MAY 2024

MASTER THESIS

# Understanding the Value and Adoption of the International Patient Summary: Exploring Clinical Value, Facilitators, and Barriers

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MSC. BUSINESS ADMINISTRATION

S2147912

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The International Patient Summary
*key health data, worldwide*

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**SUBMISSION DATE**
08/05/2024

# Table of contents

Abstract ........ 4

1 Introduction ........ 5

  1.1 International Patient Summary ........ 5

  1.2 IPS's relevance: A practical example ........ 6

2 Research goal ........ 8

  2.1 Main question ........ 9

  2.2 Subtopic 1: The IPS's clinical relevance ........ 9

  2.3 Subtopic 2: Success factors and barriers ........ 9

  2.4 Subtopic 3: The IPS's implementation and adoption ........ 10

  2.5 Overall goal ........ 10

3 Research methods ........ 12

  3.1 Literature review ........ 12

    3.1.1 Goals and objectives ........ 12

    3.1.2 Methods ........ 13

    3.1.3 Information sources ........ 14

    3.1.4 Search queries ........ 14

  3.2 Interviews ........ 15

    3.2.1 Area of focus ........ 15

    3.2.2 Processing the interviews ........ 18

    3.2.3 Five-layer model ........ 18

    3.2.4 USE-IT adoption model ........ 19

    3.2.5 Interview analysis ........ 19

  3.3 Ethical permission ........ 20

4 Systematic literature review ........ 21

  4.1 Results ........ 21

    4.1.1 Study selection ........ 21

    4.1.2 Study characteristics ........ 22

    4.1.3 Individual studies' findings ........ 23

    4.1.4 Synthesis of results ........ 30

    4.1.5 Risk of bias across studies ........ 33

  4.2 Discussion ........ 33

    4.2.1 Summary of evidence ........ 33

    4.2.2 Limitations ........ 33

    4.2.3 Conclusions ........ 34

5 Interview results ........ 35

  5.1 Identified values ........ 35

5.2 Identified facilitators ........ 37
5.3 Identified barriers ........ 38
5.4 Observed key priorities ........ 39
5.5 Application to the five-layer model ........ 41
6 Synthesis of results ........ 44
6.1 Value ........ 44
6.1.1 Integration with literature ........ 45
6.1.2 Gaps with literature ........ 45
6.2 Facilitators ........ 46
6.2.1 Integration with literature ........ 47
6.2.2 Gaps with literature ........ 48
6.3 Barriers ........ 48
6.3.1 Integration with literature ........ 49
6.3.2 Gaps with literature ........ 50
7 Recommendations ........ 52
8 Conclusion ........ 56
9 References ........ 59
Appendix A: IPS elements ........ 66
Medications ........ 66
Allergies and intolerances ........ 66
Problems ........ 66
Immunizations ........ 66
Results ........ 66
Procedures ........ 66
10 Appendix B: IPS artefacts ........ 67
10.1 IPS Data Structure/Data Model – EN/ISO 27269 ........ 67
10.2 IPS FHIR IG – HL7 ........ 68
10.3 IPS CDA IG – HL7 ........ 68
10.4 IPS Terminology – SNOMED ........ 68
10.5 IPS Profile – IHE ........ 68
10.6 Interoperability, intraoperability and standardization ........ 69
Appendix C: Other IPS characteristics ........ 70
Interoperability vs intraoperability ........ 70
Standardization ........ 70
Summarization ........ 71
Appendix D: Similar health data exchange programs ........ 72
*Metspoedbeschikbaar* ........ 72
PRSB standard for patient handover ........ 72

GP data exchange ........ 72
Appendix E: Details of Table 1 ........ 74
Appendix F: Systematic literature review methods ........ 76
Study selection ........ 76
Study characteristics ........ 76
Data collection ........ 77
Data items ........ 77
Risk of bias in each study ........ 77
Risk of bias in studies ........ 79
Summary measures ........ 79
Synthesis of results ........ 79
Risk of bias across studies ........ 79
Appendix F.1: Identified factors from literature ........ 81
Appendix F.2: Table with used factors ........ 85
Appendix G: Specifications of found factors ........ 87
Appendix H: Interview form and questions ........ 89
Interview form ........ 89
Interview questions ........ 89
Concept questions doctors ........ 89
Concept questions managers/policy makers ........ 91
Appendix I: Research paper HIKM 2024 ........ 94
Exploring the clinical value of the International Patient Summary - a systematic review ........ 94
1 Introduction ........ 94
1.1 Goals and objectives ........ 94
2 Methods ........ 95
3 Results ........ 95
3.1 Study selection ........ 96
3.2 Results of individual studies ........ 96
3.3 Synthesis of results ........ 101
3.4 Risk of bias across studies ........ 102
4 Discussion ........ 103
4.1 Limitations ........ 103
4.2 Conclusions ........ 103

# Abstract

The International Patient Summary (IPS) is a set of basic clinical data that includes the most important health and care-related facts about a patient, enabling safe and secure healthcare.
This summarized version of the patient's clinical data gives health professionals the relevant information they need to provide care when there is an unexpected or unscheduled medical situation. Currently, there is insufficient information regarding the practical value of the IPS and its potential for improvement.

This study explored the potential and value of the IPS to improve healthcare delivery. Moreover, the aim was to discover how the current value of the IPS can be further improved. Through a combined approach of literature review and interviews with healthcare professionals, the research investigated the clinical relevance and value, facilitators, and barriers to IPS adoption. With the combined results of these data collections, this study explores strategies and actions for successful implementation and fostering worldwide adoption.

The findings highlight the significant clinical value of the IPS. Literature shows enhanced care quality, improved communication, and reduced healthcare costs. Interviews identify improved quality of care, more efficient access to relevant data, and enhancement of patient safety by ensuring healthcare providers have access to crucial patient information. However, challenges such as data security, technical limitations, and implementation costs hinder widespread use.

The research emphasizes the importance of addressing these barriers to maximize the IPS's potential. Key strategies include ensuring data privacy, fostering interoperability between electronic health records, and actively involving clinicians in the implementation process. Additionally, establishing clear governance structures and promoting awareness will be crucial for broader adoption.

Overall, the study validates the IPS's value proposition and emphasizes the importance of prioritizing its practical implementation. This involves utilizing the existing value of the IPS, while taking into account the identified facilitators and barriers, and focusing on the necessary actions to boost its adoption. Further research is recommended to deepen the understanding of IPS implementation factors and their practical effects on healthcare. By overcoming existing barriers and fostering collaboration, the IPS has the potential to become an important and standard-used tool in global healthcare.

# 1 Introduction

This master's thesis assesses the use, (clinical) relevance, implementation, and adoption of the International Patient Summary (IPS) in the Netherlands. The IPS context is broadly discussed, taking into account the clinical and medical aspects as well as the business-related factors.

This thesis presents two perspectives that, together, form a complete picture of the IPS. The first focuses on the impact of using the IPS in healthcare processes for healthcare providers and patients in clinical settings. It has direct consequences for caregivers, especially clinicians and healthcare personnel. The second perspective focuses on the implementation, integration, and ability to use the IPS. The implications for information-processing environments in healthcare organizations are also discussed in this study, and the perspectives are merged to form a complete picture. Furthermore, because the international context is important, this study considers how the IPS can be implemented in other countries for global use. In summary, this thesis examines the important knowledge available on and implications of the IPS by considering care and information processes, caregivers, patients, policies, and policy adoption. To explain what the IPS is and where it is used, an explanation of the IPS will be described, followed by a practical example, highlighting the practical use of the IPS. These topics provide a background to the need for this research as well as the goal of the IPS itself.

## 1.1 International Patient Summary

The IPS provides a standard for sharing a patient summary globally.

The Trillium Bridge project's recommendation to develop IPS in Europe and the United States in 2015 marked the initial introduction of the IPS (*Trillium Bridge recommends International Patient Summary Standard*, 2015). The IPS serves as the successor to the Continuity of Care Document (CCD), which is being used across the United States of America (USA) and the European Patient Summary, accessible through the electronic cross-border services in the European Union (EU). Since then, a global endeavor has been underway, with individuals worldwide actively involved in the development, improvement, and dissemination of the IPS for universal use. However, the current scarcity of literature on the IPS underscores the ongoing nature of evolution, with the IPS being an innovation in the world of information exchange in healthcare.

The overarching goal is to establish a minimal but universal health data set that can be used in any country, for any type of care, and by any caregiver. This ensures that a patient's crucial health data is readily accessible in all situations, ranging from medical emergencies to routine check-ups. While there is a perceived high value in using the IPS and progress is evident in its adoption globally, a lack of convincing evidence regarding its clinical relevance highlights the necessity for more comprehensive information on its value and the factors influencing its adoption, while also looking at the barriers hindering the adoption of the IPS. This study aims to provide a thorough overview of the added value of using the IPS in healthcare practice while identifying both barriers and facilitators.

The IPS is intentionally called "international" to emphasize its novelty and global focus, yet it can serve as a standard patient summary both locally and nationally. It resulted from the cooperative efforts of healthcare experts around the world, especially in Europe and the United States, to define and implement an international patient summary. The summary of patient information enables quick and easy retrieval of the most valuable information in any clinical situation. Figure 1 presents an overview of the data in a summary. The IPS consists of six elements that form the patient's health picture: medication, allergies and intolerances, health problems, immunizations, results, and procedures. Each element provides different information that can assist caregivers in helping the patient as quickly and accurately as possible. Short descriptions of these elements are included in Appendix A.

*Figure 1. The content of the IPS (IPS Web Editorial Team, n.d.)*

As clarified by the introduction, which is also visible on the IPS website (IPS Web Editorial Team, n.d.), the IPS provides a standardized way to globally share and use the most important data of a patient in different healthcare contexts, aiming to streamline healthcare processes and enhance patient-care outcomes. Despite the advancements in IPS development (D'Amore et al., 2021), challenges persist in its widespread implementation and adoption, warranting further inquiry.

To address these challenges and contribute to the continued progress of IPS adoption, this research attempts to delve deeper into its clinical relevance and the pathways to its successful implementation. To create the most relevant research questions, it is important to take into consideration the current knowledge gaps. First, even though the IPS is increasingly gaining international attention, its actual practical and clinical value remains unknown. Determining this value would entail assessing the impact of the IPS on caregivers and patients and confirming whether it enhances care quality. Second, this study must determine the current factors affecting the success of the IPS and the barriers hindering its full realization. Having this information is important, as the full implementation of the IPS has not been achieved yet. Research on success factors and barriers can speed up the adoption process and support further work and implementation. By exploring the factors that stimulate or hinder IPS adoption, this study aims to provide insights into and recommendations on suitable implementation strategies. Third, this research focuses on the complexities of IPS implementation and adoption, addressing the organizational and technical requisites for integration in different healthcare settings and contexts.

By aligning these gaps in knowledge with the overarching aim of enhancing IPS value, this study seeks to fill the gaps in existing knowledge and offer actionable insights. Ultimately, the study aspires to contribute to the evolution of IPS usage, fostering its integration into global healthcare ecosystems and ensuring its value in improving patient-care outcomes on a global scale.

## 1.2 IPS's relevance: A practical example

One of the most important aspects of the IPS is its practical value, which is also applicable to this research. The objective is to enhance the implementation and relevance of the IPS in practice, improving the quality of care delivered worldwide as well as patient and caregiver satisfaction.

Figure 2 presents an example of the IPS for a fictitious patient named Henk, who lives in Enschede in the Netherlands and is on holiday in Portugal. This example shows how the IPS is used in his local hospital, Medisch Spectrum Twente MST in Enschede, and the University Hospital Centre of Algarve (UHCA) in Faro, Portugal.

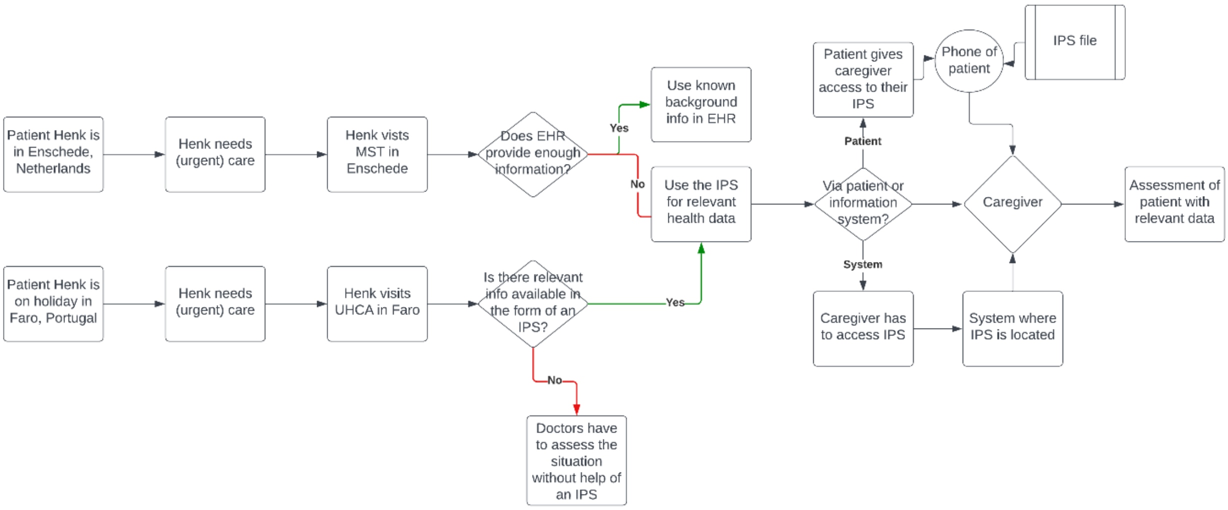


*Figure 2. An example of the process of using the IPS for a fictional patient, Henk, in his home country and abroad.*

1. The top pathway is an example of how to use the IPS locally. In a patient's local hospital, the IPS can provide benefits in terms of care, as all essential aspects of the patient's medical data are clearly described in the IPS. Having the IPS makes it easy for the caregiver to review all relevant data without bothering the patient with extra questions, as this data already exists in systems accessible by the hospital.
2. The bottom pathway is an example of how to use the IPS in a foreign country while on vacation. Often, medical data from an incoming patient from another country is absent. However, in cases of medical emergencies, it is essential for caregivers to have the most important information available as quickly as possible. In this case, it is helpful to have the IPS, as doctors can immediately review the most important health information, improving decision-making pertaining to diagnosis and treatment. This information is sometimes vital. For example, Henk has an extreme allergy to a medicine that can be used to treat his symptoms. However, due to a lack of information, his doctors do not know of his allergy and give him the medicine, exposing him to unnecessary risks. The use of the IPS would prevent such a situation from arising.

# 2 Research goal

Although much work has already been done on developing the IPS, there are still challenges that need to be addressed to further implement it and demonstrate the value of using it in healthcare practice.

One of the IPS's characteristics, which is also a challenge, is its ability to be implemented and integrated globally. The IPS is especially useful, as it can be used globally. By allowing more patients everywhere to receive better treatment around the world, the IPS can lead to better healthcare outcomes worldwide. Global implementation and adoption are important, as global health outcomes may witness improvement when the IPS is more widely adopted.

Much is already known about the use and specifications of the IPS, but many questions remain regarding how to make its implementation widespread and successful. These questions concern the IPS's relevance in clinical practice and its impact on caregivers and patients. Furthermore, implementation and integration in healthcare organizations are also points of interest; the main questions in this context are how the IPS can be implemented successfully in different organizations and how interoperability and intraoperability can be achieved locally and internationally. Finally, some form of IPS is already in use in different countries, such as the Netherlands and Canada. In the Netherlands, this process occurs with GPs and *metspoedbeschikbaar* in hospital emergency departments. In this regard, the questions are: what makes the process successful in such situations, and what knowledge can be gained from these situations to make the IPS more widely applicable?

A careful investigation of both the available and missing information resulted in the following research objectives: 1) to closely examine the clinical relevance of the IPS in practice; 2) to review the current success factors and barriers; and 3) to consider the condition of wider implementation of the IPS. These three goals present a clear vision of the information gap in existing research and focus on collecting valuable information to improve the IPS. In Figure 3 below, a graphical view of the different aspects of this thesis is presented.

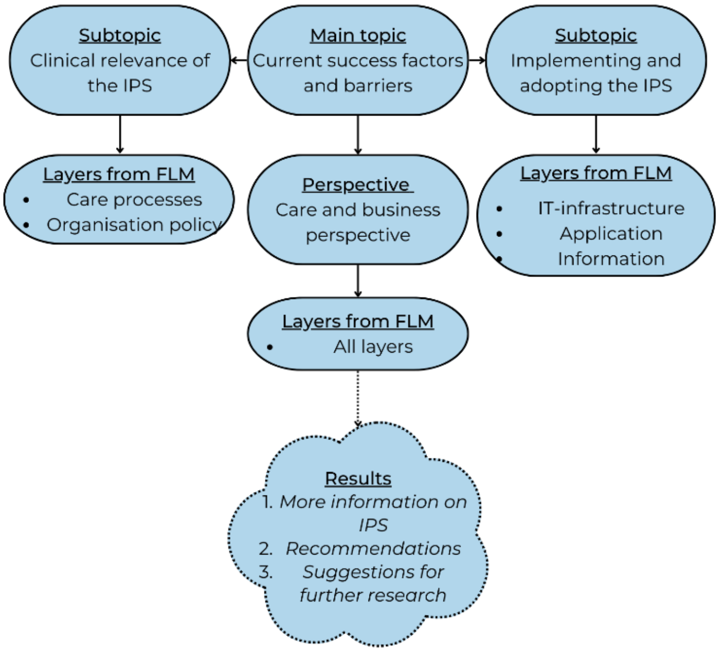


*Figure 3. Illustration of the research topics*

Figure 3 depicts the division of the topic into three subtopics, which form a complete picture for this study. The data collection is centered on these topics to create a clear picture of the current state of the IPS. However, the primary focus is on identifying the current value of the IPS, as well as identifying the facilitators and barriers that may respectively stimulate or hinder its further implementation and adoption. As a result, all three subtopics are included in the research. The research will be conducted from both a healthcare and business perspective, taking into account all these different factors. This collected information, which improves knowledge on value, facilitators, and barriers, can then lead to the following:

1. Information about the value and relevance of the IPS (value)
2. Recommendations for further use and implementation of the IPS (facilitators/barriers)
3. Suggestions for further research that should be done to promote the use of the IPS worldwide (further research, what should be done?)

The theory supports the background information and challenges, enabling the formulation of research questions that yield accurate and relevant information, thereby reinforcing the significance of this thesis for sustained IPS use. All the sub-questions fall under the purview of the main research question and are aligned with the topics presented in Figure 3, providing a complete picture of the IPS.

## 2.1 Main question

The main question addressed in this thesis is the following:

> *How can the added value of the International Patient Summary be improved to support its further adoption in healthcare practice?*

This main question covers the topic broadly, and specific questions about the IPS are addressed in the sub-questions below. This research focuses on the relevance and usefulness of the IPS in combination with its implementation. It addresses the adoption, implementation, and manner of use of the IPS and the factors that stimulate or hinder its adoption and implementation.

## 2.2 Subtopic 1: The IPS's clinical relevance

The first subtopic examines the IPS's clinical relevance in practice. This topic is especially pertinent to the field of health sciences. The layers of care processes and organizational policies of the FLM are relevant for this goal, which addresses whether the IPS provides an advantage in the daily practice of caregivers and the quality of care for patients.

The first subquestion, which pertains to the clinical relevance of using the IPS, addresses the content of the IPS and the influence of using the IPS in practice:

> *What is the clinical relevance of the International Patient Summary?*

## 2.3 Subtopic 2: Success factors and barriers

The second subtopic examines the factors that currently stimulate and hinder the IPS's success in practice. Both health sciences and business administration can relate to this broad topic; success factors and barriers can be associated with understanding the IPS, implementing it, using it in clinical settings, or adjusting IT or other systems to make the IPS functional in additional situations and different contexts.

Specific topics related to the factors that stimulate or impede IPS use may be added because of the information gathered from the literature and reports. The practical barriers derived from Nictiz (2022) are also included in the data collection, as they relate to the practical problems facing the IPS:

- Identification and authentication
- Shared patient data
- IPS content
- Integration of IPS information into the Electronic Patient Dossier (EPD)

In the second subquestion, the factors that determine the IPS's success and restrict its use are addressed. These factors can form a great guideline for determining what needs to be done in the future to further the worldwide adoption of the IPS.

*Which factors currently facilitate and restrain the use of the International Patient Summary in healthcare practice?*

## 2.4 Subtopic 3: The IPS's implementation and adoption

The final subtopic assesses further implementation and adoption of the IPS. This topic is related to the domains of business and healthcare. It focuses on IT systems, which can include information and organizational policy. While subtopic 1 discusses clinical relevance and practical use, this topic deals with implementation and adoption. Once the value and identified facilitators and barriers from subtopics 1 and 2 are clear, consideration can be given to how the IPS can be adopted more widely across the world—that is, how different countries can adopt the IPS while exchanging information without problems. This adoption, in turn, influences the care provided in emergency (and other unplanned) situations. Implementation and adoption directly involve hospitals, caregivers, IT staff, and others, making these issues part of the healthcare consideration.

The third subquestion addresses the implementation of the IPS:

*What organizational and technical changes are necessary to improve the value of the International Patient Summary and extend its adoption?*

## 2.5 Overall goal

This study aims to explore two key areas: (1) the clinical relevance and value of the IPS, and (2) the actualization of this potential clinical relevance or value. These goals are examined through a literature review and interviews, translating essential information into success factors and barriers, thereby facilitating the development of concrete and practical recommendations and new insights into the IPS.

On the one hand, the IPS focuses on health from a clinical perspective. Therefore, it is essential to determine whether it has clinical relevance. It is also important to examine whether its adoption improves health processes. Consideration can also be given to how caregivers and patients feel about using the IPS. The study must also examine how it can be implemented in doctors' current routines and workflows. Similarly, information on how well the IPS is currently functioning provides valuable insights into its advantages, as well as the barriers that must be overcome to make it more successful.

On the other hand, the IPS has a business perspective, which focuses on the IPS's information, application, and IT infrastructure. Special attention is paid to the interoperability of these systems. Examining the implementation of such a system in various healthcare organizations across Europe and other global regions is necessary. Moreover, how the IPS specifications should be made available or communicated to different stakeholder groups needs to be addressed. It is also important to consider how the IPS can be made practical and easy to understand for end-users. Considering that end users, who are mostly doctors and nurses, already have to use many administrative processes and systems, adding the IPS to their routines should be easy. It should not increase their clinical burden; however, it is important to evaluate how additional complex work for clinicians can be prevented.

In summary, this research aims to investigate two separate yet equally crucial topics: (1) the clinical relevance of the IPS and (2) the path to implementation and adoption. These subjects are examined in the literature review and through interviews with stakeholders, with the intention of identifying success factors and barriers. This information facilitates the development of practical recommendations and new insights into the IPS. From a health perspective, questions are raised about the IPS's clinical relevance and ability to improve health processes compared to its non-use. Additionally, the experiences of caregivers and patients using the IPS in their care are explored, along with its integration into existing workflows. A business perspective is also considered, focusing on the information, application, and IT infrastructure of the IPS, with a particular emphasis on interoperability. This perspective addresses how to introduce the system into various healthcare organizations in different countries and how to communicate IPS specifications to stakeholder groups.

Finally, it is essential to ensure that the IPS is user-friendly and does not increase the clinical burden of doctors and nurses, who already have numerous systems and administrative tasks to manage. Further research is required to fully address these issues and ensure the IPS's successful implementation and adoption.

# 3 Research methods

To answer the research questions, this study employs research methods that include collecting information through a literature review and interviews with healthcare professionals. These two methods each have their advantages for obtaining the necessary data.

## 3.1 Literature review

To provide a theoretical background for this research, a literature review was conducted to explore the literature on the value of using the IPS in healthcare practice. Additionally, information on factors that hinder and encourage the implementation and adoption of the IPS was considered. The PRISMA method (Moher et al., 2009) was used to systematically research the available and relevant literature through a broad search within multiple databases. The relevant literature was extracted, and the studies were assessed and analyzed. The findings were separated by value, facilitators, and barriers. These three themes form a complete theoretical picture of the current state of patient data exchange in healthcare, and conclusions were drawn about the value of using the IPS in healthcare practice. The findings from the literature review were used to develop the interview questions for the second data collection phase of this research.

The lack of convincing evidence regarding the IPS's clinical relevance confirms the need for more information on its value and the factors that facilitate or hinder its adoption. The goal of this systematic literature review was to provide a comprehensive overview of the added value of using the IPS in healthcare practice, identify barriers and facilitators, and create a foundation for conducting interviews (the second phase of the data collection). By achieving these goals, the systematic review provides a solid basis for generating new insights and recommendations regarding the IPS in healthcare practice.

As described in the "Research goal" chapter, this question is important for confirming the clinical relevance of using the IPS in healthcare practice, as convincing evidence is lacking. Although the IPS is becoming more popular across the world, clinical evidence to support its advantages is insufficient. Moreover, the factors that facilitate and hinder the value of the IPS in healthcare practice are also important. These data provide insights into which factors are relevant when considering the value of the IPS, and they form the basis for the interviews in the second part of this thesis. The literature review clarifies what is currently known about the subject, and the interviews also provide clarity about topics that the literature has not addressed yet.

### 3.1.1 Goals and objectives

The primary objective of this systematic literature review is to gather as much relevant information as possible to address the research question. However, it is important to acknowledge that the question may not be completely answered by this review alone. The following specific goals have been formulated, which are presented in Figure 4:

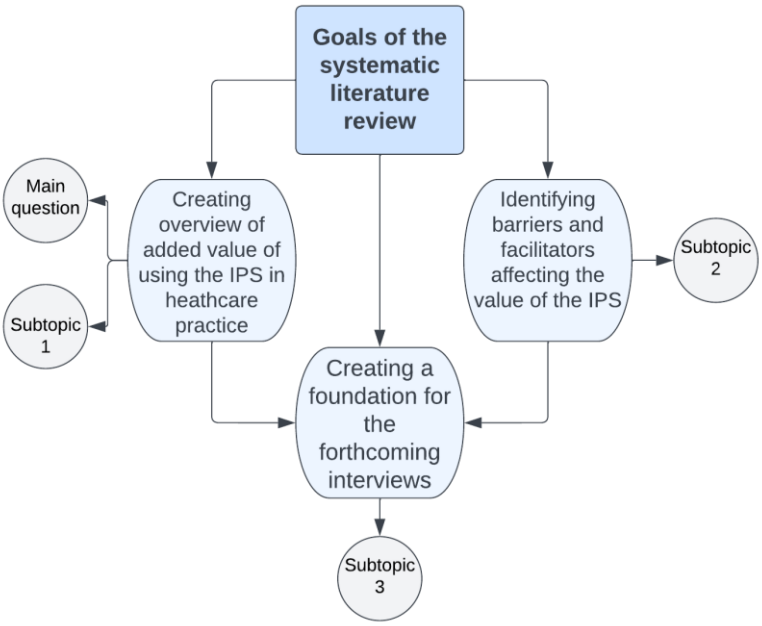


*Figure 4. The goals and objectives of the systematic literature review in relation to the research topics and questions*

- To provide a comprehensive overview of the added value of using the IPS in healthcare practice, in terms of both its value and clinical relevance (main question and subtopic 1)
    - This section focuses primarily on what makes the IPS relevant for use in healthcare practice.
- To identify the barriers and facilitators that affect the value of using the IPS in healthcare practice (optionally analyzing how these factors impact its implementation) (subtopic 2)
    - Facilitators and barriers influence the value that can be created by using the IPS in practice. Facilitators are the factors that increase the chance of successful adoption and, thereby, value.
    - Barriers hinder the adoption, use, and value creation of an IPS.
- To create a foundation for conducting interviews on how the aforementioned subjects (value, clinical relevance, barriers, and facilitators) affect the implementation and adoption of the IPS and allow for the exploration of the experiences and perspectives of healthcare professionals (subtopic 3)

### 3.1.2 Methods

This section outlines the methodology used to conduct the systematic review and provides a foundation for the analysis and discussion of the findings. Because the research question is relatively new, it is crucial to identify and analyze all articles that provide valuable information on the topic. Additionally, the selection process, search queries, data collection, and synthesis methods are discussed in this study, highlighting the steps taken to ensure that all relevant information is included in the review.

