-time insights into the epidemiological situation and decision-making on public health measures.

4.6. Next-of-Kin, Legal Guardians, and Authorized Representatives

Family members and legal representatives are often recipients of information about treatment and contact persons for healthcare service providers. Data on next-of-kin and legal guardianship enable automatic authorization of parents and guardians to perform digital services on behalf of children and wards (e.g., booking an eAppointment or digital access to healthcare documentation). Data on next-of-kin are important for public health measures, such as contact tracing in case of infectious diseases, scheduling childhood vaccinations, or organizing preventive health examinations in pediatrics [53]. People lacking digital skills or being unable to use digital services due to poor health can benefit from authorizing other trusted individuals the use digital services on their behalf. Such authorized representatives can help to empower vulnerable populations by overcoming digital barriers.

4.7. Health Insurance and Employment

In the process of calculating and reimbursing costs associated with sick leave, PDD serves as a cornerstone within health insurance information systems. This data is crucial not only for ensuring the accuracy and efficiency of administrative procedures but also for the financial processing of healthcare claims. By integrating PDD, health insurance systems can more effectively manage patient records, verify eligibility, and streamline the reimbursement process. Additionally, PDD provides valuable insights that can help tailor healthcare services to meet the specific needs of different population groups, ultimately improving the overall effectiveness and fairness of healthcare delivery [55]. Data on employment or employers of the active population are useful for occupational medicine and determining individual health risks, as well as to support targeted public health activities. During the COVID-19 epidemic, employment data facilitated the monitoring of disease incidence in individual companies and economic sectors. It is also useful for managing public health threats, such as interventions in accidents that occur on business premises.

4.8. Data on Students and Pupils

Data on schools and classes are crucial for organizing preventive checks of students and pupils. Health institutions need them for sending invitations, assigning school physicians, and scheduling appointments. Assigned school physicians can be automatically authorized to access EHRs, contributing to a higher quality of health service. Information on the individuals in certain schools and classes enables targeted public health measures and interventions in the face of health threats [56]. In combination with other data sources, such as the electronic vaccination registry, it enables effective measures to manage outbreaks of communicable diseases [57].

4.9. Chosen Personal Physicians and Other Authorized Healthcare Workers

In Slovenia, the organization of primary care is based on chosen pediatricians and family physicians who are the entry points to the healthcare system and are responsible for the continuity of care for their patients. Such physicians need access to the entire EHR and are authorized to issue digital documents (e.g., ePrescription, eReferral). Data on chosen personal physicians enables automated authorization for the usage of national digital health services and access to healthcare databases.

A similar principle can be applied to other health professionals involved in treatment. Information on healthcare teams treating specific patients enables the authorization of team members for digital health services. Contact information for healthcare teams is necessary for establishing secure telecommunication channels between patients and healthcare institutions. Such communication links can be assigned to specific clinics, treatments, or encounters. In conjunction with timetables and work shifts, this facilitates the development of effective digital applications for telehealth, as well as for managing complex healthcare organizations. The prudent use of information on authorized physicians and healthcare teams, combined with data on healthcare services and health outcomes, holds significant potential for improving healthcare system organization and shaping health policies [58]. It allows, for example, monitoring the workload of individual physicians and healthcare teams and evaluating service quality at the level of individual physicians or teams. Comparing results between teams providing similar services enables targeted measures to improve care quality and increase healthcare institutions' efficiency [59]. Contact details of healthcare teams are also valuable in implementing public health measures and responding to health threats (e.g., preventing the spread of infectious diseases in healthcare settings, reducing occupational risks for healthcare workers, and conducting epidemiological surveillance).

4.10. District Nursing

District nursing (home care service) is organized territorially, so to provide adequate applicable support, it is necessary to connect the authorizations of home care nurses with geographical data on residences. Information on the district nurse responsible for a specific area allows for the automatic allocation of authorizations to access the EHRs of the respective residents [60]. Organizers of home care services thus gain an overview of the geographical distribution of the population, enabling better organization of work and monitoring of the quality of care. Data on districts are also helpful in public health measures, especially when direct interventions at certain locations or the patient's home are needed.