#### *3.1.2.1 Review protocol*

While the PRISMA methodology recommends having a review protocol, this study did not employ one, as this review was conducted as part of a university master's thesis. Creating an official protocol was not deemed necessary or feasible given the time constraints, but the review process is thoroughly explained in this chapter. For this review, no registration information or registration number is available.

#### 3.1.2.2 Selection criteria

To ensure that the literature review included only high-quality, relevant articles, several selection criteria were used. These criteria were designed to narrow down the search results, exclude articles that do not meet the research objectives, and develop a focused and comprehensive literature review.

#### 3.1.2.3 Study characteristics

The selection criteria for eligible studies included the following aspects:

- The study must be published in English, as that is the language of this research.
- The study must report the value, impact, barriers, or facilitators of using the IPS in healthcare practice, as they constitute the focus of this research.
- The study must include sufficient and relevant outcomes for measuring the value of using the IPS in healthcare practice.

#### 3.1.2.4 Report characteristics

Additionally, the following report characteristics were considered:

- The publication year was not restricted, as the IPS is a relatively new concept, and all relevant literature is important.
- Only articles published in peer-reviewed journals were considered, besides relevant and reliable grey literature.
- Only full-text articles were included in order to ensure that they could be assessed for eligibility.

### 3.1.3 Information sources

Two information sources were consulted for this study: PubMed and Scopus.

#### 3.1.3.1 PubMed

PubMed is a free research database that allows for searching and retrieving literature on life sciences and biomedicine, aiming to improve health at both the individual and global levels (PubMed, n.d.). More than 35 million citations and abstracts are included in this database, often accompanied by links to full texts from the publisher or via PubMed Central. This database is excellent to use because there is a tremendous amount of literature available that matches this research topic.

#### 3.1.3.2 Scopus

Scopus combines a comprehensive database, which contains expertly curated abstracts and citations, with enriched data and linked scholarly literature across multiple disciplines (Elsevier, n.d.). This database is widely used in this sector and provides many relevant articles, making it a suitable second database for this study.

### 3.1.4 Search queries

This study's search strategy involved developing a search string that would yield accurate and relevant results. This was achieved by iteratively testing different search terms and assessing their impact on the yield. Once an adequate number of results were obtained, the predetermined criteria (see "Selection criteria") were applied to identify all relevant articles and exclude the irrelevant ones. Some search strings returned irrelevant results; hence, the selection criteria were used to exclude those search terms from the final search string. Multiple search strings were tested to ensure that the most relevant literature was captured. After excluding the irrelevant results, the literature was analyzed and presented.

The final search query applied is discussed in the "Results" chapter. It attempts to partly answer the main research question:

> *"How can the added value of the International Patient Summary be improved to support its further adoption in healthcare practice?"*

The query *("clinical relevance" OR "Health Care" OR "quality of care") AND "value" AND ("international patient summary" OR "IPS" OR "Health Information Exchange") AND ("benefits" OR "advantages")* led to the following results:

*Table 1. Number of results divided per information source*

| Information source | Number of results |
|---|---|
| PubMed | 29 |
| Scopus | 48 |

## 3.2 Interviews

The second data collection method involved conducting interviews with a group of healthcare professionals working in (emergency) patient care. This approach is used to gain practical insights into the IPS's value, barriers, and facilitators, as well as to address the proposed research questions. The interviews focused on capturing the professionals' experiences with a patient summary in the daily practice of delivering care to patients of which they had no prior knowledge or record.

Additionally, the interviews covered topics related to the organizational and technological changes necessary to improve the adoption of the IPS, in alignment with subquestion 3. By gathering input from the interviewed medical professionals, the interviews will provide valuable insights and perspectives on the value of the IPS, along with identified facilitators and barriers and, lastly, organizational and technological changes they would want to see, contributing to a more nuanced understanding of its implementation and utilization in healthcare practice.

The interviews provided an opportunity to delve deeper into the experiences and perspectives of the professionals. Through these interviews, the findings from the literature review will be validated or contradicted. Furthermore, nuances that may not have been captured in the existing research will be explored.

### 3.2.1 Area of focus

In order to create relevant and reliable results, it is important to set clear frameworks within which the practical data will be gathered. To narrow down the aim of the interviews, the following observations and changes are made:

1. **Focus on The Netherlands**

The interviews focus on Dutch medical specialists who work with patient summaries in their daily work, as the aim is to research the context and possibilities of the IPS in the Netherlands. Foreign medical specialists are excluded.

## 2. Different use-cases

While the IPS itself is not yet fully implemented in the Netherlands, it is important to look at the different use cases of patient summaries in the country. Patient data and summaries are used in a variety of contexts, including the following four:

1. GP out-of-hours offices
2. Emergency care
3. European Patient Summary (EPS)
4. International Patient Summary

Securing interview participants from healthcare professionals using the IPS or EPS (use cases 3 and 4) is nearly impossible, as the usage in the Netherlands is almost nonexistent, leading to difficulties in recruiting suitable participants. Moreover, the maturity of using patient summaries in ER-departments (use case 2) can be diminished due to the absence of dedicated patient summaries via a national broad system, where patient consent is necessary for foreign hospitals to access relevant data in the first place. Patients can grant permission to healthcare providers to access and use their information for healthcare delivery. However, this is not nationally implemented, where it practically only applies to the patient's own hospital and healthcare providers. It depends on the GP and the permissions of the patient to determine which information is available. Often, reliable and sufficient information is only available when the patient is in their local hospital.

This all leads to the conclusion that the GPs (use case 1) are the only suitable group of healthcare professionals that can participate in this research. Professionals from the other use case groups have been contacted, but they have confirmed that their use case is not suitable for this type of research due to the scarcity of professionals with sufficient knowledge and experience in this field.

## 3. Level of maturity

The next step entails looking at the maturity of the use of these patient summaries. For the purpose of doing interviews and having enough relevant healthcare professionals available to interview, it is crucial to look at the maturity of using patient summaries in workflows. Only use cases, where the interpretation of patient data through patient summaries is routine and mature enough, are suitable for interviews, as other use cases may not provide sufficient data for analysis and use in this research. Presently, only one hospital in the Netherlands has the capability to receive patient summaries from other European countries. Moreover, the number of countries capable of sending patient summaries to the Netherlands is limited, as point-to-point tests are required to ensure interoperability. The frequency of live exchanges in recent years has been minimal in the Netherlands (Bruthans & Jiráková, 2023), posing significant challenges in sourcing interview participants as the available expertise and experience may not be sufficiently developed for research purposes.

Similarly, in the Netherlands, the integration of patient summaries into emergency care practices is still in the process of being implemented. The national implementation program concluded in July 2023 with the acknowledgment that further work is needed, as not all organizations comply with the revised guidelines for information exchange in emergency care ("Met spoed beschikbaar," 2023). These findings indicate the need for an alternative approach to gathering data from interviews. Concluding, the level of maturity also points to the GPs as a suitable group for research through interviews.

## 4. Focus on GP Out-of-hours Offices

When taking into account the above restrictions, the outcome is that GPs, with their work in out-of-hours offices, are suitable for the interviews. In the emergency setting, working at the out-of-hours office with unknown patients who are potentially critically ill or injured, they represent the best group for giving information about the value and use of patient summaries in the Netherlands. GPs in the Netherlands have years of extensive experience using patient summaries, particularly those who handle patients from other GPs outside regular office hours through dedicated GP out-of-hours offices. While the context and level of internationality may differ, these GPs can provide valuable insights into the use of patient data exchange systems like the IPS. As a result, the focus will be on interviewing GPs to gain a comprehensive understanding of their experiences and perspectives, ensuring a scientifically relevant view of the value, facilitators, and barriers associated with IPS usage in practice. Given the impracticality in the Dutch context, this approach is deemed more relevant than attempting to recruit participants from each use case, which would result in less valuable and relevant results.

The restriction of one suitable group of participants required this research to follow a case study-centered approach. This ensures that the results from the GPs are valid and can still be used for scientific evidence without taking into account practical insights from other use cases. The methodology employed in this research aligns with the established guidelines of Yin (2003), emphasizing a rigorous approach to data collection within the constraints of the study context. Given the unavoidable challenges in accessing participants from multiple use cases, the focus was directed towards the use case most widely represented in the Netherlands—the GPs. These GPs serve as integral stakeholders in patient care and possess comprehensive knowledge and experience regarding patient data exchange systems and summaries, particularly within the context of GP out-of-hours offices. Through a series of interviews with GPs, a relevant understanding of their experiences and perspectives on the utilization of patient summaries will be gathered. The validation process involves GPs cross-verifying each other's statements, enhancing the credibility and trustworthiness of the gathered data.

Moreover, to ensure the overarching validity of the findings and to adhere to the case study guidelines of Yin (2003), an additional interview will be conducted with a medical specialist and/or policy expert in the field. This expert perspective serves to cross-validate and assess the insights gathered from the GP interviews, offering a comprehensive assessment from a knowledgeable authority. A suitable expert will be selected to cross-validate the other interviews and provide additional insights into the value of the IPS, as well as identify facilitators and barriers that may not be readily apparent to healthcare professionals in the field. After this interview, an assessment will be done on the gathered information. When needed (e.g., when there are too many contradictions), an extra validating interview will be held to increase the reliability and relevance of the interview results. By combining data from both GPs and the expert(s), the research findings will be substantiated and validated, contributing to the relevance of the study outcomes.

This methodological approach, similar to a case study design, is well-suited to the complexities of the research context, where access to participants across various areas is constrained. By prioritizing GPs, who possess substantial expertise and serve as primary users of patient summaries, the research ensured the collection of relevant and insightful data. The subsequent validation by an expert in the field further stimulates the credibility and reliability of the research findings. Thus, this methodology adheres to the principles of case study research advocated by Yin, providing a scientific framework for investigating the value and utilization of patient summaries in the Netherlands.

### 3.2.2 Processing the interviews

A qualitative approach was employed to explore the value, facilitators, and barriers associated with IPS use in healthcare practice. The interviews were semi-structured and were conducted with healthcare professionals. The interviews were audio-recorded and transcribed for further analysis. To manage and analyze the interview data, a qualitative data analysis software called Atlas.TI (version 24) was utilized. The software facilitated the systematic organization and coding of the interview transcripts, enabling the identification of key themes, patterns, and emerging concepts.

### 3.2.3 Five-layer model

The five-layer model (FLM) was employed as a framework for categorizing the findings from the interviews. The FLM, embraced by Nictiz (Sprenger, 2020), offered a comprehensive structure to enhance interoperability among healthcare organizations. It consists of five distinctive layers within an organization and forms the basis of the Refined eHealth European Interoperability Framework (Kouroubali & Katehakis, 2019), demonstrating its broad applicability.

During the analysis process, the FLM organized the interview data into distinct layers, generating an overview of the value, facilitators, and barriers associated with each layer, thereby establishing a link between theory and practice. Figure 5 illustrates the model and the layers into which the interview data were organized.

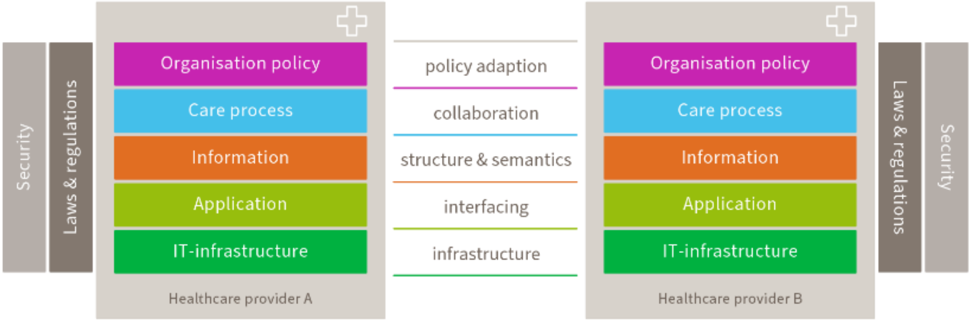


*Figure 5. The five-layer model of Nictiz (Kouroubali & Katehakis, 2019; Sprenger, 2020)*

The different layers in the figure are as follows:

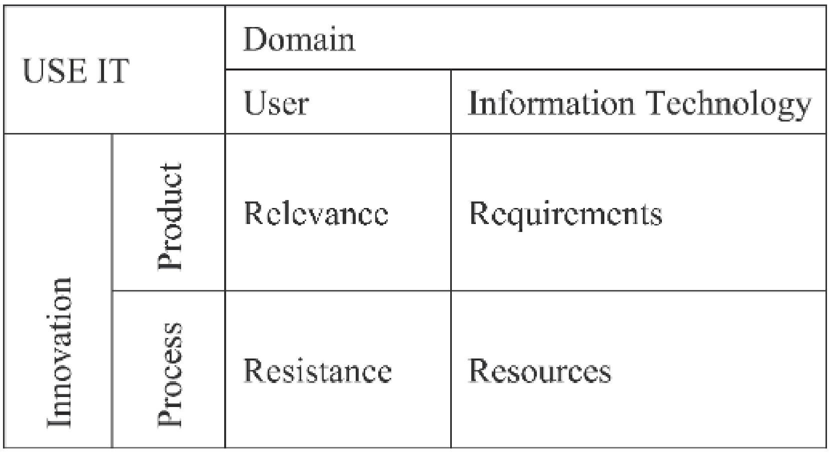
1. **Organizational policy**: This layer encompasses the organization's policies, management, and administration, providing an overview of its internal workings.
2. **Care processes**: These processes represent the entirety of care activities within a specific organizational unit.
3. **Information**: This layer includes the various types of information that support care processes. It addresses the relationships between different types of information, the structure of care processes, and the information needs and delivery by individuals and devices.
4. **Application**: This layer comprises the applications responsible for storing, processing, structuring, analyzing, and communicating information. It encompasses a range of tasks carried out by different applications.

5. **IT infrastructure**: The IT infrastructure serves as the technical foundation on which all applications operate, providing the necessary infrastructure to support the functioning of the healthcare system.

### 3.2.4 USE-IT adoption model

The USE-IT adoption model (Michel-Verkerke & Spil, 2013) offers a valuable framework for formulating the interview questions in this research. This model investigates the factors that influence the adoption and usage of IT innovations in a user domain, taking into account both the product and the process innovation. The key constructs of the USE-IT model include relevance, resistance, requirements, and resources.

The interview questions were structured and formulated using the USE-IT adoption model, which provides a framework to systematically organize the questions and relate them to factors such as relevance, resistance, requirements, and resources.



| USE IT | | Domain | |
|---|---|---|---|
| | | User | Information Technology |
| Innovation | Product | Relevance | Requirements |
| | Process | Resistance | Resources |

*Figure 6. The USE-IT model (Michel-Verkerke & Spil, 2013)*

By incorporating the USE-IT model into the research design, this thesis aimed to gain knowledge of the factors influencing the adoption and implementation of the IPS in healthcare practice. Hence, the relevance of the IPS to patient-care improvement, resistance to implementation, the requirements for successful adoption, and the necessary resources for effective adoption were explored by integrating them into the interview questions.

### 3.2.5 Interview analysis

In total, five interviews were conducted, with each session lasting approximately 40 minutes. The interviews were semi-structured, allowing for open-ended questions to stimulate detailed responses and exploration of important topics. The interview questions focused on various aspects of IPS adoption, including its perceived value, facilitators, and barriers.

The first step was the transcription of all the interviews. Following the transcription, the data were analyzed using a qualitative analysis software called Atlas.TI (version 24). Before the coding process, the code groups "Value," "Facilitators," and "Barriers" were established, as most codes were expected to fall into one of these three groups. Subsequently, the transcripts were coded to identify key themes and patterns related to value, facilitators, and barriers. Other important or relevant quotations were also coded to be taken into account when grouping later. The codes were then organized into code groups, including the pre-defined groups of “Value,” “Facilitators,” and “Barriers” and newly added code groups of “Importance of information” and “Five-layer model,” which were formulated while analyzing the data. Many of the participants’ observations pertained to information characteristics, while other codes could be grouped in the “Five-layer model” for further analysis and contextualization within the model.

The interviews were planned to understand the real-world benefits of using the IPS in healthcare. The main question that needed to be answered was the following: “*How can the added value of the International Patient Summary be improved to support its further adoption in healthcare practice?*” The professionals played a crucial role in understanding the value and possible improvements. While the systematic literature review provided a basic understanding of the value, facilitators, and barriers influencing IPS adoption, the interviews served to bridge the gap between theory and practice.

## 3.3 Ethical permission

The BMS Ethical Commission of the University of Twente granted ethical approval (number 230020) on 6 March 2023. This approval ensures that the research is conducted ethically and responsibly, and that the participants' welfare and rights are protected. All the participants involved in the interviews provided informed consent, and their anonymity and confidentiality will be respected. This approval also includes guidelines for data storage, handling, and analysis to ensure the protection of participants’ personal information.

# 4 Systematic literature review

In this chapter, the results of the systematic literature review are presented to form the theoretical basis for this thesis. This review forms the basis for further research performed via interviews. The selection of articles within this systematic review will be performed in accordance with the guidelines of the PRISMA statement (Moher et al., 2009).

Note that the literature review has been submitted and accepted for presentation at the Health Information Knowledge Management Conference, with the research being published by ACM (Schippers & Stegwee, 2024). The paper is included in Appendix I.

## 4.1 Results

This section describes the selection process, characteristics, risk of bias within and across the studies, the results of the individual studies, and the synthesis of the results. Furthermore, any additional optional analyses are presented when relevant.

### 4.1.1 Study selection

In this systematic review, the initial step was to identify relevant studies to include in the analysis. A comprehensive search was conducted in PubMed and Scopus using a predetermined search strategy. This search strategy included keywords related to clinical value and relevance, healthcare, quality of care, the IPS, health information exchange, benefits/facilitators and barriers, which led to the following results:

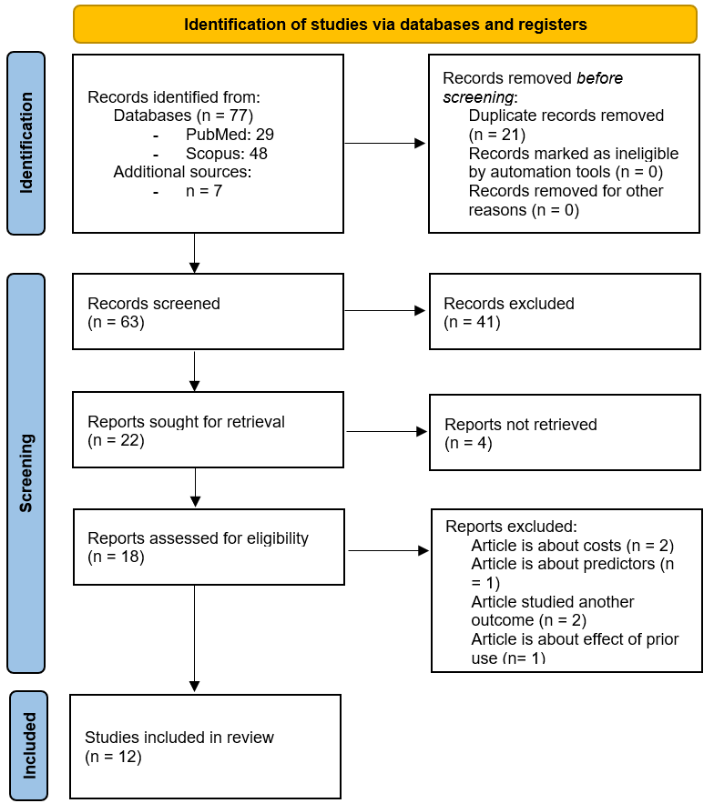


*Figure 7. Systematic review PRISMA flow diagram for articles reporting on the value of using the IPS in healthcare practice (PRISMA, 2020)*

A total of 84 studies were identified and screened for eligibility. Following the screening process, 70 studies were excluded for various reasons, including irrelevant outcomes or study design. The remaining 12 studies were included in the final analysis. A flow diagram depicting the study selection process is presented in Figure 7. The selected studies all presented results on either value, facilitators, or barriers.

### 4.1.2 Study characteristics

The studies included in this systematic review covered a range of topics related to health information exchange and the value of using the IPS in healthcare practice. The studies included were the following:

*Table 2. Included studies.*

| **Study title** | **Authors (year)** | **DOI** |
|---|---|---|
| Barriers and facilitators to exchanging health information: A systematic review | Eden et al. (2016) | 10.1016/j.ijmedinf.2016.01.004 |
| Despite the spread of health information exchange, there is little evidence of its impact on cost, use, and quality of care | Rahurkar et al. (2015) | 10.1377/hlthaff.2014.0729 |
| Factors related to health information exchange participation and use | Yeager et al. (2014) | 10.1007/s10916-014-0078-1 |
| Health information exchange | Qian (2020) | 10.23970/ahrqepcerta220 |
| Hidden value: How indirect benefits of health information exchange further promote sustainability | Tzeel et al. (2012) | PMID: 24991331 |
| Identification of barriers affecting the use of health information exchange (HIE) in clinicians' practices: An empirical study in the United States | Esmaeilzadeh (2022) | 10.1016/j.techsoc.2022.102007 |
| Systematic review of health information exchange in primary care practices | Fontaine et al. (2010) | 10.3122/jabfm.2010.05.090192 |
| The benefits of health information exchange: An updated systematic review | Menachemi et al. (2018) | 10.1093/jamia/ocy035 |
| The effects of health information exchange access on healthcare quality and efficiency: An empirical investigation | Janakiraman et al. (2022) | 10.2139/ssrn.2915190 |
| The impact of health information exchange on healthcare quality and cost-effectiveness: A systematic literature review | Sadoughi et al. (2018) | 10.1016/j.cmpb.2018.04.023 |
| The role and benefits of accessing primary care patient records during unscheduled care | Bowden and Coiera (2017) | 10.1186/s12911-017-0523-4 |
| The value of connected health information: Perceptions of | Tharmalingam et al. (2016) | 10.1186/s12911-016-0330-3 |

| | | |
|---|---|---|
| electronic health record users in Canada | | |

### 4.1.3 Individual studies' findings

The results of the individual studies are discussed in this section. This research divides the results into three main subjects: value, facilitators, and barriers. A complete table of all identified factors is included in Appendix F.1.

#### *4.1.3.1 Value*

The literature review identified several key factors that contribute to the value of using the IPS in healthcare practice. Table 3 presents an overview, focusing on the articles that explicitly mention these factors and excluding those without them. The factors discussed below have been mentioned in at least three of the analyzed studies, which indicates their significance in the literature.

*Table 3. Identified factors for "value"*

| **Factor**<br>**Article** | Improved quality of care | Improved communication among healthcare providers | Reduced healthcare costs | Hospital readmission rate | Health record completeness | Improved patient safety |
|---|---|---|---|---|---|---|
| **Qian (2020)** | X | X | X | X | X | |
| **Tzeel et al. (2012)** | X | X | X | | | |
| **Menachemi et al. (2018)** | X | X | X | | X | |
| **Janakiraman et al. (2022)** | X | | | X | | |
| **Sadoughi et al. (2018)** | X | X | | X | X | X |
| **Tharmalingam et al. (2016)** | X | X | | | | X |
| **Fontaine et al. (2010)** | X | X | X | | | |
| **Rahurkar et al. (2015)** | | | | X | | |
| **Esmaeilzadeh (2022)** | | | | | | X |
| **Bowden and Coiera (2017)** | | | | | | |

The most mentioned subject regarding value is improved quality of care. Qian (2020) observed this heightened quality of care through enhanced medication management, improved immunization processes, and a reduction in care disparities. Similarly, Menachemi et al. (2018) reported increased quality of care, with notable improvements in medication reconciliation, immunization, and a decrease in care disparities. The study also demonstrated a reduction in overall costs for care and diagnostic testing. Janakiraman et al. (2022) further supported these findings by highlighting how health information utilization resulted in reduced patient length of stay, thereby enhancing the quality of care delivered. Sadoughi et al. (2018) explored various aspects of improved quality of care, including the avoidance of repeat imaging and unnecessary laboratory tests, reduced repeat visits, and decreased time required to provide care. Additionally, decreased medication errors emerged as a potential benefit of using health information in practice. In a separate investigation, Tharmalingam et al. (2016) assessed the quality of care through evaluations of Integrated Electronic Health Records (iEHR). The study highlighted positive aspects, such as improved clinical decision support, access to more reliable external information sources, and enhanced care coordination. Fontaine et al. (2010) focused on the effects of health information on quality, taking into account its relationship to efficiency. They reported that improved access to test results and a streamlined process for handling referrals and claims processing significantly contributed to efficiency, while better health outcomes and enhanced patient safety (reduced prescribing errors and readmissions) underscored the quality improvement. On a broader scale, Tzeel et al. (2012) emphasized the indirect value of healthcare information exchange, leading to shorter patient lengths of stay in clinical settings, potentially reducing associated costs, and ultimately benefiting the entire community's health by granting clinicians access to patients' medical histories. These collective findings underscore the substantial value and positive impact of the IPS in enhancing the quality of healthcare delivery.

Improved communication among healthcare providers is a direct and valuable outcome resulting from the successful implementation and adoption of patient information exchange systems, as reported in multiple studies (Qian, 2020; Menachemi et al., 2018; Sadoughi et al., 2018; Fontaine et al., 2010; Tzeel et al., 2012; Tharmalingam et al., 2016). Qian (2020) highlights that the use of health information exchange leads to enhanced communication among care teams, promoting better care coordination and more informed decision-making. Menachemi et al. (2018) also emphasize the positive impact of patient data exchange on communication within and between healthcare organizations, facilitating seamless information sharing and collaboration. Additionally, Sadoughi et al. (2018) discuss improved communication as one of the valuable outcomes of health information exchange, leading to better care coordination and reduced repeat visits. Fontaine et al. (2010) underscore the significance of improved communication in enhancing care quality and safety and enabling better exchange of information among care providers. Tzeel et al. (2012) observe shorter patient lengths of stay in clinical settings using patient information exchange, indicating improved communication and streamlined care processes. Furthermore, Tharmalingam et al. (2016) highlight the positive impact of integrated electronic health records on communication, with improved clinical decision support and more reliable external information sources contributing to better care coordination.

Observations were also made regarding the effect on healthcare costs. Qian (2020) conducted a study that provides evidence of reduced healthcare costs resulting from the use of the IPS. This reduction was attributed to a decrease in unnecessary imaging and other medical procedures. Similarly, Tzeel et al. (2012) observed a reduced length of stay, which indirectly led to lower healthcare costs incurred during hospital stays. While Rahurkar et al. (2015) did not find fully conclusive evidence regarding cost reduction, their research suggested the potential for decreased healthcare costs through a reduction in diagnostic and imaging tests facilitated by patient information exchange. In Fontaine et al.'s study (2010), an exploration of the value and benefits of patient data exchange, including costs, was undertaken. The study argues that cost savings might be achievable due to evidence of increased efficiencies, such as improved access and processing. However, it is important to note that the evidence supporting cost savings in this context is not entirely conclusive.

According to several studies, the use of the IPS in healthcare practice has shown a promising impact on reducing hospital readmission rates. Qian (2020) highlighted the notable decrease in the 30-day readmission rate, indicating improved patient outcomes with access to patient information integration. Janakiraman et al. (2022) further corroborated these findings, attributing the reduction in readmissions to the availability of comprehensive health information and enhanced access to patient data. It was evident that direct access to health information played an important role in decreasing readmission rates. In the investigation by Sadoughi et al. (2018), the effects of health information access on readmission rates were explored as part of the broader assessment of healthcare quality. While the evidence was not entirely conclusive, there was a compelling indication that patient information access led to a reduction in readmission rates. Moreover, Rahurkar et al. (2015) investigated hospital readmissions as a component of overall hospital care utilization. Although variations were observed, the overall conclusion suggests a clear correlation between information exchange utilization and a reduction in hospital readmission rates. These collective findings highlight the potential value of using the IPS to improve patient care continuity and reduce the likelihood of readmissions, ultimately benefiting both patients and healthcare providers.

According to three studies, the element of health record completeness emerges as a crucial factor. Qian (2020) conducted a comprehensive study on the quality of care, wherein multiple advantages were observed, including improved health record completeness. With the integration of the information exchange, healthcare providers gained access to a more comprehensive and up-to-date health record for each patient. This finding is further supported by Menachemi et al. (2018), who found that improved quality of care was linked to the utilization of health information exchange, particularly in relation to health record completeness. The adoption of the patient data exchange allowed for the seamless exchange of patient data between different healthcare settings, ensuring that health records were comprehensive and consistent across care providers. Additionally, Sadoughi et al. (2018) reported on improved reporting completeness, which, while not identical, aligns with the finding of enhanced completeness of health records through the use of patient data exchange. The implementation of this system led to more standardized and thorough reporting practices, ensuring that crucial patient information was captured and shared efficiently. This contributed to a more comprehensive health record, facilitating better communication among healthcare providers and reducing the chances of critical information being overlooked or misinterpreted.

In three studies, the aspect of patient safety was also highlighted. Sadoughi et al. (2018) explored the impact of healthcare data exchange on patient safety as part of their study on healthcare quality. Although the evidence may not yet be entirely conclusive, the observed potential and effects of patient data exchange suggest a probable positive impact on patient safety. Similarly, the study conducted by Esmaeilzadeh (2022) revealed beneficial effects on patient safety. The investigation into the most and least preferred methods of exchanging information and data-sharing mechanisms was particularly intriguing. The study found that traditional mechanisms, such as fax or email, were the least favored, while point-to-point mechanisms, such as EHR-to-EHR sharing, emerged as the preferred options. This preference for direct exchange through secure channels is likely to enhance patient safety by minimizing the risk of data breaches or miscommunication during information transfer.

#### *4.1.3.2 Facilitators*

Regarding the subject of facilitators, research has been done on the facilitators that create value by using the IPS or assist IPS adoption. The facilitators found are shown in Tables 4 and 5, and articles without these factors have been omitted. However, due to the factors having a low number of mentions (mostly one per factor), the factors have been grouped in order to create more clear and meaningful factors, as shown in Table 6.

*Table 4. Identified factors for "facilitators" part 1.*

| Factor<br>Article | Information completeness | Organization and workflow | Technology and user needs | Patient value | Meaningful use | Cost and adequate funding |
|---|---|---|---|---|---|---|
| **Eden et al. (2016)** | X | X | X | | | |
| **Yeager et al. (2014)** | | | | X | X | X |
| **Qian (2020)** | | | | | | X |
| **Esmaeilzadeh (2022)** | | | | | | |

*Table 5. Identified factors for "facilitators" part 2.*

| Factor<br>Article | Supportive organization culture | Workflow integration considering user needs | Adoption of emergency health records | Use of clear and standardized guidelines | Potential for financial incentives |
|---|---|---|---|---|---|
| **Eden et al. (2016)** | | | | | |
| **Yeager et al. (2014)** | | | | | |
| **Qian (2020)** | X | X | X | | |
| **Esmaeilzadeh (2022)** | | | | X | X |

The identified facilitators have been grouped to create clearer and more logical groups, as stated above.

*Table 6. Identified factors for "facilitators"*

| Factor<br>Article | Enabling factors | Value enhancement | Resource factors |
|---|---|---|---|
| **Eden et al. (2016)** | X | | |
| **Yeager et al. (2014)** | | X | X |
| **Qian (2020)** | X | X | X |

The tables display three different groups of factors: enabling factors, value enhancement factors, and resource factors. The underlying factors are displayed in Figure 8, some of which are slightly rewritten to increase the clarity and meaning of the factor.

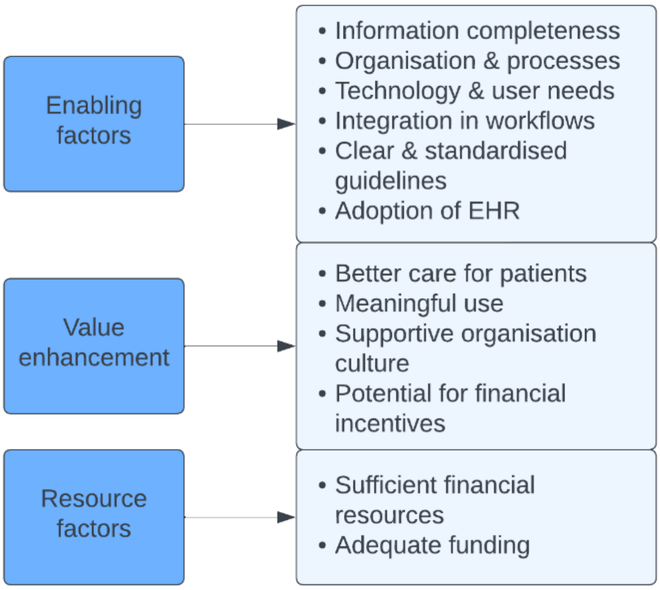


*Figure 8. The three main facilitator categories with their subtopics.*

Under the category of enabling factors, the studies reveal several noteworthy insights. Eden et al. (2016) explore various value-creating aspects of information exchange in healthcare settings. Among the enabling factors identified, facilitators in organization and workflow play a crucial role, including features like single login, ongoing training, and sufficient technical support. Additionally, technology-related facilitators, such as contextual notes, automatic integration with existing provider systems, and alerts when patient information becomes available, contribute to the successful utilization of patient data exchange. Ensuring information completeness also relies on specific enabling factors, including patient education, consent at registration or online patient authorization, and the implementation of policies and training on security and privacy. Qian (2020) further discusses facilitators, emphasizing the importance of a supportive organizational culture and a well-aligned workflow integration approach, along with the adoption of EHR and adequate funding, to enhance the implementation and adoption of IPS/information exchange. Information exchange's perceived benefits and values, such as improved quality of care, increased care effectiveness, better care coordination, ease of data transfer, improved communication, and reduced costs, also contribute positively to the implementation and adoption process.

In terms of value enhancement, multiple studies have highlighted various facilitators in this domain. Yeager et al. (2014) conducted research on factors related to participation and use of patient information exchange and identified several facilitators, including patient value, meaningful use, and cost considerations. The use of data exchange is anticipated to significantly improve coordination and quality of care, particularly for complex patients with comorbidities. Additionally, the perceived benefits of using patient information outweigh the associated costs of implementing data exchange systems within healthcare organizations. Qian (2020) documented how the use of health information systems enhanced value, especially during the 2019 coronavirus disease outbreak. These systems enabled highly coordinated and real-time monitoring of the virus's spread, exemplifying the immediate value and benefits of utilizing patient data exchange. The perceived beneficial aspects of data exchange, such as improved efficiency, quality, and care coordination, further contribute to value enhancement in healthcare settings.

The facilitator category of resource factors encompasses several key findings. Yeager et al. (2014) reported that patient information exchange programs are not only less expensive but also more appealing compared to alternative options for health information exchange. The overall costs associated with patient data exchange are relatively lower, creating more value for healthcare organizations. Additionally, the benefits gained from using information exchanges outweigh the total costs required for their implementation and adoption. Looking ahead, the adoption of an information system, such as the IPS, may prove beneficial for future healthcare reforms, including the establishment of an accountable care organization (ACO). According to Qian (2020), proper funding is a critical facilitator for the successful implementation and adoption of a Health Information Exchange (HIE) system like the IPS. Sufficient financial resources and support are essential to ensuring a smooth and effective adoption process. Moreover, the perceived value of cost reduction after adoption reinforces the expectation that successful implementation will lead to a gradual decrease in system costs, making it a financially viable option for healthcare organizations. These resource factors play a vital role in enabling the widespread adoption and sustained use of patient data exchange systems.

For more specific details and descriptions of each facilitator, please refer to Appendix F.2, which provides comprehensive information on their meanings and relevance.

#### *4.1.3.3 Barriers*

The third subject is barriers, which hinder value creation in the use and adoption of the IPS. The literature review identified several barriers, which are listed in Table 7. Articles that did not include these factors are omitted from the table. These barriers encompass various challenges that must be addressed for the successful implementation and utilization of the IPS.

*Table 7. Identified factors for "barriers"*

| **Factor**<br>**Article** | Data privacy & security concerns | Technological concerns & issues | Implementation costs & funding issues | Lack of interoperability | Lack of willingness to change |
|---|---|---|---|---|---|
| **Qian (2020)** | X | X | X | X | X |
| **Esmaeilzadeh (2022)** | X |  |  | X | X |
| **Fontaine et al. (2010)** | X | X | X |  |  |
| **Bowden and Coiera (2017)** | X | X |  | X |  |
| **Tharmalingam et al. (2016)** | X | X |  |  | X |
| **Yeager et al. (2014)** | X | X | X |  |  |
| **Rahurkar et al. (2018)** |  |  | X |  |  |

Data privacy and security concerns emerge as prominent barriers to the successful implementation and adoption of patient information exchange systems across multiple studies (Qian, 2020; Esmaeilzadeh, 2022; Fontaine et al., 2010; Bowden and Coiera, 2017; Tharmalingam et al., 2016; Yeager et al., 2014). Ensuring the confidentiality and integrity of patient data is crucial to building trust among stakeholders (Esmaeilzadeh, 2022). Security measures are vital to protect against data breaches and unauthorized access, emphasizing the need for robust systems (Qian, 2020). Concerns about data accuracy and integrity are also raised, calling for mechanisms to ensure data quality (Bowden and Coiera, 2017). Standardized data formats are recognized as essential for seamless exchange (Tharmalingam et al., 2016), and the interplay between data privacy, security, and efficiency in patient information exchange is acknowledged (Fontaine et al., 2010). Addressing these concerns through comprehensive security measures and standardized data exchange formats will be essential to fostering confidence and overcoming the barriers associated with data privacy and security.

Technological concerns and issues present significant barriers to the successful implementation and adoption of patient information exchange systems, as highlighted in multiple studies. Qian (2020) identifies challenges related to system usability and technical support, underscoring the need for user-friendly interfaces and ongoing technical assistance to enhance adoption rates. Fontaine et al. (2010) emphasize the importance of addressing technical disruptions and system downtime to ensure uninterrupted access to patient information. In the context of health information exchange, Bowden and Coiera (2017) discuss challenges associated with interoperability, stressing the need for standardized data formats and compatible systems to enable seamless data exchange between different platforms. Tharmalingam et al. (2016) highlight the importance of considering user needs and preferences when designing patient information exchange systems to ensure an optimal user experience. Additionally, Yeager et al. (2014) found that technological issues, such as system complexity, could hinder participation and use in the exchange program. These collective findings underscore the significance of addressing technological concerns and issues to create a seamless and user-friendly patient information exchange system.

The successful implementation and adoption of patient information exchange systems are often hindered by substantial implementation costs and funding challenges, as evident in several studies. Qian (2020) emphasizes the necessity of proper funding to ensure a successful Health Information Exchange (HIE) implementation. Sufficient financial resources are required to support the infrastructure, ongoing maintenance, and technical support necessary for effective system utilization. Fontaine et al. (2010) discuss the complexities of cost allocation for implementing health information exchange systems across different organizations and healthcare settings. The study highlights the importance of shared funding models and cost-sharing agreements to facilitate widespread adoption. Additionally, Yeager et al. (2014) found that the perceived cost-effectiveness of joining a patient information exchange program compared to other health information exchange options influenced adoption decisions. However, Rahurkar et al. (2018) reported on potential funding barriers for smaller healthcare organizations, as limited financial resources might impede their ability to adopt patient information exchange systems. These collective findings underscore the significance of addressing implementation costs and funding issues through collaborative funding approaches and tailored financial support to promote equitable and sustainable adoption of patient information exchange systems.

Lack of interoperability emerges as a significant barrier to the successful implementation and adoption of patient information exchange systems, as reported in multiple studies. Qian (2020) discusses the challenges associated with integrating various health information systems and platforms, particularly in heterogeneous healthcare environments. The lack of standardized data formats and communication protocols hinders seamless data exchange between different systems and organizations. Similarly, Esmaeilzadeh (2022) highlights the complexities of achieving interoperability, especially in the context of exchanging health information across different care settings and healthcare providers. The study emphasizes the need for standardized data exchange frameworks and seamless data sharing protocols to overcome these challenges. Tharmalingam et al. (2016) delve into the difficulties of interoperability in the context of integrating Integrated Electronic Health Records (iEHR). The study emphasizes the importance of developing effective strategies to ensure data compatibility and seamless information exchange between disparate systems. Collectively, the findings underscore the need for concerted efforts to address interoperability barriers and develop standardized data exchange frameworks to promote information sharing across healthcare settings and systems.

The lack of willingness to change represents a noteworthy barrier to the successful implementation and adoption of patient information exchange systems, as discussed in several studies. Healthcare professionals encounter resistance when transitioning to new systems and processes, as highlighted by Qian (2020). The study underscores the importance of change management strategies to address the concerns and reservations of stakeholders. Similarly, Esmaeilzadeh (2022) explores the reluctance among healthcare providers to adopt new information exchange practices due to concerns about disruption to established workflows and practices. The study emphasizes the need for comprehensive training and support to alleviate the apprehension surrounding the adoption of patient information exchange systems. Tharmalingam et al. (2016) also discuss the challenges related to the willingness to change among healthcare providers. The study underscores the importance of engaging healthcare professionals in the design and development of new systems to ensure their active participation and willingness to embrace change. These findings collectively underscore the significance of addressing the lack of willingness to change as a critical aspect of the successful implementation and adoption of patient information exchange systems.

For detailed specifications and descriptions of each barrier, please refer to Appendix F.2, which provides comprehensive information on the meanings and implications.

### 4.1.4 Synthesis of results

The articles investigating the value, facilitators, and barriers of using an IPS in healthcare have provided valuable insights into the factors relevant to implementation and value creation. Figure 9 displays the most important values, facilitators, and barriers.

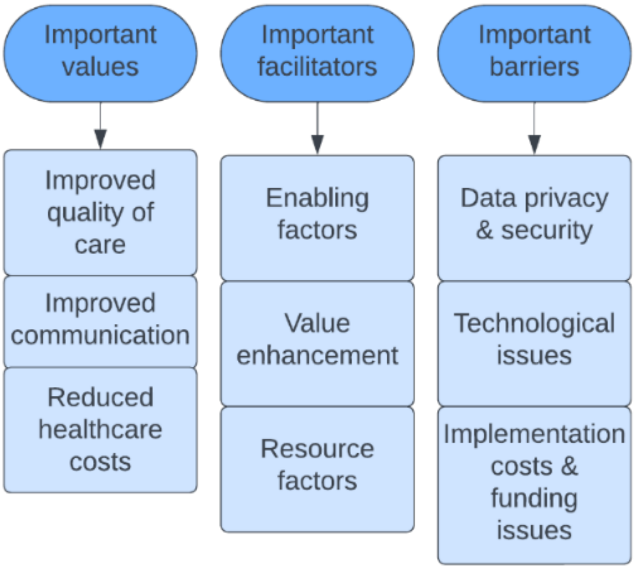


*Figure 9. The most important identified values, facilitators and barriers*

Multiple studies highlight the benefits of IPS implementation in healthcare practice. Improved quality of care is a prominent outcome, as evidenced by enhancements in medication management, immunization processes, and reductions in care disparities. Additionally, IPS usage shows promise in reducing healthcare costs through decreased unnecessary procedures and shortened hospital stays, although conclusive evidence on cost savings is lacking. Furthermore, IPS utilization correlates with reduced hospital readmission rates, attributed to comprehensive health information access. Health record completeness is ensured through IPS integration, facilitating better communication among healthcare providers and minimizing critical information oversights. Patient safety is also enhanced, with IPS implementation minimizing data breaches and miscommunication risks during information exchange. Lastly, improved communication among healthcare providers is facilitated by IPS adoption, promoting better care coordination, informed decision-making, and streamlined care processes.

Facilitators were also identified, including completeness of information, organization and workflow, technology and user needs, patient value, meaningful use, cost and adequate funding, a supportive organization culture, a workflow integration approach that considers user needs, the adoption of emergency health records, clear and standardized guidelines in use, and the potential for financial incentives to encourage adoption. These presented facilitators are important because, according to the literature, they facilitate the value of using the IPS in practice.

Furthermore, the literature review highlighted several barriers to effective use and adoption of the IPS. They include data and privacy concerns, technological concerns and issues, (implementation) costs and funding issues, a lack of interoperability, and a lack of willingness to change. Barriers stand in the way of making sure the IPS offers value and is adopted worldwide, which is why identifying barriers was the final goal of this literature review. Understanding and addressing these barriers is crucial for promoting widespread IPS use and unleashing its full potential.

Multiple actions can be used to maximize value and ensure that barriers are overcome. Data privacy and security should be sufficiently safeguarded, and the concerns of professionals and the public should be eased. Technological and interoperability issues should be addressed so that these systems can function well, even when exchanging information between different care types, countries, and systems. Sufficient financial resources should also be allocated. Finally, the willingness to change should be improved. The potential and demonstrated value of using the IPS in practice should persuade the broader public, healthcare professionals, and experts that further use and adoption of the IPS improves healthcare.

The facilitators in Figure 9 also paint a clear picture of the things that need attention to increase the value and adoption of the IPS. Considering these findings and strategies for addressing current barriers, focus must be directed towards three important aspects, which we call the 'three E’s': enabling the environment for seamless integration, enhancing the value of IPS through opportunity maximization, and engaging resources to ensure strong and adequate support for personnel.

**Enabling (of technology)** signifies creating an environment where incorporating the IPS seamlessly aligns with daily workflows, making it not just feasible but also intuitive for healthcare professionals to use the IPS. This entails addressing identified facilitators, such as workflow integration, technological integration, and organizational support. Barriers to this element may include resistance to change and the need for substantial adjustments in established workflows, which should be addressed to foster adoption.

**Enhancement (of processes)** focuses on seizing opportunities to fully realize the potential value of the IPS. This entails taking full advantage of the identified benefits, such as improved patient care, cost reduction, and enhanced communication. Different actions to foster these values include using technology to its fullest, ensuring data security and privacy, and stimulating a culture of continuous improvement and change. Challenges may arise in overcoming technological complexities and ensuring acceptance of change.

**Engagement (of resources)** is important to ensure both direct and supporting personnel have the necessary space and support for successful IPS implementation and continued use. Things like adequate training and financial resources are important components. Challenges here may include budget constraints, a lack of training and understanding, and competing priorities in resource allocation.

This makes it clear that achieving widespread IPS implementation requires not only addressing specific values, facilitators, and barriers but also an integral approach where focus should be directed to strategic enabling of integration into existing workflows, enhancement of the utilization of IPS potential benefits, and the allocation of sufficient resources for successful implementation and sustained usage.

The findings confirm that there is indeed value in using the IPS as a way of exchanging health information, improving patient care, reducing costs, enhancing communication, improving patient safety, and reducing readmissions. To achieve these values, one must comply with facilitating factors, align workflows with IPS use, and pay attention to cost control, technology, and user needs. Overcoming barriers, such as safeguarding data privacy, addressing technological and interoperability issues, allocating sufficient financial resources, and improving the willingness to change, is essential for a smooth adoption process.

A focus on the willingness to change should also be mentioned. The potential and demonstrated value of using the IPS in practice should persuade the broader public, healthcare professionals, and experts that further use and adoption of the IPS improves healthcare.

Figure 10 displays the relationship between value, facilitators, and barriers, demonstrating how the various elements influence the implementation and adoption of the IPS.

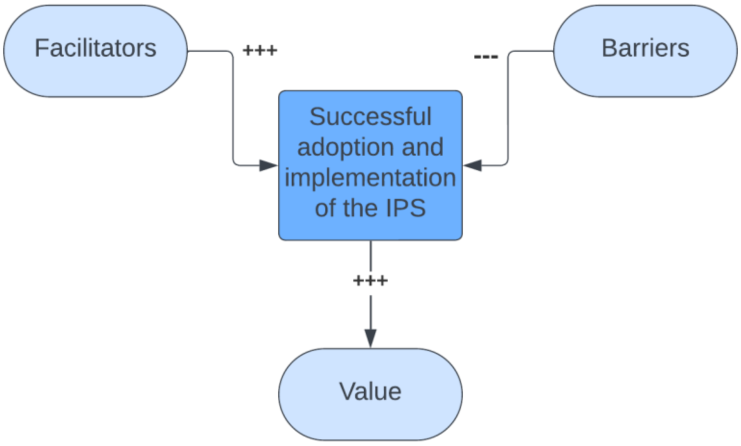


*Figure 10. Relations of value, facilitators, and barriers to the adoption and implementation of the IPS.*

Overall, the findings from the literature review provide a robust framework for examining the value, facilitators, and barriers associated with using the IPS in healthcare. By comparing these findings with real-world practices, organizations can gain a comprehensive understanding of the factors influencing the successful adoption and implementation of the IPS. Addressing the identified barriers and leveraging the facilitators will be important in achieving the full benefits of the IPS and improving healthcare outcomes.

### 4.1.5 Risk of bias across studies

The 14 studies on the value and effectiveness of using an IPS in healthcare practice had varying degrees of bias risk. Several studies were observational, which could lead to selection bias and confounding variables. Some studies relied on self-reported data, which could introduce social desirability bias. However, several studies used well-chosen study designs, such as systematic reviews, which can help minimize bias. Overall, while there are some limitations to the studies, the available evidence provides valuable insights into the research topic.

## 4.2 Discussion

This systematic review synthesizes and assesses the available evidence on the value of using an IPS in healthcare practice. In addition, facilitators and barriers were also researched to create a broader perspective about the influential factors, value, and use of the IPS. Through a comprehensive search and selection process, 12 studies were identified that investigated various aspects related to IPS use and outcomes, including care quality, patient safety, cost-effectiveness, provider perspectives and attitudes, and patient outcomes. This chapter discusses the implications and limitations of the findings, as well as conclusions and recommendations for future research and practice.

### 4.2.1 Summary of evidence

The main findings of this systematic review highlight the potential benefits of using an IPS in healthcare: improvements in quality of care, cost reduction, and readmission rates. The review also identifies key facilitators that contribute to the successful adoption and utilization of the IPS. When these facilitators are effectively implemented in healthcare organizations, the likelihood of IPS adoption increases. However, significant barriers to the implementation and use of the IPS have been identified, emphasizing the need for proactive measures to address these challenges. These findings have important implications for various stakeholders, including healthcare providers, policymakers, and patients.

For healthcare providers, the evidence suggests that incorporating an IPS can enhance communication, both internally within the healthcare team and externally with other providers, ultimately improving care and patient outcomes. Policymakers can utilize this information to inform decision-making processes related to funding and implementation of the IPS on a global scale. Patients can also benefit from using an IPS, as the process has the potential to improve the quality of their care and reduce the risk of medical errors. However, it is first necessary to address barriers to ensure the IPS and other health information exchange systems are implemented effectively and securely. Overall, these findings serve as a valuable summary of the evidence, emphasizing the positive impact of the IPS while acknowledging the need to overcome barriers for successful implementation.

### 4.2.2 Limitations

It is important to acknowledge the limitations of this systematic review. Even though the review provided useful information, several limitations should be noted:

- The risk of bias across the 14 studies could affect the validity of the findings. Some of the studies had small sample sizes, were observational, or were conducted in specific regions, limiting the generalizability of the results.
- Some studies examined the value of health information exchange systems in general rather than the IPS specifically, which is the focus of this research.
    - Because of the limited research on the IPS itself and the similarities between the two subjects, this was deemed necessary to gain a better understanding of IPS use. However, the limitations of this approach should be considered when interpreting the results.
- Incomplete retrieval of research studies and the potential for reporting bias are also limitations that could have affected the comprehensiveness of this review.

### 4.2.3 Conclusions

This systematic review suggests that using the IPS or an information exchange system can have a positive impact on healthcare and patient outcomes. However, significant barriers to implementation and use exist, including concerns about privacy, security, interoperability, and usability. Facilitators may form a basis for organizations to determine what is important in fostering IPS adoption. This information, combined with the data collected through interviews in the second part of this thesis, provides a complete picture of the IPS and how its adoption and value can be further improved.

#### *4.2.3.1 Implications for further research*

Despite the positive findings, this systematic review highlights the need for further research to fully understand the impact of using the IPS and exchanging health information. Additional studies are required to understand the specific factors that influence implementation and use, as well as their impact on healthcare quality and cost-effectiveness. Furthermore, research that specifically examines the impact of using the IPS should be done, as many of the existing studies examine health information exchange in general. Finally, future research should also address the limitations identified in this review, such as the risk of study- and outcome-level bias, as well as reporting bias.

The literature review also posed implications for part two of this research, focusing on the situation in practice through interviews. This combined data provides a comprehensive picture of how the value of the IPS can be improved, and further adoption is possible. Moreover, because this thesis consists of theoretical and practical components, it establishes the difference between theory and practice. The gap and relevant experiences in practice provide clarity on what can be done to ensure the IPS's continued adoption worldwide.

# 5 Interview results

This chapter presents the insights gathered from a series of interviews conducted with healthcare professionals involved in GP care, with a particular focus on emergency care. One professional had experience in specialist healthcare, as a CMIO, and in healthcare policy.