4.11. Cross-Border Perspective

The aforementioned examples can be extended to the cross-border sharing of electronic health data for both primary use (treatment of the individual) and secondary use (population health) [61]. When a patient is treated outside their home country, sharing electronic health records is only possible upon providing the identifier. In cases where a child or a ward is treated abroad, information on next-of-kin or a legal guardian can assist in providing authorization for a service (e.g., dispensing prescription medication in another country based on an electronic prescription issued in the country of affiliation). Linking identifiers with electronic identification enables patients to electronically access and share their data in cross-border scenarios (e.g., eIDAS regulation) [62]. PDD can be highly valuable for an efficient response to cross-border health threats, especially when linked with geodetic data and EHR [63]. Having in mind an outbreak of an infectious disease or an environmental incident located in the proximity of the state border, health authorities on both sides of the border can utilize PDD and immediately reach out to the residents of the affected area and identify the most vulnerable individuals (e.g., by age, residence, or comorbidities). Accordingly, they can proceed with coordinated countermeasures and improve the efficiency of the response.

4.12. Applications and Implications of PDD in Healthcare Digitalization Initiatives

The views and statements expressed by focus group participants highlight that PDD serves as a cornerstone in the digital transformation of healthcare systems, forming a critical foundation for improving health service delivery and fostering innovation. Despite often being overlooked, this data is essential for ensuring the quality, accuracy, and functionality of EHRs and other digital healthcare tools. Beyond its primary role in supporting healthcare operations, PDD enables diverse secondary applications, driving progress in public health, policymaking, and healthcare analytics. The integration of PDD into healthcare digitalization initiatives enables a more nuanced understanding of patient populations [64]. By incorporating PDD, healthcare systems can transition from fragmented to cohesive data frameworks. Such enriched datasets could support precision medicine, personalized treatment plans, and data-driven decision-making across various healthcare domains.

The significance of PDD extends beyond the national context, playing a vital role in cross-border healthcare initiatives. With globalization and increased mobility, patients frequently seek medical care outside their home countries, necessitating interoperable and standardized PDD datasets. Such interoperability ensures continuity of care, supports informed clinical decision-making, and enhances the coordination of responses to cross-border health threats, such as pandemics. Cross-border applications also reveal the broader utility of PDD for secondary uses, including epidemiological research and health policy analysis on a global scale. By fostering international collaboration, PDD insights help bridge gaps in healthcare access and quality, ultimately advancing global health equity.

While PDD holds transformative potential for healthcare, lessons can be drawn from its application in other sectors. These practices could provide valuable insights into how healthcare systems might optimize their use of PDD for predictive analytics, resource planning, and intervention strategies. Standardization and harmonization of PDD across sectors can enhance its usability, fostering innovations that address critical societal challenges. Investments in research and infrastructure to improve data quality, governance, and interoperability will be crucial for realizing the full potential of PDD. By addressing current limitations and embracing a cross-sectoral approach, healthcare digitalization initiatives can leverage PDD to create more resilient, equitable, and efficient healthcare systems.

5. Discussion

This study aimed to examine the role and usability of PDD in healthcare digitalization initiatives in Slovenia. Using a multiple-case study methodology, the research combined qualitative insights from expert focus group discussions with secondary data drawn from business intelligence reports by the CRPD and a comprehensive literature review. The goal was to understand how PDD contributes to healthcare delivery, public health, policymaking, and cross-border coordination, while identifying key areas that require systemic improvement. This approach provided a thorough understanding of both the current applications and the unrealized potential of PDD in a digitally evolving healthcare landscape.

The findings of this study underscore the multifaceted significance of PDD in the healthcare domain. The convergence of focus group participants' opinions, previous research findings, and real-world statistical data consistently underlines the importance of PDD in enhancing the quality and functionality of healthcare systems, suggesting that it is not merely an operational asset but a strategic enabler of healthcare transformation.