For this research, GPs with different backgrounds and experience levels have been interviewed. The following healthcare professionals participated in the research, displayed in Table 8:

*Table 8. Description of interview participants*

| **Job description** | **Elaboration** |
|---|---|
| GP + GP out-of-hours office | Junior in the field of GP care and GP out-of-hours office |
| GP + GP out-of-hours office | Intermediate experience in the field of GP care and GP out-of-hours office |
| GP + GP out-of-hours office | Senior (15+ years) in the field of GP care and GP out-of-hours office |
| GP + GP out-of-hours office | Senior (20+ years) in the field of GP care and GP out-of-hours office alongside service as board chairman of the out-of-hours office |
| Medical specialist, ex-CMIO, and policy advisor | Senior in medical specialist care, CMIO, and policy advisor on the subject of health information (exchange/building blocks) |

In total, five interviews were conducted. The GPs served as the main information source, with each of them contributing different perspectives to this research with their various backgrounds and experience levels. Participants with junior, intermediate, and senior levels of experience were included, along with a participant who had experience as the board chairman of a GP out-of-hours office, with extra experience and strategic knowledge. After conducting four interviews, an adequate level of information saturation was attained, as not much more information was expected from further interviews from the corresponding perspective of GP-care. Therefore, the research, conducted through interviews with GP's, concluded after four participants. Afterward, the doctor and policy specialist verified the information obtained from the GPs due to their expert knowledge on the subject. The opinion of the medical specialist was in line with that of the participating GPs, validating the collected information. After these interviews, an interview with the medical specialist and policy expert was conducted to check the overarching validity of the interviews from the eyes of an expert in the field. These results strengthen the case study strategy of this research, with relevant information collected and validated by an expert in the field. The interview with the expert led to, on the one hand, lots of (background) information about the values and challenges of IPS; on the other hand, the expert agreed with the statements that the GPs made. It was not deemed necessary to further validate the findings. Due to the research approach used, the collected information in this research was confirmed to be relevant and scientifically valuable.

## 5.1 Identified values

The IPS is a potential game-changer in healthcare, offering a standardized and readily accessible overview of a patient's medical history, medications, and allergies—all three of which are deemed the most important in emergency care and the treatment of unknown patients. The IPS empowers both patients and healthcare professionals by facilitating enhanced patient care, improved clinical decision-making, and efficient information exchange across different healthcare systems. Multiple participants highlighted the importance of having readily available patient information. One participant stated:

> *"Missing certain kinds of information is just not good. It really creates a risk for the patient. Having that information available is thus very useful."*

By providing clinicians with recent and comprehensive patient information, the IPS eliminates the requirement for repeated medical history retellings, streamlining communication and reducing the risk of errors. This process ultimately translates to improved quality of care for patients. The scope for improvement in quality of care became especially clear from the multiple mentions of patient data not being up-to date by the participants. In other cases, the relevance and "age" of the information would be unknown, making it difficult for the healthcare provider to trust the information. The expert on the field stated the following:

> *"I think it took 1600 keystrokes and 500 mouse movements to get through the patient file."*

Furthermore, the IPS empowers clinicians with better-informed and faster decision-making, which is particularly crucial in critical situations such as ambulance transport and emergency departments. Timely access to relevant patient data enables healthcare professionals to make potentially life-saving decisions.

Moreover, by standardizing patient data, the IPS facilitates seamless data exchange between diverse healthcare providers and settings. This process eliminates the need for manual data entry and reduces the associated risk of errors.

Beyond its immediate benefits, the IPS has the potential to fundamentally transform healthcare. By enabling the sharing of essential patient information across borders and healthcare systems, it ensures continuity of care regardless of the location or the provider, making global patient data sharing achievable. It also allows healthcare professionals to provide holistic treatment by transferring relevant patient data between different systems and contexts. Two GPs expressed concerns about the current system:

> *"At this time, we do not know if these data are indeed the latest. You do not know that about the medication either. You also do not know whether the last list you receive is the most current."*

In emergency situations where access to patient history is limited, the IPS proves to be critical for providing timely and appropriate care. Accessing essential details such as medications and allergies allows for informed decision-making and prevents potential adverse reactions. The participants especially mentioned ambulance personnel, who often operate under time constraints and have limited access to patient information. For them, the IPS provides a concise and readily available patient summary. This availability lets them make more informed decisions and improve their response during emergencies.

The need for a standardized patient summary extends beyond individual professions. All interviewed GPs recognize its broad applicability and potential impact across various healthcare disciplines, highlighting its universal value in improving patient-care delivery. Furthermore, integrating the IPS into existing clinical workflows can standardize information retrieval, thereby enhancing efficiency, reducing the time spent searching for data, and leading to improved patient outcomes and satisfaction.

In conclusion, the IPS is a potent tool that revolutionizes the review of information in emergency care, promotes enhanced patient care, aids in informed clinical decision-making, and streamlines information exchange throughout the healthcare system. Its implementation holds significant promise for the future of healthcare, paving the way for a more interconnected, efficient, and patient-centered way of exchanging patient information.

## 5.2 Identified facilitators

The participants identified several facilitators that need to be used to foster further adoption and increased value.

The idea of access to and control over patients' medical records in a complex healthcare landscape presents both opportunities and challenges. While patients are legally recognized as the owners of their medical records (emphasizing their autonomy and control), ensuring that they can adequately access and effectively manage their data requires a nuanced approach. A GP states that one key challenge lies in recognizing that not all patients may possess the necessary digital literacy or capacity to manage their EHRs independently. It is particularly true for vulnerable populations facing health concerns or having limited digital skills. As a result, alternative access methods must be considered to ensure that these individuals receive proper medical care without hindering their access to critical information.

Furthermore, fostering collaboration among healthcare providers and integrating systems becomes crucial to ensuring seamless access to accurate and up-to-date medical information. Having seamless access to accurate and up-to-date information is a requirement that all GPs agree on. This interconnectedness enables healthcare professionals across different settings to make informed decisions based on a complete picture of the patient's medical history, facilitating improved patient care. This idea refers back to the value that the IPS provides if the necessary interoperability is in place.

However, building trust in the healthcare system remains important, especially when it comes to confidentiality and data security. One participant states the following, making clear that there is work that needs to be done regarding the gaining of trust:

> *"Distrust of the government, distrust of healthcare, distrust of the judiciary. You can see distrust in all areas. We need to gain trust again."*

Robust safeguards must be in place to address concerns regarding patient privacy and data protection. Examining successful models from other countries can provide valuable insights into implementing ethical and secure EHR systems.

One potential approach to data sharing involves an opt-out system, where patients can actively choose not to share their data. This approach aims to strike a balance between respecting patient autonomy and facilitating beneficial data exchange among healthcare providers, with the aim of having as much data available as possible, as that is a very important condition for healthcare providers to be able to actually use the data in a beneficial manner. When the information is available but cannot be accessed, it has no value. One GP proposed this option, and two other GPs agreed with this approach.

Additionally, centralizing patient data, potentially through a national EHR system, can help improve data accessibility and reduce administrative burdens for both patients and healthcare professionals. However, such initiatives require careful planning, strong governance, and active governmental involvement to ensure their successful implementation and compliance with clear regulations.

Finally, it is critical to actively involve clinicians in the development and implementation of patient summaries, such as the IPS. Their practical expertise ensures that the systems are not only effective, but also usable and user-friendly in their clinical practice. This was confirmed by the other GPs. One GP stated the following for the best possible development of a patient data exchange system:

> *"In any case, when developing such a system, I think it is important that clinicians remain involved at every step."*

By acknowledging the complexities and making use of these facilitators, the IPS, as a data access system, can evolve into a powerful tool for empowering patients, improving care coordination, and ultimately fostering a more patient-centered healthcare system.

## 5.3 Identified barriers

Despite the potential benefits of patient data sharing, several significant barriers prevent its adoption. These challenges necessitate careful consideration and innovative solutions to ensure the IPS's continued implementation and further adoption.

Access issues, particularly for transient patients seeking care outside their usual healthcare system, pose a major hurdle. Incomplete or inadequate medical information due to access limitations can negatively impact patient-care decisions. This is the main problem, which was pointed out by every participant. One GP states the problems it can cause when taking in an unknown patient for consultation:

> *"I do not know anything about that person. The patient states that his own GP can share everything. That is a link to the local GP post, but I cannot see anything. I have absolutely nothing."*

Additionally, obtaining informed consent for data sharing presents challenges, potentially leading to limitations in accessing essential medical data that can be crucial for comprehensive care. People are not yet aware of the fact that giving consent is crucial for their data to be shared with other healthcare professionals. Even with this consent, data sharing (just within the Netherlands, not even abroad), is still challenging, as visible from the above citation.

Furthermore, the lack of interoperability between disparate electronic medical record (EMR) systems poses a significant obstacle. This incompatibility hinders information exchange, particularly in emergency situations or when patients seek care outside their established health network, potentially compromising the quality of care provided.

Concerns regarding patient privacy and data security remain a major barrier, impacting the willingness of both healthcare providers and patients to share medical information. Some of the solutions mentioned include robust data protection measures and clear communication around data governance. Considering how the data can be as safe as possible while also safeguarding patient privacy is crucial for building trust and encouraging participation in data-sharing initiatives.

The regulatory landscape, including frameworks such as the General Data Protection Regulation (GDPR), significantly influences data-sharing practices. Navigating these legal and regulatory complexities necessitates careful consideration and adherence to ensure compliance and responsible data governance, as the validating interview has demonstrated. More focus on governance and collaboration is needed to overcome these challenges.

Furthermore, technical challenges also contribute to difficulties in accessing and sharing patient information. Inadequate infrastructure, disparate information systems, and the burden of manual data entry led to inefficiencies and hindered seamless data exchange. These are challenges that all GPs face. Implementing standardized formats and interoperable systems are crucial steps toward overcoming these technical hurdles.

Moreover, a lack of awareness among healthcare professionals regarding initiatives such as the IPS and the EPS highlights the need for more awareness of these tools and how they can support them as healthcare professionals. The medical specialist states the following about colleagues' ignorance of IPS:

> *"If I may make an estimate, I think that 80/90% of my colleagues in hospitals and general practitioners have no idea. They may have heard of the EPS, but they have no idea what is in it. I even think the percentage is higher."*

Increased awareness and understanding can significantly promote the adoption and effective use of these tools, enhancing the benefits of patient data sharing in the digital age. Indeed, every interview participant noted the advantage of using an IPS as a way to retrieve patient information.

Finally, establishing effective governance and clear policies is essential for addressing the identified barriers and facilitating successful data exchange across healthcare settings. Such frameworks should define responsible data practices, ensure compliance with legal regulations, and foster trust among all stakeholders involved in the healthcare ecosystem.

## 5.4 Observed key priorities

Providing healthcare professionals with the essential information they need for effective consultations is crucial. It includes access to a patient's medical history, medications, allergies, and significant past episodes, allowing for comprehensive understanding and informed decision-making.

However, the relevance and recentness of information play a critical role, particularly in urgent care settings. Recent medication, allergy, and episode updates are critical for accurate diagnoses and appropriate treatment plans.

To ensure access to the most up-to-date data across diverse healthcare settings, GPs mentioned a centralized system or register to store patient information. This system must be robust, secure, and readily available to authorized healthcare professionals, enabling seamless access and information sharing.

Furthermore, standardization and interoperability across healthcare systems emerge as key priorities. Ensuring standardization and interoperability would facilitate consistent data representation and fluent information exchange, enabling healthcare professionals to receive a clear and comprehensive picture of patients' medical histories, regardless of the source or origin.

However, the responsibility for ensuring effective information management does not solely lie with centralized systems. Clinicians play a crucial role in accurately documenting information from various sources, including specialist letters and test results, to ensure that patient records are complete and reliable.

Unfortunately, current systems often lack interoperability, creating challenges when exchanging information between different healthcare providers and settings. This disconnect can lead to delays in accessing critical information, potentially compromising patient-care quality and hindering timely decision-making. One GP made perfectly clear why it is so important to have relevant and up-to-date information available for treating an unknown patient:

> *"It must be up to date, because I worked at the GP post, and I still had to go through the entire medication list with a patient. Then, at the end, I did not know whether they understood it correctly. Half of them do not realize what they are taking."*

Beyond healthcare professionals' access, there is a growing recognition of the importance of patient access to their own medical information. This access may be facilitated through digital platforms or wearable devices, which can empower patients to be active participants in their own healthcare information management.

Furthermore, integrating information systems and streamlining access to patient data are crucial for improving both the efficiency and quality of care delivery. Doing so requires optimizing information systems to prioritize relevant information and facilitate data exchange, ultimately leading to improved patient outcomes and clinician efficiency.

Clinicians emphasize the importance of accessing concise and relevant patient information without being overwhelmed by excessive detail. This emphasis highlights the necessity of prioritizing essential information while maintaining clarity and avoiding information overload. Reliable and up-to-date data are crucial for providing quality care and avoiding errors in clinical decision-making.

Finally, even though excessive details are not favorable, striking a balance between comprehensive information and information overload remains crucial. Defining standardized information sets for essential details such as medications, allergies, diagnoses, and treatment preferences can significantly enhance data exchange and interoperability while simultaneously ensuring that clinicians have easy access to the most important information. Additionally, simplifying and streamlining the process of retrieving patient information from various sources can further enhance clinical workflow and support informed decision-making.

To conclude the data gathered from interviews, a schematic overview of the most important identified factors per category (value, facilitators and barriers) is visible in Figure 11.

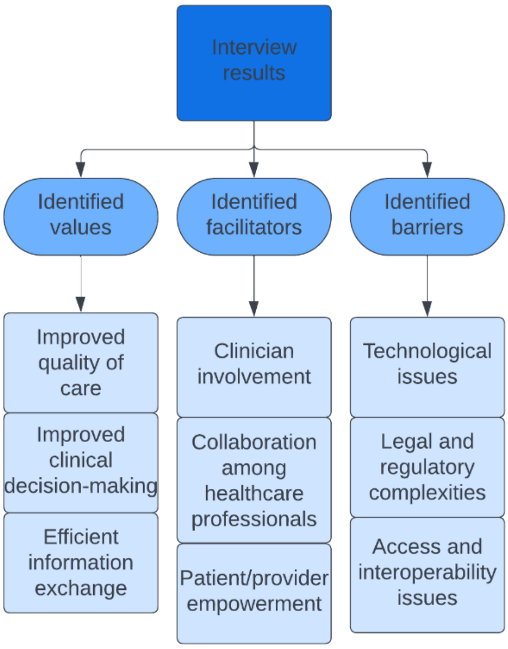


*Figure 11. Most important factors identified from the interviews*

## 5.5 Application to the five-layer model

The findings from the interviews can be mapped onto the FLM, illustrating the challenges and considerations at each layer of the healthcare infrastructure. It is important to note that certain subjects may fit multiple categories, and that a subject in one layer cannot be solved without the cooperation of another layer. However, this overview is a simplified way of displaying the layers that are associated with the different findings, focusing on the aspects that need attention in order to increase the value of using the IPS.

The most important findings (Figure 9 and 11) will be described in relation to the different layers in the FLM. It is worth noting that the identified values (apart from reduced costs) cannot be placed within FLM, as in this context, the model is especially well-suited to map the facilitating factors and barriers into the different layers.

**Organizational layer**: Clear leadership and decision-making are essential for driving standardization efforts and ensuring stakeholder alignment. Solutions should be developed to form a clear governance plan for the IPS's worldwide adoption. Doing so is crucial, as there are numerous different interests. Most countries have their own systems and clinical terms, which creates challenges in managing global adoption. To oversee IPS adoption and tackle barriers in terms of policies and regulations, appropriate governance should be established.

The organizational layer also entails the facilitator “resource factors” (existing of sufficient financial resources and adequate funding) and the barrier “implementation costs and funding issues”. The IPS requires sufficient resources and funding to advance its adoption and enhance the value of healthcare. Without these resources, the underlying layers will suffer, as the IPS cannot be used to its full potential without the correct resources in place.

**Process layer**: In order to integrate the IPS into existing practices, efforts in this layer should focus on streamlining workflows, checking, and, if necessary, optimizing clinical processes. This process includes ensuring that healthcare providers are trained on how to use the IPS effectively, as well as that workflows are designed to support its adoption. The interview participants found it very important that the processes for using the IPS are well suited to their working environments. This need is underlined by the fact that one of the advantages of the IPS is the improvement in the efficiency of steps and processes for receiving all relevant information about a patient.

The process layer also entails the value “reduced healthcare costs” and the barrier “implementation costs”. Optimizing healthcare processes is particularly effective in achieving reduced costs. As stated in the literature, the process of receiving and using patient data can be improved by the IPS, possibly also leading to fewer (diagnostic) tests, such as medical imaging, which leads to faster, more efficient, and cheaper healthcare. However, this layer also faces the barrier of implementation costs, as it requires investments to enhance the processes.

**Information layer**: Improving data quality and ensuring that all relevant data are available at the right time constitute critical factors at the information layer. Data standardization efforts are required to ensure that patient information is accurate, complete, and easily accessible across different healthcare settings.

The information layer also corresponds with the “enabling factors” identified as facilitators (existing of “information completeness”, “organization & processes”, “technology & user needs”, “integration in workflows”, “clear & standardized guidelines” and “adoption of

EHR"). The factors in this group are strongly linked to the presence and quality of information about healthcare processes. A suitable integration of the IPS in existing workflows, along with clear guidelines and broad adoption of EHR, will lead to better information being available for healthcare professionals to use in their daily practice.

**Application layer**: Investments in IT infrastructure and interoperable applications are necessary to support the storage, retrieval, and exchange of patient information in a secure and easy manner. It may entail implementing EHR systems that are compatible with the IPS and ensuring that data exchange protocols are standardized and widely adopted so that the IPS can be used in a global context. The IPS needs to be able to transform local terms into SNOMED CT or international terms for healthcare providers in other countries/regions to efficiently retrieve and interpret patient health information.

The application layer also entails the barriers “technological issues” and “data privacy & security”. For optimal use of the IPS, it is necessary that the storage and retrieval of patient data be possible without problems. Especially for the IPS, where the scale is very broad and healthcare professionals (and patients) should be able to use it across the world, it is crucial that the IPS can be consulted without technical issues, potential data leaks, or a lack of data quality.

**Infrastructure layer**: This layer contains the physical and technical infrastructure required to support the implementation of the IPS. It includes ensuring that healthcare facilities have access to reliable internet connectivity, data storage facilities, and secure communication networks. The infrastructure should be able to “read” information from all over the world, thereby making interoperability, once again, an important factor to consider.

The infrastructure also entails some factors from the “resource factors” facilitator group, along with “technological issues” as barrier. Also, identification and authorization of (end) users have to be considered in the infrastructure layer, together with interoperable systems. Apart from technology, user needs, and processes in organizations, it is important whether systems are (globally) able to give authorization to the right person when needed. Of course, this also means that data privacy and security are involved, as the sensitive data in a patient summary should only be accessible by the right person in the situation when it is needed to be used. Finally, interoperability is also important here, as the infrastructure should be organized in such a way that it is possible to store, read, and exchange patient data, no matter where in the world this takes place.

To finalize this chapter, a visual representation of the different layers with the results gathered from the literature and interviews is shown in Figure 12. Along with the observations from literature and interviews, an extra row with combined observations has been added to add clarity to the general combined points of attention, separated per layer of the FLM.

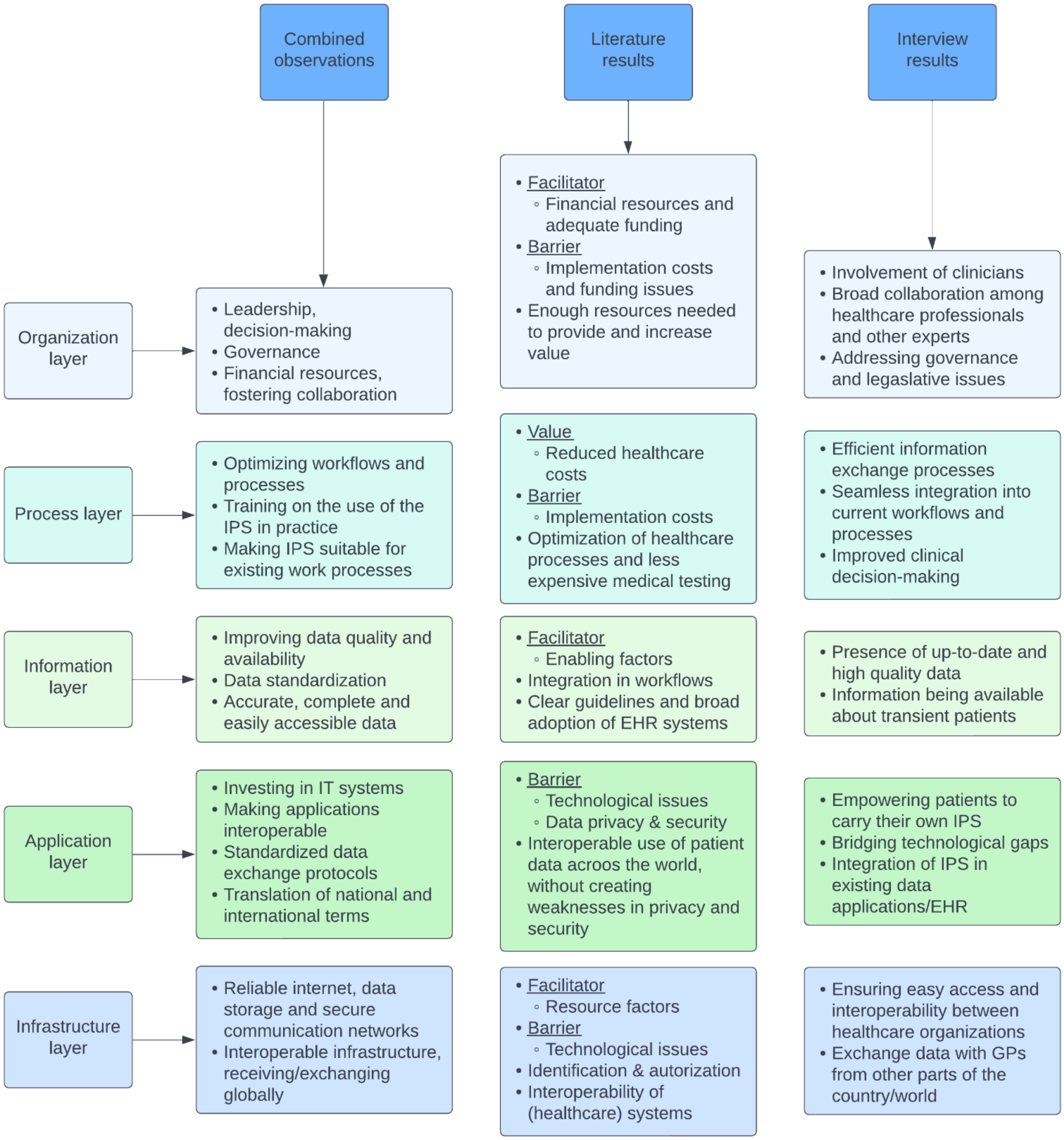


*Figure 12. Overview of the most important observations in literature and review, applied to the FLM*

# 6 Synthesis of results

From the literature, the key values were identified, along with the facilitators and barriers associated with IPS usage. The insights from the healthcare professionals who participated in the interviews complement these results, providing valuable insights into the practical realities of IPS value and adoption in clinical practice. By synthesizing these findings, the goal is to outline actionable strategies to increase IPS value and, in turn, enhance its adoption. The results attempt to answer the main research question: *"How can the added value of the International Patient Summary be improved to support its further adoption in healthcare practice?"*. In the research, with both the literature review and the interviews, the primary focus has been on (1) value, (2) facilitators, and (3) barriers. This synthesis will describe the integral results for these three parts.

## 6.1 Value

Both the literature review and the interviews with healthcare professionals highlighted the value of the IPS in healthcare.

According to the literature, the IPS contributes to improved quality of care, improved communication, fewer healthcare disparities, and reduced costs owing to the availability of a complete medical history to providers. The literature review also indicated potential cost savings due to fewer unnecessary procedures and shorter hospital stays. This benefit was confirmed by the interviews, as fewer tests and procedures have to be issued due to information already being available. While conclusive theoretical evidence on total cost-effectiveness remains limited, both sources suggest that the IPS can contribute to efficiency improvements in healthcare, leading to cost savings and improved patient care.

Furthermore, both the literature and the interviews showed that the IPS can lead to reduced patient readmission rates because medical decision-making is improved, and patient health outcomes are improved, making readmission less likely. Moreover, the healthcare professionals stated that having an IPS available makes them feel more secure in their work, as missing important information constitutes a risk for the patient. Having the relevant information from an IPS available creates value for both the healthcare professional and the patient. The accessibility of a medical history via an IPS allows healthcare providers to make better-informed decisions, as this information is otherwise not complete or outdated. The healthcare professionals also mentioned the lack of communication and, consequently, the incompleteness of medical records, which is also mentioned in the literature through the factor of health record completeness. The literature review highlighted better communication and minimal critical information oversight as consequences of record completeness, and the interview participants mentioned the need for easy implementation of medical data and diagnostics in their own records, as crucial information may be delayed or missed otherwise. The IPS creates value in this regard by solving the problem of possible miscommunication and health record incompleteness.

Finally, both sources emphasized the improved patient safety achieved through IPS. The integration of patient information from various sources, captured in an IPS, ensures a more complete and up-to-date patient record, minimizing the chance of crucial information being overlooked. Additionally, easy access to shared information fosters communication among healthcare providers, reducing misunderstandings and errors during information exchange. The interviews further emphasized the importance of secure data exchange.

The IPS's secure and encrypted storage of information reduces the risk of data breaches and mistrust by fellow healthcare professionals and patients.

Finally, the interviews with the healthcare professionals particularly emphasized the importance of reliable, privacy-protected, and secure information exchange. According to the participants, an accessible and secure IPS can transform healthcare by providing authorized healthcare providers with a complete picture of the patient, ultimately leading to improved healthcare outcomes.

### 6.1.1 Integration with literature

The three most important identified values from the literature were: 1) improved quality of care; 2) improved communication; and 3) reduced costs.

The improvement of quality of care, as identified in the literature, is underlined by the emphasis on the importance of up-to-date and comprehensive patient information for healthcare professionals. The lack of updated data and uncertainty about the relevance and timeliness of the information pose challenges that could impact the quality of care. This lines up with the findings of Menachemi et al. (2018), which underline the importance of health record completeness for the quality of care. These results also comply with the findings by Sadoughi et al. (2018), reporting a better completeness of reporting due to the use of the IPS. The availability of recent and comprehensive patient information through the IPS eliminates the need for repeated medical history retellings, improves faster communication, and reduces the risk of errors.

Interviews also shed light on improved communication, as also identified in multiple studies in the literature review (Qian, 2020; Menachemi et al., 2018; Sadoughi et al., 2018; Fontaine et al., 2010; Tzeel et al., 2012; Tharmalingam et al., 2016). According to interviews, the IPS appears to be crucial for data exchange between diverse healthcare providers and settings. The aforementioned studies support these findings, demonstrating the positive impact of health information exchange on communication with other healthcare contexts and providers. Standardizing patient data eliminates manual data entry, reducing the risk of errors. This contributes to better communication and collaboration among different healthcare providers.

The findings from the interviews also suggest that the IPS may contribute to cost savings by enabling more efficient information exchange and better decision-making, thus avoiding unnecessary repetitions and errors. This efficiency can lead to more effective resource utilization and a reduction in administrative burdens, potentially lowering operational costs. These findings are in line with the studies by Qian (2020), Tzeel et al. (2012) and Rahurkar et al. (2015). Although the evidence from each study is not conclusive, Qian observed a decrease in costs due to fewer diagnostic and other medical procedures. Tzeel discovered a reduced length of stay, leading to lower costs. Rahurkar found no conclusive evidence, but suggests a decrease in costs due to fewer imaging and diagnostic tests.

### 6.1.2 Gaps with literature

There are some findings mentioned in the interviews that could be considered additional aspects beyond the three main values from the literature.

One notable aspect is the emphasis on the importance of timely access to patient information, both in medical urgencies in GP out-of-office settings and in critical situations such as ambulance transport and emergency departments. While improved communication includes the exchange of information between healthcare providers, the urgency of accessing relevant patient data in real-time, particularly during emergencies, is not explicitly addressed in the literature's focus on communication improvement.

Additionally, the interviews highlight concerns about the reliability and recentness of patient data, which could affect clinical decision-making and patient safety. While the literature acknowledges the importance of accurate information, the specific challenges related to data reliability and currency, as mentioned by participants, are not explicitly mentioned within the context of improved quality of care.

Furthermore, the interviews emphasize the IPS's great potential to transform healthcare by enabling global patient data sharing, regardless of geographical limitations or different healthcare contexts. While the overall advantage of cost reduction is mentioned in the literature, the broader potential of the IPS in changing healthcare delivery on a global scale may differ from the normal scope of cost-saving measures. If the IPS were active in all healthcare systems and contexts, the possible savings could be much higher than thus far predicted on the scale of individual healthcare systems.

## 6.2 Facilitators

Building on the identified value of the IPS, both the literature review and the interviews with healthcare professionals indicated key facilitators that can ensure its successful implementation and adoption.

The literature review revealed multiple important factors, such as workflow integration, information completeness, technology and user needs, standardized guidelines, and the adoption of EHR. It highlighted the significant changes that need to be made to established routines in order to enable the implementation of an IPS within current work routines and processes. The interviews supported this observation, as the participants noted that healthcare professionals want the IPS to just work as intended, as well as how they want it to work. The focus should be on accessibility and efficiency. Accessing the information within the IPS should not be difficult or time-consuming, as healthcare professionals seek quick access to the right information. Especially in emergency care, it is important to be able to quickly access the right information in order to improve time-intensive clinical decision-making and, ultimately, patient care. According to the interviews, another element related to the integration of the IPS within healthcare professionals' workflows is the fact that clinicians should be involved in the whole implementation process. It is important to not lose track of what healthcare professionals actually need in their practice.

According to the literature, strong organizational support further increases the adoption and value of the IPS. Moreover, resistance to change should be decreased in order to improve further adoption and actual utilization. Results from the interviews build upon this idea by identifying the necessity of increasing trust in a tool such as the IPS for both healthcare professionals and patients. People should become more aware of what the IPS is and what its advantages are, which can stimulate more awareness of the IPS and a broader desire for its implementation.

Furthermore, the literature review and the interviews both addressed interoperability. According to the literature, interoperability is necessary in order to support data exchange between multiple healthcare providers and systems. These systems need to "talk each other" and speak each other's language in order to understand the information shared. The interviewed healthcare providers supported this finding by underscoring the importance of information from other sources being available to them. Much of the of the information in the Netherlands stays within its own dataset, making it impossible for health professionals to access it. Diagnostics results and other important data, for example, are often inaccessible to GPs, leading to missing information in patient records. Interoperability is important to increase the likelihood of global access to the most important information, regardless of its provenance. Creating an environment where IPS use is intuitive and non-disruptive, as well as addressing the abovementioned considerations, will make healthcare professionals more likely to adopt it.

Moreover, the literature review identified the need to capitalize on the identified benefits and value. Examples include utilizing technology to its full potential, ensuring data security and privacy, and fostering a culture of continuous improvement. The interview results strengthened the literature review's findings on data security and privacy, besides the need for continuous improvement, especially on the aspect of governance. The interviews also highlighted data security and privacy as key areas of focus, both for their inherent value and their role as facilitators. On the one hand, increasing the security and privacy of the data used will lead to immense value for the IPS by making the used data safe and secure against potential malicious data access. On the other hand, improving safety and privacy is a facilitator, as it may encourage people to have more trust in using such a system. The healthcare professionals also perceived the value of the IPS to be higher in the presence of adequate data safety. Associated with these observations is the need for governance, as there is currently insufficient attention to global implementation and knowledge dissemination. Many healthcare professionals and patients are unaware of what an EPS or an IPS entails or does. Ensuring that governance is increased can lead to a better division of responsibilities in the adoption process, along with strategies and concrete actions to increase worldwide knowledge dissemination and further adoption, while the existing technical barriers and difficulties should be overcome.

### 6.2.1 Integration with literature

The three most important identified facilitator groups from the literature were 1) enabling factors, 2) value enhancement, and 3) resource factors.

The interviews highlight several facilitators who contribute to the IPS's successful implementation and utilization. Access to and control over patients' health records are recognized as key opportunities, putting an accent on patient autonomy and control. These enabling factors were also observed in studies by Eden et al. (2016) and Qian (2020). Procedural facilitators such as single login and adequate training are mentioned, along with the importance of organizational culture and streamlined workflow integration. Especially the latter is important, according to interview participants; making sure that the IPS is suitable for their use and making sure that it can be easily incorporated into existing workflows.

The facilitators identified in the interviews align with value enhancement by promoting the effective use of the IPS to improve patient care coordination and empower patients. Using the IPS should be meaningful, improving the quality of care they provide. Seamless access to accurate and up-to-date medical information is essential for enhancing value, as emphasized by all interviewed GPs. These findings are consistent with those from Yeager (2014) and Qian (2020) in the literature study. Meaningful use and a focus on value enhancement are mentioned as important ways of enhancing value. The practical example of the coronavirus pandemic also showed benefits like improved efficiency and care coordination due to the use of health data exchange. Implementing interoperable systems and ensuring that the IPS is used in a meaningful and efficient way helps stimulate the value of the IPS.

Other facilitators mentioned in the interviews emphasize the need for adequate resources, including technological infrastructure and governance frameworks, to support the implementation of the IPS. Centralizing patient data, possibly through a national EHR system, can improve data accessibility and reduce administrative burdens for both patients and healthcare professionals. These resource factors are also mentioned by Yeager (2014) and Qian (2020) in the literature study. Adequate resources, such as funding and cost-effectiveness, are crucial. Moreover, making patient information exchange programs attractive should also lead to better value. However, as mentioned in interviews, such initiatives require planning, strong governance, and active governmental involvement to ensure successful implementation and compliance with regulations.

### 6.2.2 Gaps with literature

There are findings mentioned in the interviews that could be considered as additional aspects beyond the three main facilitators from the literature.

One topic mentioned in the interviews is the importance of building trust in the healthcare system. The interviews emphasize the importance of building trust in the healthcare system, particularly regarding confidentiality and data security. The participants expressed concerns about distrust in various areas, including the government and healthcare. While trust in healthcare can implicitly be linked to value enhancement, it represents a broader societal challenge that is not fully captured within the identified facilitators in the literature.

Another potential approach and point of attention mentioned in the interviews involves implementing an opt-out system for data sharing, where patients can actively choose not to share their data. This approach aims to balance patient autonomy with the benefits of more possibilities for data exchange among healthcare providers. While this can be deemed an enabling factor and value-enhancing, it also involves ethical considerations and patient rights, which have not been discussed in the identified literature.

Moreover, involving clinicians in the development and implementation of the IPS ensures its usability and effectiveness, ultimately enhancing its value in clinical practice. The interviews emphasize the crucial role of clinicians in the development and implementation of the IPS, a point that the studied literature failed to acknowledge. While this involvement aligns with value enhancement by ensuring usability and effectiveness, it also emphasizes the importance of professional expertise and user-centered design, which may explain why it was not included in the literature.

## 6.3 Barriers

Both the literature review and the interviews shed light on the existing barriers pertaining to the value and adoption of the IPS. The literature revealed the existence of multiple barriers, such as data and privacy issues, technological challenges, implementation costs, and a lack of interoperability. The interviews provided more clarity on other practical barriers, such as accessibility and efficiency concerns, trust issues and unawareness, and a lack of governance, decision-making, and knowledge dissemination.

Data are still not secure and private enough. Without secure and private data, an IPS is hard to utilize. The IPS holds all kinds of important data about a person's health and previous healthcare and diagnoses, making it very bad for the information to fall into the wrong hands. Healthcare professionals place a high value on safe, up-to-date, and relevant information. However, the literature suggests that privacy concerns are preventing many professionals from expressing enthusiasm for the IPS. Resolving this issue will greatly enhance the value of the IPS. Therefore, it is necessary to make the data accessible, relevant, safe, and secure in order to increase IPS adoption.

Technological challenges exist mainly on the application and infrastructure layers, as IT systems worldwide must be able to exchange the required health data elements captured in the IPS. The interview results showed that healthcare professionals highly value being able to quickly access the data from their workstations, thereby relying on their systems to do their job correctly. Theoretically, systems should be technically able to talk with one another, as mentioned above. As long as these challenges are not overcome, they remain a barrier, as the systems may not be capable of using the IPS, while healthcare professionals may not be able to use the IPS as they intend to use it.

Implementation costs are a barrier, according to the literature review. However, in the interviews, this barrier was not mentioned much. One expert asserted that money is not the issue in the Netherlands, given the significant amount already spent without yielding expected results, and the allocation of additional budget and financial resources poses no challenge. The literature suggested, on the other hand, that the financial issue hinders further implementation, as it is uncertain how much the implementation will actually cost and who is responsible for paying which amounts. The literature also indicates possible financial benefits of using the IPS due to decreasing healthcare costs and, thus, gaining financial resources in the end. This benefit is also subject to governance, which will be explained below.

Furthermore, unawareness and trust issues constitute barriers, according to the interview participants. The healthcare professionals highlighted the unawareness of their colleagues on this subject while also mentioning that there is not much trust from patients and civilians in the "healthcare system" as a whole. Therefore, there is less support from the wider public, healthcare experts, and politicians, reducing the adoption rate of the IPS.

Finally, a lack of governance emerges as an important barrier in the interviews. It is worth noting that this barrier was not specifically noted in the literature review. Governance is important to steer the direction of further implementation and adoption of the IPS, but it is currently insufficient. The adoption is proceeding slowly, and worldwide attention has not been achieved yet. Many healthcare professionals and medical specialists have no idea—and no interest—in these kinds of subjects, as they are more distant from their actual work. Using the existing systems is familiar, and the possibility of having a better system for receiving patient data is not a priority. Combined with the fact that, according to one expert, politics is failing to guide the further adoption of the IPS, it has led to slow adoption of the IPS. Therefore, governance needs to be improved in order to increase the value and actual use of the IPS.

### 6.3.1 Integration with literature

The three most important identified barriers from the literature were: 1) privacy/security concerns; 2) technological challenges; and 3) implementation costs and funding issues.

The interviews highlight significant barriers related to patient privacy and data security, potentially influencing the willingness of both healthcare providers and patients to share medical information. Concerns about obtaining informed consent for data sharing and ensuring robust data protection measures are crucial considerations. Esmaeilzadeh (2022) describes the necessity for security measures, confidentiality, and integrity of patient data in order to build trust among stakeholders. In order to enable seamless and safe exchange of data, standardized data formats are required (Tharmalingam et al., 2016). Lastly, there are also concerns about data accuracy and integrity identified in the literature, necessitating mechanisms for ensuring data quality (Bowden and Coiera, 2017). It is clear that both literature and interviews point to a focus on safe and privacy-secure information in order to reliably exchange information around the world. Participants further emphasize the need for clear communication around data governance and the importance of building trust through secure data practices. Moreover, the existing regulatory landscape, including frameworks such as the General Data Protection Regulation (GDPR), significantly influences data-sharing practices and requires a careful approach to ensure the necessary compliance.

Technical challenges and issues lead to difficulties in accessing and sharing patient information, contributing to barriers to seamless data exchange. Inadequate infrastructure, disparate information systems, and manual data entry hinder efficiency and interoperability. These findings are consistent with the observations made in the literature. Qian (2020) identified challenges related to system usability and technical support, while Fontaine et al. (2010) emphasize the need to address current technical disruption and system downtime to guarantee uninterrupted access to crucial patient data. Interview participants stress the importance of implementing standardized formats and interoperable systems to overcome these technical hurdles and facilitate effective data exchange across healthcare settings.

### 6.3.2 Gaps with literature

There are some findings mentioned in the interviews that could be considered additional aspects beyond the three main barriers from the literature.

The interviews highlighted access issues as a significant and specific barrier for transient patients seeking care outside their usual healthcare system. This challenge can lead to incomplete or inadequate medical information, negatively impacting patient-care decisions. While this is related to the technological challenges, it more specifically represents a barrier concerning access to healthcare services for “foreign” patients, which may be the reason that it is not identified in the literature research.

Furthermore, the interviews emphasize the lack of awareness among healthcare professionals regarding initiatives such as the IPS and the EPS. This finding underlines the importance of increased awareness and understanding in order to promote the adoption and effective use of patient data exchange in healthcare practice. This represents a unique barrier concerning healthcare professionals' knowledge and engagement with digital health solutions, which is not explicitly addressed within the literature's focus on financial implications and technological challenges, because it poses a more societal challenge.

Moreover, establishing effective governance and clear policies is highlighted as essential for addressing the identified barriers and facilitating successful data exchange across healthcare settings. The governance and policies are currently forming barriers, standing in the way of faster and more successful adoption. This barrier represents a broader consideration concerning organizational and governmental factors that influence the adoption and implementation process of the IPS worldwide.

The last additional finding through interviews is the challenges concerning patients' digital literacy and capacity to manage EHRs independently. This is especially relevant among vulnerable populations, for which healthcare is even more important. This barrier is applicable to the earlier mentioned value, where patients have their own autonomy in their sharing of medical data. Alternative access methods must be considered to ensure overall access to crucial information without hindering patient care.

The following barrier is specifically mentioned in the literature, but it is not explicitly mentioned in the interview results. These are the implementation costs and funding issues. Implementing solutions to address the aforementioned privacy issues and technological challenges often entails significant costs. Furthermore, establishing improved governance frameworks and clear policies worldwide requires an additional investment in resources and thus leads to higher costs. Overcoming technical hurdles and promoting awareness among healthcare professionals also require financial investment in education, training, and technology adoption initiatives. Thus, while not directly addressed in the interview findings, the financial implications of addressing privacy and technological challenges are unpreventable in the context of further adoption and implementation of the IPS. A possible reason is that healthcare professionals themselves have less to do with the financial resources and implementation processes, so implementation costs and funding are less of a priority.

# 7 Recommendations

The synthesis of insights from the literature review and the interviews with healthcare professionals provides a comprehensive understanding of the values, facilitators, and barriers associated with the IPS. By combining these findings, strategies and calls for action can be outlined to increase the value and enhance the adoption of IPS in clinical practice. The following recommendations address key areas of attention identified by both the sources in this study and personal experience.

From this research, it is clear that there is added value due to the use of the IPS. Theory and practice both agree on the relevance and value of using an IPS in healthcare practice. There also seem to be a lot of similarities between the theory and practice in terms of the facilitators and the barriers associated with the IPS. In the previous chapter, the synthesis was discussed, along with the points that should be changed in order to create more value, thereby realizing the facilitators and overcoming the barriers.

In addition to the identified steps and actions, the author provides additional recommendations for guidance. These recommendations are based on the author's views, apart from the research findings:

1. The IPS's value and advantages are highly promising for healthcare professionals as well as the general public. It should be ensured that more people know about the IPS and the impact it can have on healthcare. This aspect is already mentioned in the research, but it deserves some more attention. People must be educated on what IPS implementation entails and how their medical information is ready to be shared. They must be informed of the implications of IPS implementation when emergency care is needed in a foreign country or even in a province other than the one they live in. It is important to create relevance, support, and awareness. IPS implementation should become a popular subject, and governments should play a role in this knowledge dissemination, as they have a tremendous influence on what is shown to citizens—for example, through advertisements.
2. More research must be conducted on the IPS.
    2.1. One relevant topic is the value—more specifically, in certain health care systems and demographic regions—where healthcare is arranged differently. It is important to check whether there are other factors to take into account that this research missed but are still important.
    2.2. Another area of research could be comparing the results before and after implementing the IPS in a specific area. This idea was also mentioned in the literature review. It should be a case study in which certain variables and outcomes can be measured before and after implementing and using the IPS to create a clearer picture of what changes the IPS exactly brings about. This picture would be beneficial for further support and adoption.
    2.3. Furthermore, research can be conducted on specifically adopting the IPS further and finding out why the process currently is taking so long. From this research, it is clear that there are many stakeholders involved in this subject—from patients to healthcare professionals and from hospitals to standards-developing organizations and governments. This involvement probably makes it difficult to act quickly and ensure consistent progress. This observation aligns with the identification of a lack of governance. It is critical to determine exactly what is obstructing this governance and how the adoption process can be set up.
3. The final recommendation entails a worldwide shift of focus to actual adoption instead of the details of the IPS. For years, many people have been working hard to create the IPS and implement it worldwide. Unfortunately, there aren't many real-world use-cases for the IPS. The standards and requirements are largely in place; hence, it is time to

direct the entire focus to the actual implementation of the IPS. Governments, healthcare organizations, and other relevant stakeholders should collaborate with standards development organizations to determine the adoption strategy for the IPS. Changes in the little details of how certain information is displayed can be made later; adoption and actual use are more important. Following actual use, we can gather more information on aspects that require improvement.

4. For this shift of focus mentioned in number 3, different recommendations can be made to increase the adoption of the IPS and shift the focus in the right direction:
    4.1. The global implementation and overall adoption of the IPS could benefit from more clear guidelines and alignment. One possibility is to create a clear roadmap and legislative alignment in order to ensure better adoption. This roadmap should include timelines and requirements that need to be met worldwide in order to make it possible for the IPS to be used. This will create a better and more broadly known agreement to make the necessary changes for IPS adoption. The World Health Organization (WHO) is already addressing this challenge through the Global Initiative on Digital Health (GIDH) project (*Global Initiative on Digital Health*, 2024) and the Global Digital Health Certification Network (GDHCN) (*Global Digital Health Certification Network*, 2023). The GDHCN aims to establish a framework for assessing and certifying the quality, safety, and effectiveness of digital health products. It should ensure that these products meet international standards and can be trusted by healthcare providers and other users. Meanwhile, the GIDH strives to use digital technologies to improve global health outcomes and healthcare delivery. The focus is on promoting the development and adoption of digital health solutions. Key factors are collaboration among stakeholders and guidance and support for countries in the successful implementation of digital health strategies.
    4.2. The development of the European Health Data Space (EHDS) should be actively monitored in relation to the progress of the EPS. The expectation is that the EHDS will be published in the fall of 2024. If so, publication of an implementing act, in which the use of the EPS becomes mandatory, will follow within 2 years, which then comes into effect 2 years later. This means that by the end of 2028, there could be an obligation for EU countries to exchange patient summaries via a national contact point. This could greatly benefit the IPS, as European exchange should be simple, and the scale can then be broadened to the rest of the world.
    4.3. Another point of emphasis should be placed on the legislative obligations. This mainly influences the EHDS and the "Wet elektronische gegevensuitwisseling in de zorg" (Wegiz). As the whole research was done around the value of the IPS, it is necessary to ensure that the eventual value of using the IPS remains present. It can become a problem when organizations comply with the rules in such a way that they just meet the legal requirements but no more. This is caused by the fact that the main focus of legislation and rules is on product characteristics and the ability to share data, instead of the adoption of these possibilities by healthcare organizations, as well as the opportunities for a more streamlined care process. It then becomes the question of to what extent there is still an increase in value. The total focus should be on the value for the patient and healthcare providers. And therefore, individual organizations should not just comply with the existing rules but also try to seek value and widespread adoption to achieve the most profit for themselves and other beneficiaries across the world.
    4.4. Research should be conducted on the possibility of mandatory integration for EHR providers. In this way, by mandating the integration of IPS functionalities into existing EHR systems globally, better data exchange and interoperability across different healthcare settings can be established. Timelines can be established for

these EHR providers for them to adapt and comply with the IPS standards so that the incorporation of data between IPS and EHR is possible without barriers. This not only enhances efficiency and reduces the likelihood of errors, but also enhances patient care by reducing administrative workload.

4.5. Local initiatives and existing work should receive more attention. There are multiple local forms of patient summaries, as well as other work in creating standards and ways of exchanging patient data. Creating and maintaining standards costs money, enough of which has already been spent on this subject This recommendation aligns with the emphasis on advancing existing work, thereby avoiding the need to address problems directly, even when a portion of the solution already exists in another context (standard, system, organization, country, etc.). Individuals involved in the adoption of standards and/or the IPS should collaborate and learn from each other, rather than attempting to solve each problem on their own, disregarding the extensive body of existing work on the subject. This also leads to decreased costs and increased knowledge-sharing.

4.6. The active involvement of healthcare professionals is crucial for the successful implementation and widespread adoption of the IPS, which is also underlined in the interview results. Medical professionals possess in-depth clinical knowledge, which is crucial for ensuring the IPS's clinical relevance and context. Their insights guide the inclusion of essential data points, and their participation can ensure that the design is user-centered. Medical specialists understand disease processes, treatment protocols, and patient management, ensuring that the IPS includes relevant information for effective care delivery. Involving them in the IPS design leads to better integration into clinical workflows, enhancing the usability of the IPS in their workflows. Clinicians can also advocate for IPS adoption within their organizations, making sure colleagues and other stakeholders get acquainted with the value of the IPS (also see next recommendation). There should be regular feedback from clinicians to help refine and update the IPS standards, identify usability issues, and suggest enhancements to meet changing healthcare needs.

4.7. Raising awareness of medication errors and fatal healthcare errors is important for improving patient safety and driving adoption of the IPS. Despite their significant impact, these errors often receive insufficient attention. Addressing this requires a shift in perception within the medical community. There may be reluctance among physicians to acknowledge the extent of medication errors, perhaps due to concerns about reputational damage. However, recognizing the critical role of physicians as end-users highlights the importance of prioritizing patient safety initiatives. Stakeholders can be incentivized to adopt the IPS by emphasizing its clinical value in preventing medication errors and improving patient outcomes. Efforts to raise awareness can include, but are not limited to, education campaigns and collaborative initiatives that underline the IPS's role in preventing adverse events and improving healthcare delivery.

    4.7.1. Adding to this point is the recommendation to stimulate and empower medical specialists and professional federations to advocate loudly for attention to these critical issues in healthcare. If numerous physicians encounter challenges such as these medication errors and fatal healthcare errors, their collective voice can be a powerful sign for change. Medical specialists and professional groups can address their concerns and raise awareness among policymakers, healthcare administrators, and the public, thereby increasing the likelihood of adequate actions to address issues and prioritize patient safety initiatives.

4.8. Lastly, to ensure the ongoing success of IPS implementation and adoption, it's vital to establish ways for continuous monitoring and collaboration. By monitoring progress and outcomes, stakeholders can identify areas for improvement and adapt strategies accordingly. Furthermore, fostering further collaboration with international healthcare organizations and standards bodies facilitates the exchange of best practices and insights. This collaborative approach enables stakeholders to address emerging challenges effectively and drive continual improvement in IPS adoption worldwide.

# 8 Conclusion

This study aimed to investigate how the IPS's added value could be improved and how its continued adoption in healthcare practice could be supported. A systematic literature review, complemented by semi-structured interviews with healthcare professionals, provided valuable insights into the practical implications, values, facilitators, and barriers associated with IPS usage. The research can be concluded by addressing the three subtopics, followed by conclusions regarding further adoption:

### *What is the clinical relevance of the International Patient Summary?*

In conclusion, both the literature review and the interviews underscored the significant value of IPS implementation in healthcare. The IPS improves quality of care, reduces healthcare disparities, and potentially leads to cost savings. It also enhances patient safety, facilitates better communication among healthcare providers, and improves medical decision-making. The IPS ensures that healthcare professionals have access to the most important information about a patient, no matter the context in which this information is required or the provenance of the information.

### *Which factors currently facilitate and restrain the use of the International Patient Summary in healthcare practice?*

Furthermore, the literature review and interviews underscored the significance of IPS accessibility, efficiency, and clinician involvement in the implementation process. Other areas of focus include organizational support, decreasing resistance to change, and increasing trust and awareness. Utilizing these facilitators will enhance the value of using the IPS. Increasing governance and outlining a more clear way of adopting the IPS will also stimulate adoption and its value in use. However, barriers such as data and privacy concerns, technological challenges, implementation costs, unawareness, trust issues, and a lack of governance hinder IPS adoption. Addressing these barriers is critical for maximizing the IPS's potential to improve healthcare outcomes and improve patient-care delivery. It should be easy for healthcare professionals to use the IPS when data is standardized, safe, and secure and computer systems are interoperable and can send and receive information to and from other countries.

### *What organizational and technical changes are necessary to improve the value of the International Patient Summary and extend its adoption?*

The research provided a comprehensive understanding of the values, facilitators, and barriers associated with IPS adoption. There is a need for ways to ensure data accuracy and privacy. Furthermore, experts have identified a secure and accessible patient information exchange system as a solution, along with interoperability between disparate EHR systems and the active involvement of clinicians in system development and implementation. Creating and stimulating governance for IPS adoption is also necessary to increase its value. Finally, more research should be conducted to increase knowledge on the aspects of the IPS that remain unclear. When the IPS is being used more, research should be carried out on the specific consequences of using the IPS to generate more theoretical confirmation of its effects.

### *How will the IPS achieve global adoption and thus provide the value it entails?*

To achieve global adoption and realize the value inherent in the IPS, it is crucial to recognize that implementation is not a one-sided operation. Rather, it consists of numerous smaller-scale efforts within countries, gradually building toward widespread adoption. Take, for instance, the approach of countries like Canada, Brazil, and Argentina, which utilize the IPS to standardize patient data exchange within their own borders. By ensuring interoperability and compatibility among healthcare systems domestically, these nations lay the groundwork for seamless data exchange among healthcare providers within their respective countries. In contrast, in the European Union, the focus often lies on utilizing existing data to enable cross-border exchange. The IPS serves as a basis for EU countries to exchange patient data globally while adhering to standardized IPS protocols. Meanwhile, in countries like New Zealand, IPS adoption is driven by its practicality and effectiveness, regardless of specific regulatory pressures. As international attention to the IPS grows, more countries, healthcare organizations, and governing bodies recognize its value and commit to its adoption. This multifaceted approach makes clear that there are diverse reasons behind IPS adoption, while simultaneously global recognition is increasing, leading to more knowledge about the value and functionality of using the IPS.

Despite the decentralized nature of (current) IPS adoption efforts, characterized by various countries pursuing implementation based on their unique needs and contexts, these individual initiatives collectively contribute to the broader goal of global adoption. Each country's decision to implement the IPS within its borders lays the groundwork for standardized data exchange in its healthcare system. As more countries embrace the IPS and establish interoperable systems domestically, the so-called "network of IPS-compliant healthcare systems" expands. This growing network not only enhances data exchange within individual countries but also sets the stage for further cross-border collaboration and information sharing. Furthermore, regardless of the implementation approach, the IPS's role as a standardized international data exchange method facilitates seamless data exchange between countries. As more countries witness the benefits of IPS adoption and experience improved interoperability within their healthcare systems, broader acceptance and utilization of the IPS on a global scale can be achieved. Thus, while IPS adoption may begin as separate endeavors in different regions and countries, these efforts ultimately coincide, stimulating increased global adoption, supported by a shared commitment to improving healthcare delivery through standardized data exchange.