Coding in the content analysis revealed that focus group participants emphasized the need for a coherent national strategy and regulation, highlighting the importance of policy-level coordination, strict compliance, and adequate resource allocation to guide digital health transformation. Codes related to data utilization and integration, such as digital solutions, interoperability, and analytics, were also among the most frequently referenced, underscoring the perceived need to leverage PDD for digital and data-driven improvements. These findings demonstrate a strong consensus that digital innovation, while crucial, must be embedded in a stable and forward-looking regulatory framework to reach its full potential. Moreover, participants pointed out that without adequate regulatory support and long-term strategic planning, digital health projects risk being fragmented, unsustainable, or misaligned with broader health system goals. In addition, considerable attention was given to data collection and quality, as well as to privacy and ethical considerations. Codes such as methodology, accuracy, data security, and patient consent reflect participants' concerns about the integrity of data processing and the ethical implications of using PDD, while also outlining common challenges such as data fragmentation, incomplete records, and privacy risks. Participants stressed the importance of using standardized data collection procedures and official public registers as the primary sources of PDD to ensure data validity and reliability. Reliable sources of accurate PDD and related information services are often overlooked but are a crucial and indispensable factor in the digitalization of healthcare. Furthermore, they pointed out that data quality directly impacts clinical effectiveness and operational efficiency, as poor data quality often leads to suboptimal patient outcomes, administrative delays, and resource misallocation.

The results of this study generally align with existing literature and, in fact, further emphasize that beyond their foundational role in ensuring the quality of EHRs for clinical decision-making, personalized care, and healthcare processes, PDD also holds immense potential for secondary applications [41, 65]. By supplementing healthcare data with PDD, their value and usability are greatly amplified [66, 67]. In light of this, the PDD emerges as a cornerstone of the eHealth information infrastructure, serving as a vital component of existing digital solutions in Slovenian healthcare. Its capacity to centralize and manage PDD not only streamlines healthcare processes but also lays the groundwork for innovation and advancement in healthcare services and health system optimization. Furthermore, PDD serves as a prerequisite for the development of novel solutions aimed at enhancing health treatment, combating infectious diseases and other health threats, implementing preventive public health measures, and refining public health policies [68, 69]. The comprehensive understanding provided by PDD insights enables healthcare stakeholders to tailor public health interventions, allocate resources effectively, and address emerging health challenges with precision and agility [70]. Importantly, the significance of PDD exceeds national borders, carrying relevance and applicability in cross-border scenarios for both primary and secondary use of health data [71, 72]. In an increasingly interconnected world, where individuals frequently seek healthcare services across national boundaries, the seamless exchange of PDD is essential for ensuring continuity of care, facilitating informed decision-making, and coordinating responses to cross-border health threats [73]. Therefore, recognizing the multifaceted value of PDD and investing in robust infrastructure for its collection, management, and exchange are imperative steps toward harnessing its full potential in advancing digital health solutions globally.

Nevertheless, significant challenges exist in the collection, processing, and utilization of PDD. One major issue is the lack of clear and strategic orientations regarding the use of PDD in healthcare. Without well-defined guidelines or long-term strategies, efforts to harness PDD are fragmented and lack consistency. This gap hinders not only the development of robust health information systems but also the potential for integrating PDD across platforms, leading to inefficiencies and missed opportunities for leveraging these datasets to improve healthcare outcomes. Additionally, there is a lack of reliable sources and standards for collecting PDD. Inconsistent methodologies, incomplete datasets, and outdated records pose serious problems for ensuring the accuracy and reliability of PDD [74]. This is further complicated by the fact that data sources are often siloed within different public and private registers, making it difficult to access and consolidate PDD cohesively. The absence of centralized and standardized collection protocols undermines the reliability of PDD, which in turn affects the overall quality of healthcare services and public health measures based on this data.

Another significant challenge relates to the ethical and privacy concerns associated with this data. PDD, by its nature, contains sensitive personal details that require careful handling to protect individual privacy. With the growing emphasis on data-driven healthcare solutions, safeguarding privacy has become a paramount concern. Data breaches, unauthorized access, and misuse of personal information can lead to significant ethical dilemmas and legal challenges [2]. Therefore, it is crucial to implement robust data protection frameworks and ensure strict compliance with privacy regulations when collecting, processing, and sharing PDD. Ethical considerations must extend beyond privacy concerns to ensure that PDD is used fairly, without discrimination, and in ways that truly benefit individuals and society at large.

In summary, the discussion highlights that advancing the usability of PDD in healthcare digitalization requires a balanced approach, combining strategic governance, technological innovation, methodological rigor, and ethical safeguards. As revealed through the focus groups and supported by the literature, four critical domains must be prioritized: (1) national strategy and regulation, (2) data collection and quality, (3) data utilization and integration, and (4) privacy and ethical considerations. Addressing these areas through coordinated action can help Slovenia – and other countries – realize the full potential of PDD in building more resilient, equitable, and efficient healthcare systems. The findings of this study underscore the urgency of investing in robust digital health infrastructures and comprehensive policy frameworks to maximize the benefits of PDD, both nationally and across borders.