### *Will the world be able to embrace the IPS?*

In conclusion, the journey toward widespread adoption of the IPS is underway, albeit at a moderate pace. While the IPS represents an innovative shift in healthcare information exchange, its implementation is characterized by fragmented efforts on a country-by-country basis. Each nation, committed to using the IPS, pursues its adoption in a unique manner, shaped by its unique systems, priorities, and context. However, collaboration and coordination efforts are present, with various initiatives and partnerships created to further advance the global adoption of the IPS. Despite the absence of a centralized governance body regulating IPS adoption, progress is evident (*Implementations Across the Globe – the International Patient Summary*, 2021), facilitated by collaboration at both national and international levels. Collaborative endeavors involving organizations such as the WHO, the GDHP, and platforms like the G7 and G20 contribute to a shared vision of standardized healthcare data exchange worldwide. Nevertheless, the complexity of implementing the

IPS on a global scale requires a multifaceted approach, with initiatives spanning from local healthcare institutions to international collaborations. Choices must be made regarding the most effective strategies for implementation at each level, recognizing the importance of incremental progress and combining localized efforts. This research has illustrated the value of the IPS in enhancing patient care, as well as the critical facilitators and barriers influencing its adoption.

This study gathered valuable results on the value, facilitators, and barriers associated with the IPS. The value has been confirmed; however, there are also multiple facilitators and barriers identified by the research. It is essential to use these factors to accelerate the implementation of the IPS, as it is currently proceeding very slowly. The international focus should shift to the actual implementation of the IPS. By navigating these challenges and utilizing the facilitators and collaborative efforts worldwide, the world is ready to embrace the IPS as a new standard of modern health data exchange in the following years, step by step.

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# Appendix A: IPS elements

This appendix briefly describes the six elements of the IPS.

## Medications

This data element includes current and past medications. This information typically includes the medication name, dose, frequency of use and route of administration. The IPS also includes information about any adverse reactions or side effects the patient has experienced while taking medications.

## Allergies and intolerances

This data element includes any allergies or intolerances the patient has. This information is important because it helps healthcare providers avoid prescribing medications or performing procedures that may cause an adverse reaction. The IPS typically includes information about the type of allergy or intolerance, the severity of the reaction and any medications or substances that should be avoided.

## Problems

This data element includes the patient's current and past medical conditions. This information is important because it helps healthcare providers understand the patient's medical history and develop a treatment plan tailored to their specific needs. The IPS typically includes information about the type of medical condition, the date of diagnosis and any treatments the patient has received.

## Immunizations

This data element includes the patient's immunization history. This information is important because it helps healthcare providers ensure that the patient is up to date on their immunizations and avoid unnecessary vaccinations. The IPS typically includes information about the type of vaccine, the date it was administered and the dosage.

## Results

This data element includes the patient's laboratory and diagnostic test results. This information is important because it helps healthcare providers diagnose and monitor the patient's medical conditions. The IPS typically includes information about the type of test, the date it was performed and the results.

## Procedures

This data element includes any surgical or medical procedures the patient has undergone. This information is important because it helps healthcare providers understand the patient's medical history and develop a treatment plan tailored to their specific needs. The IPS typically includes information about the type of procedure, the date it was performed and any complications that occurred.

# 10 Appendix B: IPS artefacts

The IPS consists of different artefacts (standards) that form the basis of the IPS. In this paragraph, the different artefacts are briefly described to clarify the elements. The relation of the different artefacts is described in the Figure.

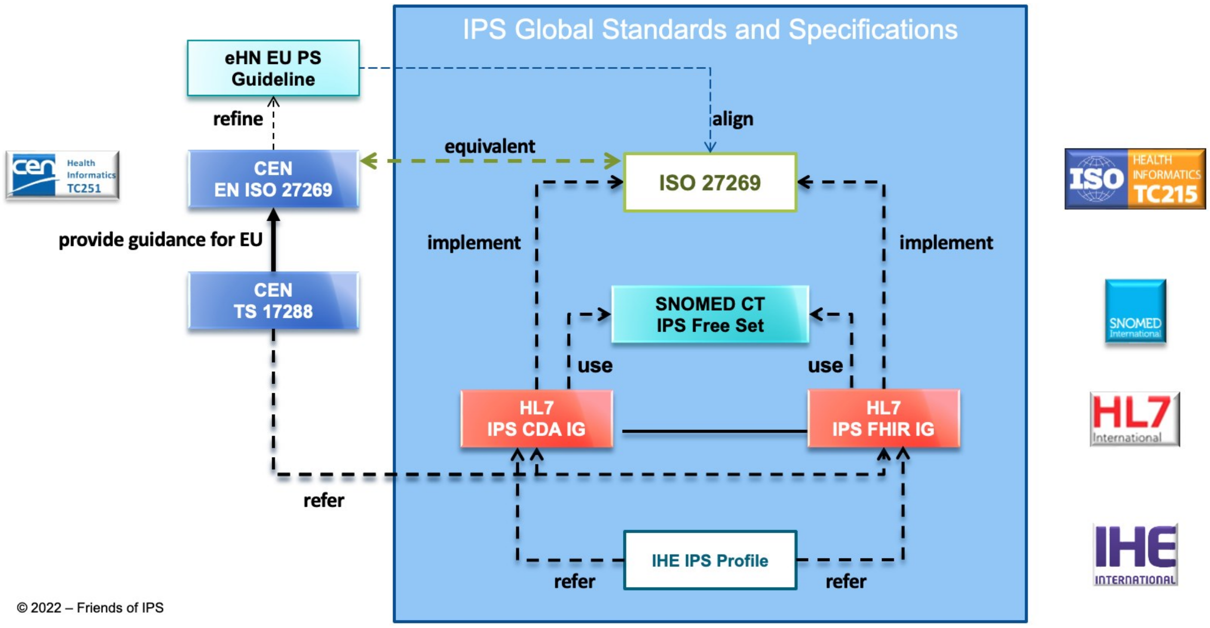

*Figure. The IPS Global Standards and Specifications from the IPS Specifications Suite*

In order to get more acquainted with the background of the IPS and its artefacts, along with some other practical examples of other patient data exchange programs, please refer to appendix B and D, where information about these subjects is described.

## 10.1 IPS Data Structure/Data Model – EN/ISO 27269

The IPS data structure/model defined in ISO standard 27269 outlines the core data set used for a patient summary document, which supports the continuity of care and coordination of healthcare (International Organization for Standardization, n.d.). It is designed for supporting scenarios in which unplanned, cross-border care is needed and is aimed at international use. While being minimal and non-exhaustive, the core data set provides robust and well-defined items, making it suitable for planned care and increasing the usefulness of the IPS worldwide. The standard was formed by combining the European Guidelines from the eHealth Network ) with other international patient summary projects to create a useful and interoperable data set specification. Specifically, this data set is aimed at unplanned care across borders. However, because the data are well-defined but minimal, they can also be used locally. The aforementioned data set from ISO follows the European guidelines from the eHealth Network as the initial source for the requirements, whereafter other IPS projects provided the right specifications. Regarding this thesis, it is important to note that compliance with IPS data does not necessarily imply technical interoperability. This interoperability can be achieved by conforming to standards indicated in the technical specifications and implementation guides.

The eHealth Network guidelines serve as the basis for the ISO standard for an IPS. These guidelines provide information about the data, protection and implementation concepts and the content of the summary (eHealth Network, 2021).

## 10.2 IPS FHIR IG – HL7

The second artefact is the IPS Fast Healthcare Interoperability Resources (FHIR) Implementation Guide, which specifies and constrains how the FHIR can communicate data related to patient summaries (HL7 International, 2022b; International Patient Summary, 2021c). The IPS consists of multiple robust, well-defined, and potentially reusable FHIR resources. It requires information about multiple patient properties, such as allergies, medications, medical problems and diagnoses, while also allowing for an array of other information to be included.

## 10.3 IPS CDA IG – HL7

The third artefact is the IPS Clinical Documentation Architecture (CDA) Implementation Guide (International Patient Summary, 2021b; HL7 International, n.d.). The FHIR and CDA Implementation Guides provide technical guidance on how to structure and communicate information regarding ISO 27269 (described above). A set of partially new rules were defined for using the CDA Implementation Guide for the IPS, optimally supporting the intended scope. A design principle of this guide is using vocabulary with SNOMED CT (Clinical Terms) as reference terminology. This guide caused IPS initiatives around the world to implement and provide feedback on the implementations.

## 10.4 IPS Terminology – SNOMED

The IPS Terminology from SNOMED International is used for the terminology in the IPS standards (SNOMED International, n.d.-a; SNOMED International, n.d.-b). SNOMED International also has a Global Patient Set (GPS), which differs from the IPS terminology; the IPS Terminology provides advanced terminology features, adding hierarchies and defining relationships and synonyms. The IPS terminology can be seen as an evolution of the HL7 IPS free set. This terminology provides the medical terms to be used in the IPS, following the SNOMED CT.

## 10.5 IPS Profile – IHE

The last artefact to discuss is the IPS profile from the Integrating Healthcare Enterprise (IHE), supporting the global adaptation of the IPS (International Patient Summary, 2021a; International Patient Summary, n.d.-a). The profile is considered an essential component of managing the quality of care across (jurisdictional) borders.

Clinical best practices have shown that obtaining a comprehensive overview of relevant clinical information during a patient's initial evaluation can improve treatment outcomes and reduce time-to-treatment and cost. Traditionally, healthcare providers have relied on patient summaries to capture essential information, such as demographics, medical history, allergies, diagnoses and treatment data. However, these documents are often locally standardized and are not consistent globally. The IPS profile provides standardized clinical data and messaging technology that can be easily accessed anywhere.

The IHE has added value to the IPS ecosystem by creating a consistent and supportive profile that complements other standard development organizations' (SDO) artefacts. This addition has strengthened conformance and testing attributes and extended the IPS's global reach through the IHE's international presence. The IPS profile has gained significant attention in various countries and regions around the world.

The IPS is a new form of a patient summary and provides a standard for defining and describing what data should be included in a patient summary (Kay, 2021). Therefore, it is important to consider the content of the IPS and the requirement of summarization. It is necessary to provide all the relevant and vital information in the IPS without losing any essential information or including too much information, as it might create difficulties in quickly interpreting a patient's IPS. Although the simplicity of the information and data in these summaries should make global implementation easy, struggles still exist regarding exactly what data should and should not be included in the patient summary. This is a hazard because non-standard variants of the patient summary are being created, making it impossible to adopt them worldwide. Different healthcare workers, governments and other stakeholders all want specific information in "their" patient summary unique to the location, healthcare system and context. Even if these local patient summaries work well in their own contexts, they usually cannot be expanded worldwide, meaning that not all healthcare staff have access to the same standardized patient summaries. It is the goal of the IPS to provide every clinician with relevant and understandable patient health data for making decisions regarding diagnosis and treatment.

As stated above, many stakeholders are involved in the IPS case, which makes it difficult to find solutions because they often disagree on certain aspects of the IPS (Kay, 2021), even though creating a functional IPS would be positive for all stakeholders. To implement the IPS effectively, interoperability should be enhanced, and the quality of the (shared) data should be adequate, using global terms, such as the SNOMED Clinical Terms (CT). Interoperability is another important requirement for the IPS to work. A citizen living in one country should have no problem having their IPS read by a caregiver in another country. This information needs to be summarized, easy to understand and consistent internationally.

## 10.6 Interoperability, intraoperability and standardization

To maximize the use and usability of the IPS, many factors must be taken into account, such as the relevance of (and the difference between) interoperability and intraoperability. In addition, questions about standardization arise. It is important to standardize the contents of the IPS so that global use is possible. Regarding this topic, extra information is included in Appendix B.

# Appendix C: Other IPS characteristics

In this appendix, additional descriptions of interoperability, intraoperability, standardization and summarization are included.

## Interoperability vs intraoperability

When assessing the use and implications of the IPS, a distinction can be made between interoperability and intraoperability. Interoperability (of data) involves the ability to correctly interpret data across systems or organizational boundaries (Iroju et al., 2013). In other words, interoperability is achieved when information, (communication) technology systems and software applications communicate and exchange data accurately and effectively, allowing the information to be used in these different systems (Dogac et al., n.d.).

Intraoperability is similar, but it applies to the systems within an organization instead of between different organizations. It entails the ability to communicate, transfer, read and use information across different systems within an organization.

For this thesis research, intraoperability is especially important, as the research questions are mainly about the clinical relevance of the IPS and how the IPS can be implemented within the already existing systems of an organization.

## Standardization

The main progress in the IPS is standardization, realizing a common purpose with the same agreed-upon content within the IPS. For the standardization of the IPS, but also in general, some common advantages and disadvantages exist (Kay, 2021), which are listed below. Note that the following advantages and disadvantages are formulated for standard sets, not lone standards. This makes the advantages and disadvantages different:

**Advantages:**

- Better governance opportunities
- Savings
- Reduced effort
- Elimination of wasteful duplication
- Fewer interfaces
- Easier maintenance

**Disadvantages:**

- Standards may become incompatible
- Standards may become conflicting and competing
- Standards may become complicated and impenetrable
- Standards may be slow to develop
- Standards may hinder innovation

It is important to use the advantages of standardization to the fullest and avoid the disadvantages as much as possible. Worldwide, via the Joint Initiative Council for Global Health Informatics Standardization, much work is already being done on creating a standard for the IPS (IPS Web Editorial Team, n.d.).

Furthermore, according to the International Organization for Standardization (ISO), standards are necessary to further improve healthcare globally. Standardization should improve safety, quality and service in healthcare (International Organization for Standardization, n.d.-b).

## Summarization

The question remains regarding what exactly should be included in the IPS. Summarizing is important in this case, as the most important data should be included. The IPS can be seen as a "summarization function applied to the known healthcare history of a patient" (Kay, 2021). Even though the summarization makes it possible to have a clear IPS, communication problems can sometimes cause the IPS reader to be less able to read and interpret the IPS, possibly leading to serious or life-threatening situations. In the Figure, the possible macroelements of the IPS are displayed. The items on the left are critical, but the optional items (on the right) are not necessary for creating a working IPS. This reinforces the initial question about what information should be included in a patient's IPS.

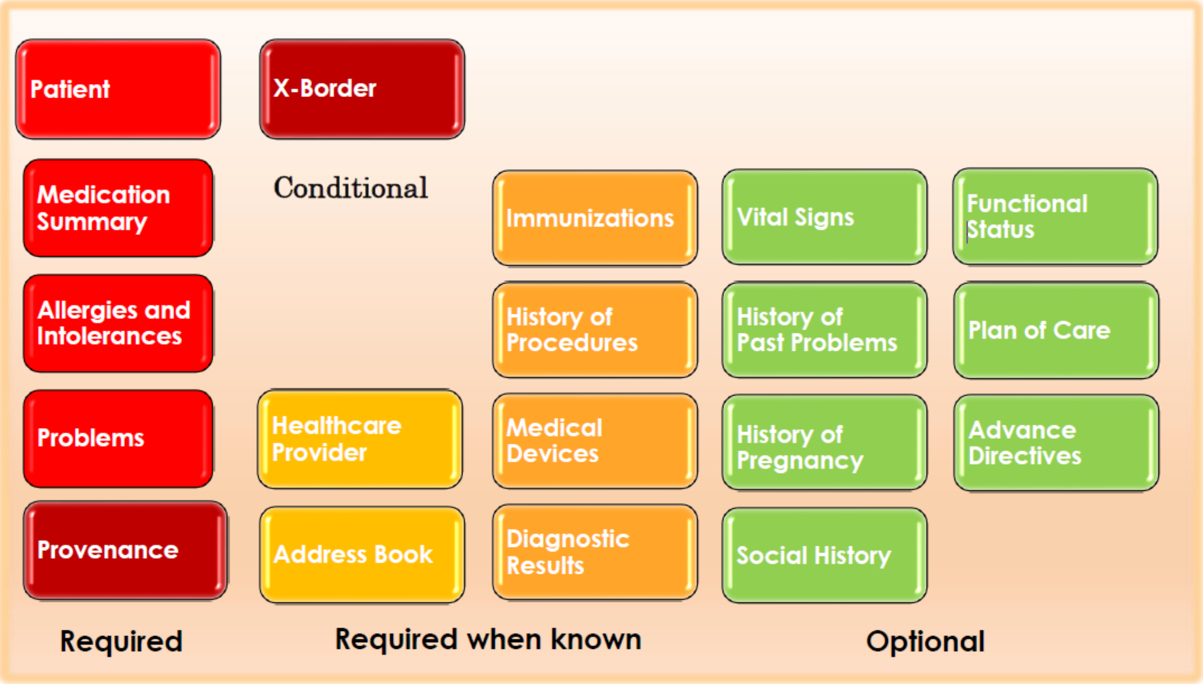

*Figure. Macroelements of the IPS (HL7 International, 2022)*

It is clear that summarizing is important for creating a clear and globally used IPS; it ensures that correct and relevant content from a patient's medical history is represented in the IPS. However, the summarization issue is less relevant for the topics of this master's thesis.

## Appendix D: Similar health data exchange programs

Some programs and initiatives already exist for sharing patient data with stakeholders in such a way that the most important and relevant data can be reviewed quickly. These data exchanges can occur between different departments in a hospital or from a general practitioner (GP) to a doctor in a hospital. These examples and their relevance to the IPS are explained here. These exchanges can be seen as precursors to the IPS and its ability to exchange essential patient data. In this appendix, multiple examples of health data exchange programs are discussed. This information creates a clear view of the other programs already available and how much they resemble the characteristics of the IPS.

### *Metspoedbeschikbaar*

*Metspoedbeschikbaar* is a Dutch program developed to foster data exchange for emergency care, and it is aimed at general practitioners (GPs), paramedics and emergency room doctors. With this program, all the data can be exchanged with the right person at the right time, so every stakeholder in the emergency care process has the appropriate information in time to (further) treat the patient. Information such as medication, medical history and procedures performed in the ambulance are included in the data that is exchanged. The following points are the goals of *metspoed beschikbaar* (Met spoed beschikbaar, 2020):

- Better health outcomes for the patient
- Faster and more efficient health processes with less administration
- More job satisfaction for caregivers
- Improved quality of care processes

### PRSB standard for patient handover

A second example is the standard for emergency patient handover developed by the Professional Record Standards Body (PRSB). This standard, "Ambulance handover to emergency care standard 1.0", is also used to provide standardized information when handing over a patient transported to the hospital by ambulance (Professional Record Standards Body, n.d.). The standard was developed with the aim of improving information sharing with clinicians who urgently need it so as to improve patient safety and high-quality care. With this standard in use, every ambulance transporting a patient has the same consistent set of information available for the emergency department.

### GP data exchange

Another well-known example of data exchange in healthcare is that by GPs. GPs, as the front line of the healthcare system, often have data to share with other caregivers, such as doctors in hospitals or other specialized professionals (e.g. physiotherapists). It also works in the opposite direction; many other healthcare professionals report information back to GPs to inform them about what they have done and what the outcomes of diagnostics and treatments are. As described by Kalankesh et al. (2014), data content and exchange are important for GPs; however, more research is needed to create a clearer framework for data exchange in GP systems.

In the Netherlands specifically, a case of quick access and patient data sharing is already common in the exchange in *huisartsenposten*. It is common to send a patient's summary to a GP outside of office hours when the patient needs to see a doctor at that moment. This fact is important for this research, as the question arises as to why this exchange of data is broadly implemented in GP care but not yet internationally. Moreover, it becomes clear that GPs also open medical records to their own patients, as 98% of the GP practices offer online access to the records (Nivel, 2022), so access by patients themselves seems to be present.

# Appendix E: Details of Table 1

Underlying topics in the table:

1.
- Include robust policies and training about privacy and security
- Consider opt-out vs opt-in for the consent process
- Obtain consent at registration or with online patient authorization
- Educate patients on health information exchange
- Use probabilistic matching algorithms

2.
- Have a single login
- Take a sociotechnical approach
- Provide ongoing training for providers and proxy users
- Collect feedback from users in an ongoing manner
- Monitor metrics of provider access and contribution
- Manage expectations of new health information exchange
- Develop thoughtful workflows and interfaces for providers and proxy users
- Have champion health information exchange users
- Have sufficient technical support

3.

- Consider when to push and when to pull data
- Have the ability to send brief reports before full access
- Provide alerts for when health information exchange is available
- Share contextual notes
- Permit automatic integration with existing provider systems
- Include providers and proxy users in the interface design

4.
- Coordination of care
- Patient portal
- Duplicate testing
- Population management

5.
- Use health information exchange (HIE) as a way to obtain meaningful use

6.
- Expense relative to alternatives
- Meaningful use benefit outweighs the cost of joining HIE
- Future health systems reform outweighs the cost of joining HIE

7.
- Patient and provider concerns about privacy and security
- Patients outside the HIE catchment area
- Poor matching of patients
- Providers stop using query-based systems when they cannot find patients or the necessary information
- Health system competition
- Providers do not exchange data because of concerns about liability and malpractice

8.
- Disruptive login, separate login, and password for the portal – too many clicks
- Policy that prohibits proxy users
- Need for more technical support
- Need for culture change about practice and to not use free text

- Need to enter data in electronic health records and the HIE

9.

- Reports in exchange may not meet the needs of the provider; too much information might exist or it might not be legible
- Lack of notes to set the context of patient information
- Lack of data standards
- HIE competes with existing hospital portals with more complete information

10.

- Patient value
- Market champions
- Stakeholder involvement
- Regional HIE or hospital systems
- Lack of a case for benefits to the business
- Population value
- Sustainability

11.

- Patient education
- Workflow
- Interface development
- Organizational resources
- Central repository model
- Data security

12.

- Workflow delays
- Training
- Patient value
- Data quality
- Liability concerns

13.

- Market competition
- Lack of a critical mass within a market

14.

- Subscription-fee pricing
- Other related costs

# Appendix F: Systematic literature review methods

Additional details on the methodology of the systematic literature review are described in this appendix.

## Study selection

The process for selecting studies involved a comprehensive search strategy to identify relevant literature. First, an appropriate search query was applied to various information sources. The search terms were chosen to ensure that all relevant studies were captured and no important studies were missed.

Next, the screening process was conducted using the web application Rayyan (Ouzzani et al., 2016). Studies were screened based on the title, followed by the abstract, and finally the full text. The inclusion and exclusion criteria were applied at each stage to ensure that only studies meeting the predefined criteria were included in the review.

The inclusion criteria included studies that investigated the value of using the IPS in healthcare practice barriers, facilitators, or perspectives from healthcare providers, patients or other stakeholders on these subjects. Studies were excluded if they did not meet the inclusion criteria, were not available in English or reported an outcome measure irrelevant to the research question. The screening process for study content and outcomes was completed manually by the author of this thesis to ensure that the inclusion and exclusion criteria were consistently applied.

In summary, the process for selecting studies involved a comprehensive search strategy using appropriate search terms, followed by a systematic screening process using the Rayyan web application. The screening process was conducted in three stages, and the inclusion and exclusion criteria were applied at each stage to ensure that only relevant studies were included in the final review.

## Study characteristics

1. Barriers and facilitators to exchanging health information: A systematic review: This study examined barriers and facilitators to exchanging health information through health information exchange (HIE) systems.
2. Despite the spread of health information exchange, there is little evidence of its impact on cost, use, and quality of care This study evaluated the impact of HIE on healthcare cost, use and quality of care.
3. Emergency department and urgent care clinician perspectives on digital access to past medical histories: This study explored emergency department and urgent care clinician perspectives on digital access to past medical histories through HIE.
4. Factors related to health information exchange participation and use: This study investigated factors related to information exchange participation and use among healthcare providers.
5. Health information exchange: This study reviewed the current state of health information exchange and its impact on healthcare.
6. Hidden value: How indirect benefits of health information exchange further promote sustainability 2.0: This study analyzed the indirect benefits of health information exchange and how they promote sustainability.
7. Identification of barriers affecting the use of health information exchange (HIE) in clinicians' practices: An empirical study in the United States: This study identified barriers to health information exchange use among clinicians in the United States.
8. Systematic review of health information exchange in primary care practices: This study involved a systematic review of health information exchange in primary care practices.

9. The benefits of health information exchange: An updated systematic review: This study provided an updated systematic review of the benefits of health information exchange.
10. The effects of health information exchange access on healthcare quality and efficiency: An empirical investigation: This study investigated the effects of health information exchange access on healthcare quality and efficiency.
11. The impact of electronic health record interoperability on safety and quality of care in high-income countries: Systematic review: This study included a systematic review of the impact of electronic health record interoperability on safety and quality of care in high-income countries.
12. The impact of health information exchange on healthcare quality and cost-effectiveness: A systematic literature review: This review examined the impact of health information exchange on healthcare quality and cost-effectiveness.
13. The role and benefits of accessing primary care patient records during unscheduled care: This study examined the role and benefits of accessing primary care patient records during unscheduled care.
14. The value of connected health information: Perceptions of electronic health record users in Canada: This study explored the perceptions of electronic health record users in Canada regarding the value of connected health information.

## Data collection

One of the key methods of data collection was manual screening of articles to extract relevant information and outcomes related to the use of IPS. The manual screening process involved examining each article to extract key information, such as measurements, outcomes and other relevant details. This allowed for a comprehensive analysis of the data and ensured that all relevant information and studies were included.

## Data items

In this study, various variables were examined: patient clinical outcomes, healthcare provider attitudes and perceptions, and the barriers and facilitators associated with the use of IPS.

Assumptions and simplifications were made to make the data collection process more manageable and to ensure that the study was feasible within the available time and resources. For example, certain clinical outcomes were prioritized over others based on their relevance to the goals and objectives, and only certain healthcare provider perceptions were included based on their potential impact on the implementation of IPS. Additionally, data from certain geographical regions were not included due to limitations in language or accessibility of information. Despite these restrictions, the study aimed to provide a comprehensive analysis of the value of using IPS in healthcare practice.

## Risk of bias in each study

In summarizing the risks of bias, the following conclusions can be drawn about each study:

1. Barriers and facilitators to exchanging health information: A systematic review: The study used a systematic review approach, which reduces the risk of bias. However, the risk of publication bias cannot be ruled out completely.
2. Despite the spread of health information exchange, there is little evidence of its impact on cost, use, and quality of care: The study used a comprehensive search strategy and a systematic review approach, which reduces the risk of bias. However, the quality of the evidence was generally low.
3. Emergency department and urgent care clinician perspectives on digital access to past medical histories: The study used a qualitative approach, which can be prone

to bias due to the subjective nature of data collection and analysis. However, the authors included steps to ensure the reliability and validity of the data.

4. Factors related to health information exchange participation and use: The study used a cross-sectional survey design, which can be prone to self-selection and response biases. However, the authors used statistical methods to control for potential confounding variables.
5. Health information exchange: The study used a narrative review approach, which can be prone to bias due to the potential for selective inclusion and interpretation of studies. However, the authors conducted a comprehensive search and used a structured approach to synthesize the evidence.
6. Hidden value: How indirect benefits of health information exchange further promote sustainability 2.0: The study used a qualitative approach, which can be prone to bias due to the subjective nature of data collection and analysis. However, the authors used multiple methods to ensure the reliability and validity of the data.
7. Identification of barriers affecting the use of health information exchange (HIE) in clinicians' practices: An empirical study in the United States: The study used a cross-sectional survey design, which can be prone to self-selection and response biases. However, the authors used statistical methods to control for potential confounding variables.
8. Systematic review of health information exchange in primary care practices: The study used a systematic review approach, which reduces the risk of bias. However, the authors noted that the quality of the evidence was generally low.
9. The benefits of health information exchange: An updated systematic review: The study used a systematic review approach, which reduces the risk of bias. However, the authors noted that the quality of the evidence was generally low.
10. The effects of health information exchange access on healthcare quality and efficiency: An empirical investigation: The study used a retrospective cohort study design, which can be prone to bias due to the potential for confounding variables. However, the authors used statistical methods to control for potential confounding variables.
11. The impact of electronic health record interoperability on safety and quality of care in high-income countries: Systematic review: The study used a systematic review approach, which reduces the risk of bias. However, the authors noted that the quality of the evidence was generally low.
12. The impact of health information exchange on healthcare quality and cost-effectiveness: A systematic literature review: The study used a systematic review approach, which reduces the risk of bias. However, the authors noted that the quality of the evidence was generally low.
13. The role and benefits of accessing primary care patient records during unscheduled care: The study used a qualitative approach, which can be prone to bias due to the subjective nature of data collection and analysis. However, the authors used multiple methods to ensure the reliability and validity of the data.
14. The value of connected health information: Perceptions of electronic health record users in Canada: The study used a qualitative approach, which can be prone to bias due to the subjective nature of data collection and analysis. However, the authors used multiple methods

It is important to note that some of the studies did not clearly discuss their risk-of-bias assessment, such as the study by Bowden et al. (2022), which involved emergency department and urgent care clinician perspectives on digital access to past medical histories. Overall, it is necessary to consider the risk of bias in interpreting the findings of these studies, possibly making the results less reliable.

## Risk of bias in studies

In this research, the systematic review included observational and other types of studies that provided relevant information on the topic. However, clinical trials were excluded, as the subject matter does not involve treatment, medication or behavior related to patients.

To ensure the quality and reliability of the studies included in the review, an assessment of the risk of bias was conducted. The studies were evaluated for potential sources of bias, including detection bias and reporting bias. The impact of these biases on the study results was considered in the data synthesis process.

The risk-of-bias assessment was used to provide a transparent evaluation of the quality of the evidence and to identify potential limitations of the studies included in the review. The identified risks of bias were considered when interpreting the results of the studies.

It does seem that much of the evidence poses limitations or uncertainties regarding the outcomes of the research. As this research was conducted because of because of a of concluding evidence, this was to be expected.

## Summary measures

Because this review is focused on evaluating the value of using the IPS in healthcare practice, common summary measures, such as risk ratios and mean differences, were not applicable in this context. Instead, the review focused on qualitatively analyzing the studies to identify common themes, key findings and areas of agreement or disagreement. The qualitative data was synthesized to provide an overview of the value, barriers and facilitators, forming the potential value of using IPS in healthcare practice. By taking a qualitative approach, this review was able to provide valuable insights into the different aspects defining the IPS value in healthcare practice.

## Synthesis of results

Since this review is focused on qualitative analysis, the methods of combining results and synthesizing data were completed without using statistical measures or meta-analysis. Instead, a narrative synthesis was conducted, which involved analyzing and summarizing the findings of the studies qualitatively. The results of each study were compared to identify common themes, patterns and discrepancies.

The synthesis involved identifying the key findings and opportunities related to the value and use of IPS in healthcare practice. The review considered the perspectives of healthcare providers and other aspects regarding IPS use. The analysis was used to identify areas of agreement and disagreement among the studies and gaps in the literature.

The qualitative approach allowed for a comprehensive analysis of the studies' findings, as it provides a deep understanding of the experiences of stakeholders, which is relevant for the second part of the data collection (interviews). The results of the review are presented in a narrative format, allowing for a clear and concise summary of the evidence on the effectiveness and feasibility of using IPS in healthcare practice.

## Risk of bias across studies

Although this review did not include a quantitative analysis, a potential still exists for biases that could affect the "cumulative evidence" of the qualitative analysis. One potential source of bias is publication bias (Nair, 2019), which occurs when studies with significant findings are more likely to be published than those with non-significant findings. Additionally, selective reporting within studies can also contribute to bias, where certain outcomes or results are selectively reported or emphasized over others (Norris et al., 2012).

To minimize the risk of bias, this review included a structured search strategy to identify all relevant studies, regardless of their publication status or findings. However, it is important to acknowledge that some biases may still be present and that the findings of the review could be influenced by these potential limitations.

## Appendix F.1: Identified factors from literature

| TOPIC | FINDINGS | STUDIES |
|---|---|---|
| **VALUE** | Hospital admission rate | - Rahurkar et al. (2015) |
| | Hospital readmission rate | - Rahurkar et al. (2015)<br>- Qian (2020)<br>- Sadoughi et al. (2018) |
| | Number of imaging tests | - Rahurkar et al. (2015) |
| | Repeat imaging tests | - Rahurkar et al. (2015)<br>- Qian (2020) |
| | Number of lab/diagnostic tests | - Rahurkar et al. (2015) |
| | Repeat lab/diagnostic tests | - Rahurkar et al. (2015) |
| | Number of ED visits | - Rahurkar et al. (2015) |
| | Number of appointments | - Rahurkar et al. (2015) |
| | High clinicians perceived value | - Bowden et al. (2022) |
| | Improved quality of care | - Qian (2020)<br>- Tzeel et al. (2012)<br>- Menachemi et al. (2018)<br>- Janakiraman et al. (2022)<br>- Sadoughi et al. (2018)<br>- Tharmalingam et al. (2016)<br>- Fontaine et al. (2010) |
| | Improved healthcare utilization | - Qian (2020) |
| | Reduced healthcare costs | - Qian (2020)<br>- Tzeel et al. (2012)<br>- Menachemi et al. (2018)<br>- Fontaine et al. (2010) |
| | Improved public health | - Qian (2020)<br>- Tzeel et al. (2012) |
| | Improved disease surveillance | - Qian (2020)<br>- Menachemi et al. (2018) |
| | Total numbers of order | - Qian (2020) |

| | | |
|---|---|---|
| | Health record completeness | - Qian (2020)<br>- Sadoughi et al. (2018)<br>- Tharmalingam et al. (2016) |
| | Reduced care disparities | - Qian (2020) |
| | Improved medication reconciliation | - Qian (2020) |
| | Improved patient safety | - Esmaeilzadeh (2022)<br>- Sadoughi et al. (2018)<br>- Tharmalingam et al. (2016) |
| | Improved continuity of care | - Esmaeilzadeh (2022) |
| | Improved communication among healthcare providers | - Esmaeilzadeh (2022)<br>- Bowden and Coiera (2017)<br>- Tharmalingam et al. (2016) |
| | Support of public health initiatives | - Tzeel et al. (2012) |
| | Improved research promotion | - Tzeel et al. (2012) |
| | Improved patient engagement | - Tzeel et al. (2012)<br>- Bowden and Coiera (2017) |
| | Reduced length of stay | - Janakiraman et al. (2022) |
| | Higher follow-up appointments after ED visits | - Janakiraman et al. (2022) |
| | Improved healthcare efficiency | - Janakiraman et al. (2022)<br>- Fontaine et al. (2010) |
| | Improved care coordination | - Sadoughi et al. (2018) |
| | Reduced adverse (drug) events | - Sadoughi et al. (2018)<br>- Bowden and Coiera (2017) |
| | Improved clinical decision-making | - Bowden and Coiera (2017) |
| | Reduce diagnostic errors | - Bowden and Coiera (2017) |
| | Enhanced patient satisfaction | - Bowden and Coiera (2017) |
| | | |
| **FACILITATORS** | Completeness of information[1] | - Eden et al. (2016) |
| | Organization and workflow[2] | - Eden et al. (2016) |
| | Technology and user needs[3] | - Eden et al. (2016) |

| | | |
|---|---|---|
| | Patient value[4] | - Yeager et al. (2014) |
| | Meaningful use[5] | - Yeager et al. (2014) |
| | Cost[6] and adequate funding | - Yeager et al. (2014)<br>- Qian (2020) |
| | A supportive organization culture | - Qian (2020) |
| | A workflow integration approach considering user needs | - Qian (2020) |
| | The adoption of emergency health records | - Qian (2020) |
| | Clear and standardized guidelines in use | - Esmaeilzadeh (2022) |
| | Potential for financial incentives to encourage adoption | - Esmaeilzadeh (2022) |
| | | |
| **BARRIERS** | Completeness of information[7] | - Eden et al. (2016)<br>- Qian (2020) |
| | Organization issues and workflow[8] | - Qian (2020)<br>- Eden et al. (2016) |
| | Technology and user needs[9] | - Eden et al. (2016) |
| | The limited reach of a health information system | - Bowden et al. (2022) |
| | Integrity of information not verified enough | - Bowden et al. (2022) |
| | Potential risk of framing bias | - Bowden et al. (2022) |
| | Value of information[10] | - Yeager et al. (2014)<br>- Bowden et al. (2022) |
| | Implementation[11] and market conditions[13] | - Yeager et al. (2014) |
| | Usability[12]/ease of use | - Yeager et al. (2014)<br>- Bowden et al. (2022) |
| | Cost[14]/Implementation costs and funding issues | - Yeager et al. (2014)<br>- Qian (2020)<br>- Fontaine et al. (2010) |
| | Technological (maturity) concerns/issues | - Qian (2020)<br>- Fontaine et al. (2010)<br>- Bowden and Coiera (2017)<br>- Tharmalingam et al. (2016) |
| | Data privacy/security concerns | - Qian (2020)<br>- Esmaeilzadeh (2022)<br>- Fontaine et al. (2010)<br>- Bowden and Coiera (2017) |

| | | |
|---|---|---|
| | | - Tharmalingam et al. (2016) |
| | Lack of data standards | - Qian (2020) |
| | Lack of training/education | - Qian (2020)<br>- Esmaeilzadeh (2022) |
| | Lack of interoperability between systems | - Qian (2020)<br>- Esmaeilzadeh (2022)<br>- Bowden and Coiera (2017) |
| | Lack of willingness to change | - Qian (2020)<br>- Esmaeilzadeh (2022)<br>- Tharmalingam et al. (2016) |
| | Risk of liability | - Fontaine et al. (2010) |
| | Lack of strategic planning and leadership | - Fontaine et al. (2010) |

## Appendix F.2: Table with used factors

The results, including all findings on each subject (value, facilitators and barriers) can be found in this table.

*Table X. Findings of the literature review, divided per underlying subject*

| **VALUE** | **FACTORS** | **STUDIES** |
|---|---|---|
| | Improved quality of care | - Qian (2020)<br>- Tzeel et al. (2012)<br>- Menachemi et al. (2018)<br>- Janakiraman et al. (2022)<br>- Sadoughi et al. (2018)<br>- Tharmalingam et al. (2016)<br>- Fontaine et al. (2010) |
| | Reduced healthcare costs | - Qian (2020)<br>- Tzeel et al. (2012)<br>- Menachemi et al. (2018)<br>- Fontaine et al. (2010) |
| | Hospital readmission rate | - Rahurkar et al. (2015)<br>- Qian (2020)<br>- Sadoughi et al. (2018) |
| | Health record completeness | - Qian (2020)<br>- Sadoughi et al. (2018)<br>- Tharmalingam et al. (2016) |
| | Improved patient safety | - Esmaeilzadeh (2022)<br>- Sadoughi et al. (2018)<br>- Tharmalingam et al. (2016) |
| | Improved communication among healthcare providers | - Esmaeilzadeh (2022)<br>- Bowden and Coiera (2017)<br>- Tharmalingam et al. (2016) |
| **FACILITATORS** | | |
| | Completeness of information[1] | - Eden et al. (2016) |
| | Organization and workflow[2] | - Eden et al. (2016) |
| | Technology and user needs[3] | - Eden et al. (2016) |
| | Patient value[4] | - Yeager et al. (2014) |

| | | |
|---|---|---|
| | Meaningful use[5] | - Yeager et al. (2014) |
| | Cost[6] and adequate funding | - Yeager et al. (2014)<br>- Qian (2020) |
| | A supportive organization culture | - Qian (2020) |
| | A workflow integration approach considering user needs | - Qian (2020) |
| | The adoption of emergency health records | - Qian (2020) |
| | Clear and standardized guidelines in use | - Esmaeilzadeh (2022) |
| | Potential for financial incentives to encourage adoption | - Esmaeilzadeh (2022) |
| **BARRIERS** | | |
| | Data privacy/security concerns | - Qian (2020)<br>- Esmaeilzadeh (2022)<br>- Fontaine et al. (2010)<br>- Bowden and Coiera (2017)<br>- Tharmalingam et al. (2016) |
| | Technological (maturity) concerns/issues | - Qian (2020)<br>- Fontaine et al. (2010)<br>- Bowden and Coiera (2017)<br>- Tharmalingam et al. (2016) |
| | Cost[14]/Implementation costs and funding issues | - Yeager et al. (2014)<br>- Qian (2020)<br>- Fontaine et al. (2010) |
| | Lack of interoperability between systems | - Qian (2020)<br>- Esmaeilzadeh (2022)<br>- Bowden and Coiera (2017) |
| | Lack of willingness to change | - Qian (2020)<br>- Esmaeilzadeh (2022)<br>- Tharmalingam et al. (2016) |

# Appendix G: Specifications of found factors

Facilitators

Multiple facilitators were mentioned, among others, in the article by Eden et al. (2016):

- Completeness of information
    - Robust policy and training about privacy and security
    - Consider opt-out vs. opt-in for the consent process
    - Obtain consent at registration or with online patient authorization
    - Educate patients on health information exchange
    - Use probabilistic matching algorithm
- Organization and workflow
    - Single login
    - Take a sociotechnical approach
    - Provide ongoing training for providers and proxy users
    - Collect feedback from users in ongoing manner
    - Monitor metrics of provider access and contribution
    - Manage expectations of new health information exchange
    - Develop thoughtful workflow and interface for providers and proxy users
    - Have champion health information exchange users
    - Have sufficient technical support
- Technology and user needs
    - Consider when to push and when to pull data
    - Ability to send brief report before full access
    - Provide alerts for when health information exchange is available
    - Share contextual notes
    - Automatic integration with existing provider systems
    - Include providers and proxy users in design of interface

The article by Yeager et al. (2014) states that there are multiple facilitators facilitating the value and use of patient information exchange, including the following:

- Patient value
    - Coordination of care
    - Patient portal
    - Duplicate testing
    - Population management
- Meaningful use
    - HIE as a way to obtain meaningful use
- Cost
    - Expense relative to alternatives
    - Meaningful use benefit outweighs cost of joining HIE
    - Future health systems reform outweighs cost of joining HIE

The article by Qian (2020) also states some facilitators fostering the use and further implementation of patient data exchange systems, such as the IPS. Facilitators include a supportive organizational culture, a workflow integration approach considering user needs, the adoption of emergency health records, and proportional funding. The value and perceived value of using this data exchange, as mentioned in the part above, also help facilitate the adoption and implementation of such systems.

The article by Esmaeilzadeh (2022) presents a few facilitators, such as the need for clear and standardized guidelines for the use of the IPS and the potential for financial incentives to encourage adoption.

The article by Fontaine et al. (2010) studied the facilitators of using data exchange in healthcare, leading to the following benefits: a more efficient workflow, improved quality of care, cost savings, and increased revenue.

Barriers

Multiple barriers were mentioned, among others, in the article by Eden et al. (2016):

- Completeness of information
    - Patients and providers concerned about privacy and security
    - Patients outside of the HIE catchment area
    - Poor matching of patients
    - Providers stop using query-based systems when they cannot find patients or needed information
    - Health system competition
    - Providers do not exchange over concern about liability, malpractice
- Organization and workflow
    - Disruptive login, or separate login & password to portal—too many clicks
    - Policy that prohibits proxy users
    - Need for more technical support
    - Need for culture change about practice and need to not use free text
    - Need to enter data in EHR and the HIE
- Technology and user needs
    - Reports in exchange may not meet needs of the provider; there may be too much information or not legible
    - Lack of notes to set context in patient information
    - Lack of data standards
    - HIE competes with existing hospital portals with more complete information

# Appendix H: Interview form and questions

## Interview form

For the form it is important that all relevant information will be collected from participants. Questions should be created in advance of the interviews to make sure that the information that is needed, will be collected. However, the people being interviewed will (nearly) all be professionals with relevant experiences and valuable opinions on the matter, so there needs to be room for extra input from the participants. That is the reason that the interviews will be semi-structured. There will be a list of questions, but during the interview there will be room to ask further on certain parts where necessary. This probably leads to the most and best information being collected from the participants.

## Interview questions

For the interview for doctors, it is important to gather information about how the doctor perceives the value of the IPS. For the doctor(s) who already worked with the IPS, it is vital to gain insight into their experiences with it. For other doctors, having experience with patient data exchange, not being the IPS, it is important to see what they value on data exchange, together what facilitates and barriers this value creation.

In the second group, managers, policy makers, and other key stakeholders who play critical roles in decision-making processes and shaping healthcare policies will be involved. Their perspectives will be explored to uncover the macro-level challenges and opportunities associated with IPS implementation, funding, and strategic planning. The insights gained from these stakeholders will aid in identifying organizational and systemic factors that can influence the successful integration of IPS within healthcare institutions.

## Concept questions doctors

1. How does your work process looks like on average? So what happens from the moment you receive the care of a patient?
    1. In which steps of the care process do you need and/or use patient data/IPS?
        - ➢ What are the goals when using them?
        - ➢ What do they add to your work processes?
    2. How do you receive the IPS?
        - ➢ And how do you get access to this data?
        - ➢ Do you need to authenticate yourself?
        - ➢ Are there possibilities to improve the way this all works?
    3. What is in your opinion the most relevant information within an IPS/patient summary?
        - ➢ How does this information influence your further diagnosis and treatment?
    4. How do you translate information from the patient summaries to actions in you work?
        - ➢ Is this also documented somewhere?

    5. Is there any possibility to capture the IPS data into another source (e.g. the EPD), so it get integrated in their medical records? Or is this completely separate?

2. Can you share any experiences or examples where the use of the IPS has contributed to improved quality of care for patients? (Or, overall impact in general: positive/negative?)
    1. In your opinion, how has the IPS helped you in diagnosing patients? What was the value?
    2. In your opinion, how has the IPS helped you in treating patients? What was the value?
    3. Overall, what can you say about the value of using IPS/patient summaries?
    4. Were there things that could be different or better, so that care can be improved?
2. What challenges or barriers have you encountered in using patient summaries?
    1. How did you solve these barriers and challenges?
    2. Are there still challenges or barriers present that hinder the value?
3. Taking into account your education and own knowledge, how would you do things differently in the case there is no information about the patient available? (so you judge the patient on only the things you can see and measure)
    1. Does the availability of information thus gives you value in treating a patient?
        - ➢ Which elements of the patient summary appear the most relevant for you?
        - ➢ Do these elements provide benefits to the care you give?
        - ➢ Are there also barriers, hindering the quality of care you give?
    2. Would it be a significant disadvantage to miss this background information of the patient?
4. Has it been easy (challenges/barriers) to incorporate the IPS into your daily routine?
    1. Are there any specific facilitators or supporting factors that you believe have been instrumental in successfully using the IPS in your daily practice?
        - ➢ How can other organizations learn from this when adopting the IPS?
    2. Did you face any challenges or barriers on this regard?
    3. If yes, how did you overcome or fix them?
5. Are there now still barriers or challenges present that you would like to be seen solved?
    1. What are these barriers and challenges?

    2. How do you think these challenges can be addressed and solved?
6. Have you experienced any data privacy or security concerns related to the IPS, and how have you addressed them?
7. Do you always trust data you see in an IPS or health record/EHR?
    1. If not, what triggers this distrust?
    2. What would you do then, in case of distrust/other problems?
        - How do you verify/refute the data you do not trust?
        - What can be done to make information and sources more reliable?
8. Do you require any more knowledge, support, technical changes or any other requirements in order to increase the value of using the IPS in you work?
9. Is there currently any room for improvement regarding the use of the IPS?
    1. What additional resources or support would you find beneficial in further enhancing the value and effectiveness of the IPS in emergency care?
10. Do you have any other important or relevant things to take into account when using/implementing the IPS that might be useful for this interview?
11. Other value, advantages or barriers/challenges not yet mentioned? Other things that might be handy for organizations also being busy adopting the IPS?

## Concept questions managers/policy makers

1. What is the context in which you aim to introduce the patient summary?
    1. Which processes does it influence?
    2. How does it influence the work processes of the users?
    3. Can you explain how the use of IPS works from start to finish? Think about access, authentication, consulting, registering and integration of patient information
2. In your experience, what was the motivation for implementing a patient summary?
    1. What values did you want to achieve for the doctors using it?
    2. Did you actually succeed in realizing these values?
3. Have you observed any specific value/benefits resulting from the adoption of the IPS?
    1. What are these and how do they provide value?
    2. Can you share any experiences or examples where the use of the IPS has contributed to improved quality of care for patients?
4. Were there any organizational and workflow changes necessary to successfully implement the IPS?

    1. What were these changes?
    2. How have they contributed to added value?

5. Speaking of changes necessary to implement the IPS, where there any technical changes necessary? Think about, IT, computers, software or software integration.
    1. Are there more challenges or things that have to be addressed technically?
        - If yes, how should this be dealt with?
6. Did you came across any resistance from doctors in using this type of patient information in their work processes?
    1. Could you took away this resistance? If yes, how?
    2. Did you do any other things to further encourage or teach doctors to make use of the IPS?
7. Did the implementation of the IPS bring along any associated costs?
    1. Can they be offset against the value and benefits the IPS provide?
    2. Are there ways to decrease the costs associated with adopting the IPS?
8. Did you come across factors/situations that supported the adoption and integration of the IPS into healthcare practices?
    1. What were these factors and/or situations?
    2. How and why did these factors/situations facilitate the adoption of the IPS?
9. Did you come across factors/situations that hindered the adoption and integration of the IPS into healthcare practices? So what challenges or barriers did you face?
    1. What were these factors and/or situations?
    2. How did you address them?
    3. Did you successfully overcome these?
        - What did you do to overcome these?
    4. Are there still challenges or barriers that need an solution? Do you know how?
10. Have you experienced any data privacy or security concerns related to the IPS?
    1. How have you addressed them?
11. Is there currently any room for improvement regarding the use of the IPS?
    1. What are these possible improvements?
12. What additional resources or support would you find beneficial in further enhancing the value and effectiveness of the IPS in emergency care?
13. Do you have any other important or relevant things to take into account when using/implementing the IPS that might be useful for this interview?

1. Barriers?
2. Other advantages?
3. Things to take note of which are important for other organizations busy with adopting the IPS?

# Appendix I: Research paper HIKM 2024

# Exploring the clinical value of the International Patient Summary - a systematic review

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This systematic review examines the impact of the International Patient Summary (IPS) in healthcare based on fourteen studies. Key findings highlight its benefits, including enhanced care quality, improved communication, and cost-effectiveness. Sufficient financial resources and adequate funding emerge as significant facilitators, while barriers such as privacy and interoperability concerns underscore the need for proactive measures. Further research is crucial to delve into specific factors influencing IPS implementation and its practical effects on healthcare, fostering a comprehensive understanding for practical adoption, and stimulating the further adoption of the IPS worldwide.

Patient data sharing, Digital Health Integration, **International Patient Summary**

**Additional Keywords and Phrases:** Health Information Exchange (HIE), Data Interoperability, Clinical Decision Support, Global Healthcare Integration, Patient Empowerment

## 1 Introduction

The Trillium Bridge project's recommendation to develop the International Patient Summary (IPS) in Europe and the United States in 2015 marked the initial introduction of the IPS [1]. In a way, the IPS forms the successor of the Continuity of Care Document (CCD), which is being used across the United States of America (USA) and the European Patient Summary, which is available through the electronic cross-border services in the European Union (EU). Since then, a global endeavor has been underway, with individuals worldwide actively involved in the development, improvement, and dissemination of the IPS for universal use. However, the current scarcity of literature on the IPS underscores the ongoing nature of evolution, the IPS being an innovation of the world of information exchange in healthcare.

The overarching objective is to establish a minimal but universal health data set applicable in any country, for any type of care, and by any caregiver. This ensures that a patient's crucial health data is readily accessible in all situations, ranging from medical emergencies to routine check-ups. While there is a perceived high value in using the IPS, and progress is evident in its adoption globally, a lack of convincing evidence regarding its clinical relevance highlights the necessity for more comprehensive information on its value and the factors influencing its adoption, while also looking at the barriers hindering the adoption of the IPS. This systematic literature review aims to provide a thorough overview of the added value of using the IPS in healthcare practice, while identifying both barriers and facilitators.

The proposed research question in this overall research is the following: "*What is the added value of using the IPS in healthcare practice?*" Answers to this question create a clearer picture of which factors are relevant when considering the value of the IPS. This literature review offers a comprehensive perspective on the existing knowledge about the subject.

## 1.1 Goals and objectives

The primary objective of this systematic literature review is to gather as much relevant information as possible to achieve more knowledge about the value of the IPS, while also addressing current and possible arising issues for implementing the IPS worldwide. However, it is important to acknowledge that the question may not be completely answered by this review alone. It is important to note that despite the original intention to include the patient perspective in the research, it could not be incorporated in this study. The following specific goals have been formulated, which are presented in Figure 1.

- To provide a comprehensive overview of the added value of using an IPS in healthcare practice, in terms of both its value and clinical relevance (main question).
    - This examines what makes the IPS relevant for use in healthcare practice.
- To identify the barriers and facilitators that affect the value of using an IPS in healthcare practice (optionally analyzing how these factors impact its implementation).
    - Facilitators and barriers influence the value that can be created by using an IPS in practice. Facilitators are the factors increasing the chance of successful adoption and thereby value.

- Barriers hinder the adoption, use, and value creation of an IPS.

Looking at the goals and objectives, it is worth noting that the IPS is connected to the term Health Information Exchange (HIE), a term that will be mentioned more often in this article. The HIE is an infrastructure, used extensively in the USA, to support the exchange of the aforementioned CCD and other clinical documents. Because there is a lot more research done on the value of HIE, this will be included in this systematic review under the assumption that the results will be applicable to the IPS as well. The theory and lessons learned from this literature can be applied to further implement and adopt the use of the IPS in clinical practice.

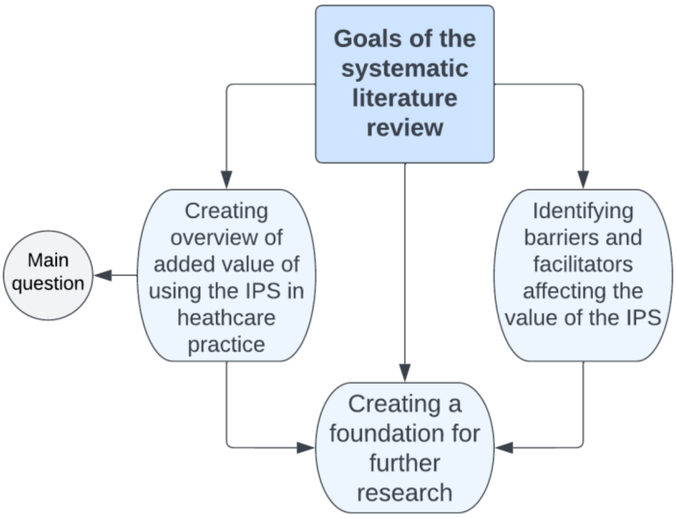

**Figure 1.** **The goals and objectives of the systematic literature review in relation to the research topics and questions**

## 2 Methods

This section outlines the methodology used to conduct the systematic review and provides a foundation for the analysis and discussion of the findings. As the research subject, and therefore the research question is relatively new, it is crucial to identify and analyze all articles that provide valuable information regarding the topic. The selection process, search queries, data collection and synthesis methods are discussed, highlighting the steps taken to ensure that all relevant information is included in the review.