5.1. Relevance Beyond the Slovenian Context

While this study was conducted within the Slovenian healthcare system, many of its findings and implications extend beyond the national context. The main challenges identified – ranging from inefficient digital solutions and insufficient normative frameworks to methodological flaws and unresolved security concerns – are not unique to Slovenia but are shared by healthcare systems worldwide, particularly in countries undergoing digital transformation [16]. Similarly, the identified enablers of success – strategic governance, high-quality data collection, integrated digital solutions, and strong ethical commitments – constitute universally relevant pillars for the effective implementation of PDD in healthcare digitalization initiatives [75]. By situating the Slovenian case within this broader framework, the study offers transferable insights that can inform policy and practice in other settings. The identified thematic categories and practical lessons learned from the Slovenian experience may serve as a valuable reference for stakeholders in other countries seeking to develop or refine their own digital health ecosystems. Moreover, the systemic approach adopted in this study – combining expert-driven focus group discussions, business intelligence reports from the CRPD, and a literature review – could serve as a methodological platform for similar investigations in other healthcare environments. In this regard, the Slovenian experience provides both a context-specific evaluation and a reflection of broader global trends in digital health, highlighting the imperative for effective national and cross-border strategies to harness the potential of PDD in enhancing health outcomes.

5.2. Limitations of the Study and Future Research Directions

The presented study on the role and usability of PDD in healthcare digitalization initiatives, while promising, is not without its limitations. Although Slovenia has made significant progress in the digitalization of healthcare and can showcase several highly effective and sophisticated digital solutions, the potential effects of PDD, particularly in areas such as secondary use, informed decision-making, and cross-border health threats, have been partly hypothesized without concrete empirical validation in the actual healthcare environment, as these areas are not yet fully developed. As a result, the projected implications and potentials of PDD, and the related discussion about future digital solutions in these areas, may raise questions, while the research outcomes may remain open to debate. Another limitation lies in the methodological and substantial difficulties of analyzing PDD across different systems. The lack of standardized protocols for data collection and processing often leads to inconsistencies that complicate cross-sectional studies or comparisons between different digital solutions, healthcare settings, and even more so within different sectors. Accordingly, the integration of PDD with data types from different sectors is still in its early stages, making it difficult for researchers to explore multidimensional features that could provide richer insights. Consequently, research outcomes may be skewed or fail to capture the full spectrum of impacts of PDD on digital solutions and subsequently on health and other services.

In light of these issues, future research in the field of PDD is both urgent and necessary. Future experiments should include a detailed investigation of the applications and implications of PDD, encompassing simulations of its use and testing within real healthcare environments. There is a pressing need for comprehensive studies aimed at developing more reliable and standardized methods of PDD collection and processing. Research should focus on formulating recommendations for establishing structures that enable efficient and timely collection, integration, and utilization of PDD, as well as exploring emerging technologies like AI to improve data quality. Furthermore, developing ethical guidelines for the use of PDD, particularly in cross-border healthcare scenarios, is essential. Ensuring data security, privacy, and compliance with national and international regulations will be critical in fostering trust in digital solutions operating on PDD platforms. Finally, future research should prioritize exploring ways to fully leverage PDD for predictive analytics, public health planning, and personalized medicine, as this could represent a crucial step toward unlocking the full potential of digital healthcare solutions.

6. Conclusion

The article provides a comprehensive overview of the critical role of PDD in the digitalization of the healthcare system in Slovenia and outlines its versatile usability, which could hopefully encourage other countries to build similar data structures and solutions. It highlights the importance of PDD in facilitating efficient healthcare delivery, managerial, administrative, and financial processes, and public health interventions. By contextualizing the outlined research findings within the global digital health landscape, this article can significantly enrich ongoing debates on PDD and its implications in designing digital health solutions and developing digital health policies.

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Transparency:

The authors confirm that the manuscript is an honest, accurate, and transparent account of the study; that no vital features of the study have been omitted; and that any discrepancies from the study as planned have been explained. This study followed all ethical practices during writing.

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