To ensure that the literature review included only high-quality, relevant articles, several selection criteria were used. These criteria were designed to narrow down the search results, exclude articles not meeting the research objectives and develop a focused and comprehensive literature review.

The selection criteria for eligible studies included the following aspects:

The study must be published in English, as it is the language of this research.

The study must report on the value, impact, barriers, or facilitators of using the IPS in healthcare practice, as this is the focus of this research.

The study must include sufficient and relevant outcomes for measuring the value of using the IPS in healthcare practice.

Additionally, the following report characteristics were considered:

The publication year was not restricted, as the IPS is a relatively new concept, and all relevant literature is important.

Only articles published in peer-reviewed journals were considered, apart from relevant and reliable grey literature.

Only full text articles were included so that they could be assessed for eligibility.

## 3 Results

The search strategy used in this study involved developing a search string that would yield accurate and relevant results. This was achieved through iterative testing of different search terms and assessing their impact on the yield. Once an adequate number of results were obtained, the predetermined criteria (see above paragraphs) were applied to identify all relevant articles and exclude irrelevant ones. Some search

strings returned irrelevant results, so selection criteria were used to exclude those search terms from the final search string. Multiple search strings were evaluated to ensure that the most relevant literature was captured. After filtering out irrelevant results, the literature was analyzed and presented. The following search query was used: *("clinical relevance" OR "Health Care" OR "quality of care") AND "value" AND ("international patient summary" OR "IPS" OR "Health Information Exchange") AND ("benefits" OR "advantages").*
We limited our search to PubMed and Scopus, the most relevant databases in the field of Health Sciences. *The results of this query are reported in* Table 1.

**Table 1. Number of results divided per information source.**

| Information source | Number of results |
|---|---|
| PubMed | 29 |
| Scopus | 48 |

## 3.1 Study selection

The search strategy included keywords related to clinical value and relevance, healthcare, quality of care, the IPS, health information exchange, benefits/facilitators, and barriers, which led to the search string mentioned above. The given articles were filtered according to the PRISMA selection, as seen in Figure 2.

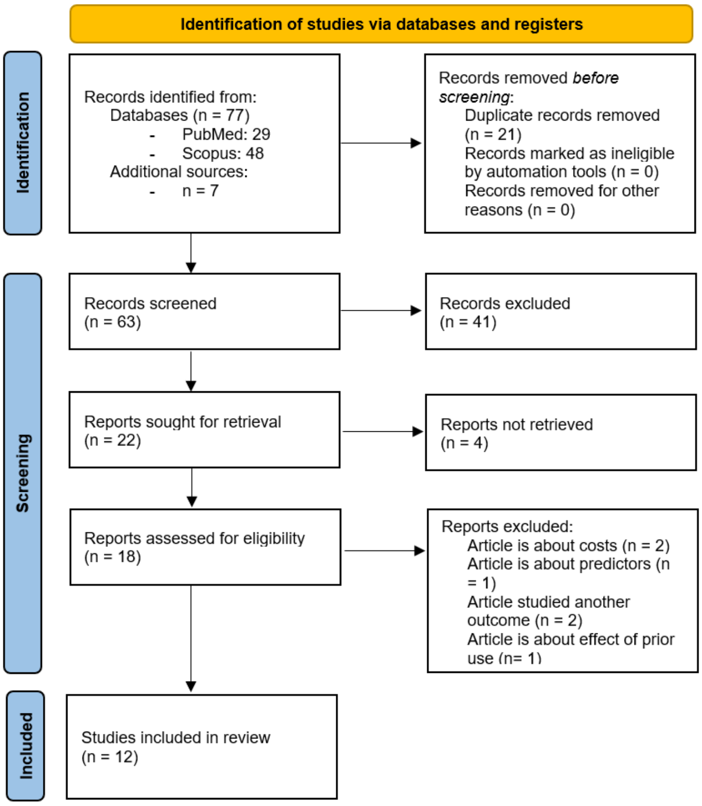

**Figure 2. Systematic review PRISMA flow diagram for articles reporting on the value of using the IPS in healthcare practice [2]**

*A total of 84 studies were identified and screened for eligibility. Following the screening process, 70 studies were excluded for several reasons, including irrelevant outcomes or study design. The remaining 12 studies were included in the final analysis. A flow diagram depicting the study selection process is presented in* Figure 2*. The selected studies all presented results on either value, facilitators, or barriers.*

## 3.2 Results of individual studies

The results of the individual studies are discussed in this section. The results are divided into the three main subjects of this research: value, facilitators, and barriers.

### 3.2.1 Value

The literature review identified several key factors that contribute to the value of using the IPS in healthcare practice. Table 2 presents an overview, focusing on the articles that explicitly mention these factors. The factors discussed below have been mentioned in at least three of the analyzed studies, which indicates their significance in the literature.

**Table 2. Identified factors for "value."**

| **Factor**<br>**Article** | Improved quality of care | Improved communication among healthcare providers | Reduced healthcare costs | Hospital readmission rate | Health record completeness | Improved patient safety |
|---|---|---|---|---|---|---|
| Qian (2020) | ✗ | ✗ | ✗ | ✗ | ✗ |  |
| Tzeel et al. (2012) | ✗ | ✗ | ✗ |  |  |  |
| Menachemi et al. (2018) | ✗ | ✗ | ✗ |  | ✗ |  |
| Janakiraman et al. (2022) | ✗ |  |  | ✗ |  |  |
| Sadoughi et al. (2018) | ✗ | ✗ |  | ✗ | ✗ | ✗ |
| Tharmalingam et al. (2016) | ✗ | ✗ |  |  |  | ✗ |
| Fontaine et al. (2010) | ✗ | ✗ | ✗ |  |  |  |
| Rahurkar et al. (2015) |  |  |  | ✗ |  |  |
| Esmaeilzadeh (2022) |  |  |  |  |  | ✗ |

The most mentioned subject regarding the value is improved quality of care. An observation is the heightened quality of care through enhanced medication management, improved immunization processes, and a reduction in care disparities [3]. Similarly, increased quality of care, with notable improvements in medication reconciliation, immunization, and a decrease in care variance were reported [4]. Further findings support these findings by highlighting how health information utilization resulted in reduced patient length of stay, thereby enhancing the quality of care delivered [5]. Various aspects of improved quality of care, including the avoidance of repeat imaging and unnecessary laboratory tests, reduced repeat visits, and decreased time required to provide care were explored [6]. Additionally, decreased medication errors emerged as a potential benefit of using health information in practice. In a separate investigation, the quality of care through evaluations of Integrated Electronic Health Records (iEHR) were assessed [7]. The study highlighted positive aspects, such as improved clinical decision support, access to more reliable external information sources, and enhanced care coordination. Another study focused on the effects of health information on quality, considering its link to efficiency [8]. They reported that improved access to test results and a streamlined process for handling referrals and claims processing significantly contributed to efficiency, while better health outcomes and enhanced patient safety (reduced prescribing errors and readmissions) underscored the quality improvement. On a broader scale, the indirect value of healthcare information exchange were emphasized, leading to shorter patient length of stay in clinical settings, potentially reducing associated costs and ultimately benefitting the entire community's health by granting clinicians access to patients' medical history [9].

Further findings, specifically about healthcare costs were observed in certain studies. There is evidence of reduced healthcare costs resulting from the use of the IPS [3]. This reduction was attributed to a decrease in unnecessary imaging and other medical procedures. Similarly, observations were made on a reduced length of stay, which indirectly led to lower healthcare costs incurred during hospital stays [9]. While another study did not find fully conclusive evidence regarding cost reduction, their research suggested the potential for decreased healthcare costs through a reduction in diagnostic and imaging tests facilitated by patient information exchange [10]. Other results provide an exploration of the value and benefits of patient data exchange, including costs [8]. The study argues that cost savings might be achievable due to evidence of increased efficiencies, such as improved access and processing. However, it is important to note that the evidence supporting cost savings in this context is not entirely conclusive.

The utilization of the IPS in healthcare practice has demonstrated a promising impact on reducing hospital readmission rates, as shown by several studies. A notable decrease in the 30-day readmission rate, indicating improved patient outcomes with the integration of access to patient information were highlighted [3]. These findings were further corroborated, attributing the reduction in readmissions to the availability of comprehensive health information and enhanced access to patient data [5]. It was evident that direct access to health information played a significant role in decreasing readmission rates. In another study, the effects of health information access on readmission rates were explored as part of the broader assessment of healthcare quality [6]. While the evidence was not entirely conclusive, there was a compelling indication that patient information access led to a reduction in readmission rates. Moreover, hospital readmissions were investigated as a component of overall hospital care utilization [10]. Although variations were observed, the overall conclusion suggests a clear correlation between the utilization of information exchange and a reduction in hospital readmission rates.

The element of health record completeness emerges as a crucial factor, as highlighted by three studies [3, 4, 6]. The first study conducted a comprehensive study on the quality of care, wherein multiple advantages were observed, including improved health record completeness. With the integration of the information exchange, healthcare providers gained access to a more comprehensive and up-to-date health record for each patient [3]. This finding finds further support in the second study, where enhanced quality of care was linked to the utilization of health information exchange, particularly in relation to health record completeness. The adoption of the patient data exchange allowed for the seamless exchange of patient data between different healthcare settings, ensuring that health records were comprehensive and consistent across care providers [4]. Additionally, the third study reported on better completeness of reporting, which, while not identical, aligns with the finding of enhanced completeness of health records using patient data exchange [6]. The implementation of this system led to more standardized and thorough reporting practices, ensuring that crucial patient information was captured and shared efficiently. This contributed to a more comprehensive health record, facilitating better communication among healthcare providers, and reducing the chances of critical information being overlooked or misinterpreted.

The aspect of patient safety also garnered attention in multiple studies [6, 11]. One study explored the impact of healthcare data exchange on patient safety as part of their study on healthcare quality [6]. Although the evidence may not yet be entirely conclusive, the observed potential and effects from patient data exchange suggest a probable positive impact on patient safety. Similarly, another study revealed beneficial effects on patient safety [11]. Of particular interest was the investigation into the most and least preferred methods of exchanging information and data-sharing mechanisms. The study found that traditional mechanisms, such as fax or email, were the least favored, while point-to-point mechanisms, such as EHR to EHR sharing, emerged as the preferred options. This preference for direct exchange through secure channels is likely to enhance patient safety by minimizing the risk of data breaches or miscommunication during information transfer.

Improved communication among healthcare providers is a direct and valuable outcome resulting from the successful implementation and adoption of patient information exchange systems, as reported in multiple studies [3, 4, 6, 7, 8, 9]. One finding highlights that the use of health information exchange leads to enhanced communication among care teams, promoting better care coordination and more informed decision-making [3]. The positive impact of patient data exchange on communication within and between healthcare organizations was also emphasized, facilitating seamless information sharing and collaboration [4]. Additionally, improved communication as one of the valuable outcomes of health information exchange was discussed, leading to better care coordination and reduced repeat visits [6]. The significance of improved communication in enhancing care quality and safety was underscored, enabling better exchange of information among care providers [8]. Moreover, shorter patient lengths of stay in clinical settings using patient information exchange were observed, indicating improved communication, and streamlined care processes [9]. Furthermore, the positive impact of integrated electronic health records on communication were highlighted, with improved clinical decision support and more reliable external information sources contributing to better care coordination [7].

### 3.2.2 Facilitators

Research has been done on the facilitators that create or stimulate value by using the IPS or assist IPS adoption. The facilitators found are shown in Table 3, and articles without these factors have been omitted.

However, due to the factors having a small number of mentions (one per factor), the factors have been grouped to create more clear and meaningful factors. The different subfactors included in the newly created factors will be described below.

**Table 3. Identified factors for "facilitators."**

| **Factor**<br>**Article** | Enabling factors | Value enhancement | Resource factors |
|---|---|---|---|
| Eden et al. (2016) | X | | |
| Yeager et al. (2014) | | X | X |
| Qian (2020) | X | X | X |

The tables display three distinct factors, being enabling factors, value enhancement and resource factors. The underlying factors are displayed in Figure 3.

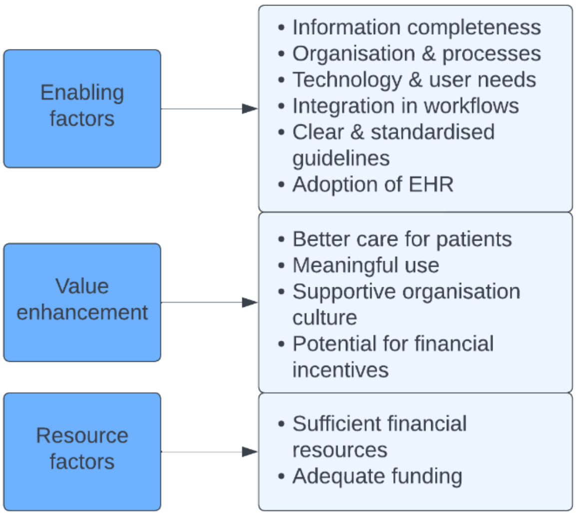

**Figure 3. The three main facilitator categories with their subtopics**

Within the spectrum of enabling factors, studies underscore critical insights [3, 12]. Study reveals organizational and procedural facilitators like single login, ongoing training, and robust technical support [12]. Technological elements, including contextual notes and seamless integration with existing systems, amplify the effectiveness of patient data exchange. Achieving information completeness hinges on factors such as patient education, consent processes, and the robust implementation of security policies. The facilitators are complemented by findings on emphasizing the importance of organizational culture, streamlined workflow integration, electronic health record (EHR) adoption, and adequate funding for the successful implementation and adoption of IPS/information exchange [3]. The recognition of perceived benefits, such as improved care quality, enhanced coordination, streamlined data transfer, and cost reduction, serves as a positive influencer in the adoption process.

Shifting the focus to value enhancement, several studies pinpoint facilitators [3, 13]. Key factors were identified, including patient value, meaningful use, and cost considerations [13]. The utilization of patient data exchange is anticipated to significantly improve care coordination, particularly for complex patients. Additional findings provide a real-world example of value enhancement during the coronavirus pandemic, emphasizing benefits like efficiency and improved care coordination [3].

Resource factors emerge as pivotal facilitators [3, 13]. The cost-effectiveness and attractiveness of patient information exchange programs were noted [13]. Lower overall costs enhance the value proposition for healthcare organizations. Adequate funding is identified as a critical facilitator for IPS adoption [3], ensuring a seamless and effective implementation process. The expectation of reduced costs over time positions IPS as a financially viable option for healthcare organizations, aligning with future reforms such as the establishment of an accountable care organization.

### 3.2.3 Barriers

The third focus area is barriers, hindering the value creation in the utilization and adoption of IPS. Various barriers have been identified through the literature review, shown in Table 4, excluding articles not covering these factors. These challenges span diverse areas that necessitate attention for successful IPS implementation and utilization.

Foremost among the barriers are data privacy and security concerns, evident across multiple studies [3, 7, 8, 11, 13, 14,]. Maintaining confidentiality and integrity of patient data is important for building trust among stakeholders [11]. Robust security measures are essential to safeguard against data breaches and unauthorized access, emphasizing the need for resilient systems [3]. Concerns extend to data accuracy and integrity, necessitating mechanisms for ensuring data quality [14]. Standardized data formats are deemed crucial for seamless exchange [7], acknowledging the intricate relationship between data privacy, security, and efficiency in patient information exchange [8]. Comprehensive security measures and standardized data exchange formats are essential for establishing confidence and addressing barriers linked to data privacy and security.

Technological concerns emerge as significant barriers, as highlighted in multiple studies [3, 7, 8, 13, 14]. Challenges related to system usability and technical support were identified, emphasizing the need for user-friendly interfaces and ongoing technical assistance [3]. Moreover, the importance of addressing technical disruptions and system downtime were stressed, to ensure uninterrupted access to patient information [8]. In the context of health information exchange, challenges associated with interoperability became clear, emphasizing the need for standardized data formats and compatible systems [14]. The importance of considering user needs and preferences is underscored, when designing patient information exchange systems [7]. Additionally, technological issues, such as system complexity, could hinder participation and use in the exchange program [13].

**Table 4. Identified factors for "barriers."**

| **Factor**<br>**Article** | Data privacy & security concerns | Technological concerns & issues | Implementation costs & funding issues | Lack of interoperability | Lack of willingness to change |
|---|---|---|---|---|---|
| Qian (2020) | X | X | X | X | X |
| Esmaeilzadeh (2022) | X | | | X | X |
| Fontaine et al. (2010) | X | X | X | | |
| Bowden and Coiera (2017) | X | X | | X | |
| Tharmalingam et al. (2016) | X | X | | | X |
| Yeager et al. (2014) | X | X | X | | |
| Rahurkar et al. (2018) | | | X | | |

Implementation costs and funding challenges pose substantial barriers to the successful adoption of patient information exchange systems [3, 8, 10, 13]. The emphasis is on the necessity of proper funding to ensure successful HIE implementation [3]. Adequate financial resources are required to support infrastructure, maintenance, and technical support. Other findings discuss the complexities of cost allocation for implementing health information exchange systems across different organizations [8]. The study highlights the importance of shared funding models and cost-sharing agreements to enable widespread adoption. Additionally, the perceived cost-effectiveness of joining a patient information exchange program influenced adoption decisions [13]. Finally, a study reported on potential funding barriers for smaller healthcare organizations [10]. These collective findings underscore the significance of addressing implementation costs and funding issues through collaborative funding approaches and tailored financial support.

Lack of interoperability surfaces as a significant barrier to the successful implementation and adoption of patient information exchange systems [3, 7, 11]. Challenges associated with integrating various health information systems and platforms, particularly in heterogeneous healthcare environments were identified [3]. The lack of standardized data formats and communication protocols hinders seamless data exchange between different systems and organizations. Similarly, the complexities of achieving interoperability, especially in the context of exchanging health information across different care settings and healthcare providers were highlighted [11]. Another study delved into the difficulties of interoperability in the context of integrating Integrated Electronic Health Records (iEHR) [7], leading to a significant importance of developing effective strategies to ensure data compatibility and seamless information exchange between disparate systems.

The lack of willingness to change represents a noteworthy barrier to the successful implementation and adoption of patient information exchange systems [3, 7, 11]. A resistance has been encountered from healthcare professionals when transitioning to new systems and processes, emphasizing the importance of change management strategies [3]. Similarly, reluctance among healthcare providers to adopt new information exchange practices due to concerns about disruption to established workflows have been found [11]. Furthermore, studies discuss challenges related to the willingness to change among healthcare providers [3, 7], underscoring the importance of engaging healthcare professionals in the design and development of new systems [7]. These findings collectively underscore the significance of addressing the lack of willingness to change as a critical aspect of successful implementation and adoption of patient information exchange systems.

## 3.3 Synthesis of results

The articles investigating the value, facilitators, and barriers of using an IPS in healthcare have provided valuable insights into the factors relevant to implementation and value creation. Figure 4 presents a schematic view of the most important findings, categorized per subject. The number of findings is less than these described in the results, to create a more clear and concise view of the most important results. Certain findings have been grouped to create this more concise view.

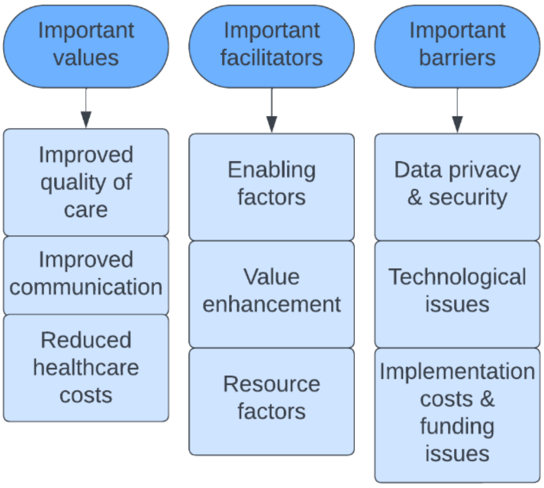

**Figure 4. Most important identified values, facilitators, and barriers**

The identified values demonstrate the practical benefits of using the IPS, while the facilitators and barriers give insight into the crucial factors impacting the integration and actual use of the IPS. The usage of the IPS could make a substantial impact on the delivery of care, but there are still obstacles in the way, preventing the IPS from worldwide implementation. When overcoming the barriers and making sure that the identified facilitators are used in health care organizations, the value of healthcare will increase by gaining the extra value that the IPS can provide.

Considering these findings and strategies for addressing current barriers, focus must be directed towards three important aspects, which we term the 'three E's': enabling the environment for seamless integration, enhancing the value of IPS through opportunity maximization, and engaging resources to ensure strong and adequate support for personnel.

**Enabling** signifies creating an environment, where incorporating the IPS seamlessly aligns with daily workflows, making it not just feasible but also intuitive for healthcare professionals to use the IPS. This involves addressing identified facilitators such as workflow integration, technological integration, and organizational support. Barriers in this element may include resistance to change and the need for substantial adjustments in established workflows, which should be addressed to foster the adoption.

**Enhancement** focuses on seizing opportunities to fully realize the potential value of the IPS. This entails taking full advantage on the identified benefits, such as improved patient care, cost reduction, and enhanced communication. Different actions to foster these values include using technology to its fullest, ensuring data security and privacy, and stimulating a culture of continuous improvement and change. Challenges may arise in overcoming technological complexities and ensuring acceptance of change.

**Engagement of resources** is important to ensure both direct and supporting personnel have the necessary space and support for successful IPS implementation and continued use. Things like adequate training and financial resources are important components. Challenges here may include budget constraints, the lack of training and understanding, and competing priorities in resource allocation.

Achieving widespread IPS implementation requires not only addressing specific values, facilitators, and barriers, but also strategically enabling seamless integration into existing workflows, enhancing the utilization of IPS potential benefits, and allocating sufficient resources for successful implementation and sustained usage.

The findings confirm that there is indeed value from using the IPS as a way of health information exchange, improving patient care, reducing costs, enhancing communication, improving patient safety, and reducing readmissions. Achieving these values necessitates compliance with facilitating factors, alignment of workflows with IPS use, and attention to cost control, technology, and user needs. Overcoming barriers, such as safeguarding data privacy, addressing technological and interoperability issues, allocating sufficient financial resources, and improving the willingness to change, is essential for a smooth adoption process.

A focus on the willingness to change should be mentioned. The potential and demonstrated value of using the IPS in practice should persuade the broader public, healthcare professionals and experts that further use and adoption of the IPS improves healthcare.

The relationship between value, facilitators, and barriers is depicted in Figure 5, illustrating how these elements influence IPS implementation and adoption. Facilitators positively impact (+++) successful adoption, thereby increasing the gained value, while barriers have a negative impact, decreasing (---) the overall value.

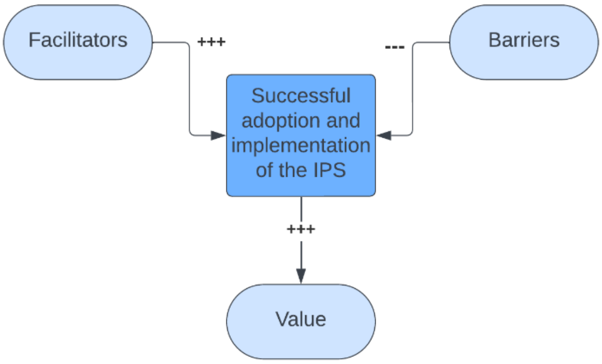

**Figure 5.** Relations of value, facilitators and barriers on the adoption and implementation of the IPS

Overall, the findings from the literature review provide a robust framework for examining the value, facilitators, and barriers associated with using the IPS in healthcare. By comparing these findings with real-world practices, organizations can gain a comprehensive understanding of the factors influencing the successful adoption and implementation of the IPS. Addressing the identified barriers and utilizing the facilitators will be important in achieving the full benefits of the IPS and improving healthcare value.

## 3.4 Risk of bias across studies

The identified studies on the value and effectiveness of using an IPS in healthcare practice had varying degrees of risk of bias. Several studies were observational, which could lead to selection bias and confounding variables. Some studies relied on self-reported data, which could introduce social desirability bias. However, several studies employed alternative study designs, including systematic reviews, although not without certain drawbacks. These reviews offered extensive information and presented relevant data that might have been missed in a literature search focused solely on individual articles. Despite these limitations, the collective evidence offers valuable insights into the research topic.

# 4 Discussion

This systematic review synthesizes and assesses the available evidence on the value of using an IPS in healthcare practice. Through a comprehensive search and selection process, 12 studies were identified that investigated various aspects related to IPS use and outcomes. This chapter presents implications and limitations of the findings, along with conclusions and recommendations for future research and practice.

## 4.1 Limitations

It is important to acknowledge the limitations of this systematic review. Even though the review provided useful information, several limitations should be noted:

The detailed analysis was conducted by the first author only, which raises the issue of classification errors. However, the classification employed is very straightforward, so no double-blind classification was deemed necessary.

The risk of bias across the studies could affect the validity of the findings. Some of the studies had small sample sizes, were observational, or were conducted in specific regions, limiting the generalizability of the results.

Some studies examined the value of health information exchange systems in general rather than of the IPS specifically, which is the focus of this research.

As mentioned, the focus of the research shifted a little more to health information exchange in general due to the new nature of the IPS. Despite the broadened scope, the substantial similarities between health information exchange practices and the workings of the IPS (being a form of HIE) allow for assumption of the application of the results for the IPS. Hence, while the search was broadened, the positive outcomes and applicability of the results to the IPS context remain evident.

Due to the used search string and the subject of the research being relatively new, chances are present that not all relevant articles are used in the research. However, the retrieved articles formed a clear view on the research objectives, so that the research question could be answered. For future research, it could be useful to consider additional literature that could also be relevant to gather more information about the value, facilitators, and barriers of using the IPS in practice.

## 4.2 Conclusions

This systematic review suggests that using the IPS can have a positive impact on healthcare and patient outcomes. However, significant barriers to implementation and use exist, including concerns about privacy, security, interoperability, and usability. Facilitators may form a basis for organizations to determine what is important in fostering IPS adoption. This information provides a more complete picture of the IPS and how its adoption and value can be further improved.

### 4.2.1 Implications for further research

This study has created clarity on the value, facilitators, and barriers of the use of the IPS in healthcare practice. Despite the positive findings, this systematic review highlights the need for further research to fully understand the impact of using the IPS and exchanging health information. Additional studies can be conducted to understand and especially track the effects of the use of the IPS in practice. Lessons can be learned from implementation and the consequences from using the IPS to gain more insight on the changes in healthcare practice due to using the IPS. Research can be focused on the differences between the situation before implementation of the IPS and after, so that the actual value can be confirmed afterwards. Additionally, the assumption was made that the results for HIE would be applicable for using the IPS, but it would be worth researching if this is indeed the case. If so, more information would be available to consider in practice. As mentioned in the introduction, it is important for future research to assess the patient perspective on this matter. Understanding the viewpoint of the 'receiver,' being the patient, is crucial, as they are at the forefront of experiencing improved care. Moreover, future research should also investigate the specificity and generalizability of the IPS. Changes in the IPS are to be expected due to the major differences that exist between different countries and parts of the world, however, a certain degree of generalizability would be preferred.

## ACKNOWLEDGMENTS

This work was completed without external financial support. We extend our gratitude to the supervisors from the University of Twente for making this project possible, as it would not have been achievable without their support.

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