

Health Information Exchange: Understanding the Policy Landscape and Future of Data Interoperability

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Summary

Objectives: To review recent literature on health information exchange (HIE), focusing on the policy approach of five case study nations: the United States of America, the United Kingdom, Germany, Israel, and Portugal, as well as synthesize lessons learned across countries and provide recommendations for future research.

Methods: A narrative review of each nation's HIE policy frameworks, current state, and future HIE strategy.

Results: Key themes that emerged include the importance of both central decision-making as well as local innovation, the multiple and complex challenges of broad HIE adoption, and the varying role of HIE across different national health system structures.

Conclusion: HIE is an increasingly important capability and policy priority as electronic health record (EHR) adoption becomes more common and care delivery is increasingly digitized. While all five case study nations have adopted some level of HIE, there are significant differences across their level of data sharing infrastructure and maturity, and each nation took a different policy approach. While identifying generalizable strategies across disparate international systems is challenging, there are several common themes across successful HIE policy frameworks, such as the importance of central government prioritization of data sharing. Finally, we make several recommendations for future research to expand the breadth and depth of the literature on HIE and guide future decision-making by policymakers and practitioners.

Keywords

Health Information Exchange, interoperability, data sharing, health information technology, electronic health records

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1 Introduction

As health care has modernized in the 21st century, moving away from paper-based record keeping to digital workflows following the broad adoption of electronic health records (EHRs), health information exchange (HIE) and data interoperability – the process of electronically sharing data across unaffiliated organizations including care delivery providers, payers, public health agencies, and more – have become increasingly crucial components of a modern health system [1, 2]. Not only is widespread HIE critical to providing clinicians with a full picture of patient health status at the point of care to ensure quality and safety, robust interoperability could also slow medical cost growth through a reduction in duplicative utilization [3], and may reduce administrative burden on patients by letting their data follow them seamlessly across the continuum of care [4]. Further, the COVID-19 pandemic has illustrated the importance of readily-available patient and population-level health data aggregated across care delivery organizations – one of several critical HIE use cases [5]. Building a robust interoperable health system is therefore an important policy goal, and is essential to realizing the value of the significant investment made in digitizing health care delivery over the past several decades.

HIE appears simple in concept – the idea that all health data should be readily available to the patient and clinicians at the point of care, regardless of where that data was generated. However, the implementation

of large-scale, robust HIE infrastructure and capabilities has proven difficult in health systems across the world [6, 7]. Building connectivity between unaffiliated health care organizations presents a wide array of challenges, ranging from technical issues around data standards, governance problems with what data is shared and who owns it, privacy and security concerns for both patients and organizations, costs of technology and implementation, competitive disincentives to allow data to flow easily to other organizations, and workflow questions on how to best present busy clinicians with actionable knowledge without burdening them with irrelevant information. These challenges are situated within the broader policy framework of each nation, both their specific approach to HIE as well as how they organize care delivery in general. For example, in some nations HIE faces financial disincentives as health care organizations are reluctant to share patient data that they see as a key strategic asset in a competitive market [8, 9]. Additionally, while the theoretical benefits of HIE are obvious, demonstrating value to patients, clinicians, and health systems at scale has been more difficult. There remain critical unanswered questions around HIE and interoperable data exchange, including how different public policy approaches have resulted in varying levels of HIE adoption and use, best practices for integrating HIE into clinical, reporting and administrative workflows, and identifying where HIE can generate the most value across a range of clinical, financial, and administrative scenarios.

In this survey paper, we discuss the concept and types of HIE, the benefits and challenges of implementing HIE systems, and use national case studies to highlight the diverse set of approaches to HIE from five different countries. We focus our review specifically on examining the policy frameworks employed by our case study nations around data sharing between acute care delivery organizations, and how they have influenced the development of HIE in each country. We then synthesize the current literature on HIE and provide recommendations for future work. Focusing on recent literature, we provide readers with a look at the current state of global research relating to HIE and identify opportunities for the informatics community to advance our knowledge and understanding of HIE across a range of domains.

2 Methods

We conducted a narrative review of the HIE and interoperability literature in both the peer reviewed and grey literature, focusing on highlighting the history, current state, and future strategy of five case study nations: the United States of America, the United Kingdom, Germany, Israel, and Portugal. We specifically focused on identifying literature from the last three years but did not exclude older or non-peer reviewed articles which provided important context or the most up-to-date information. The search strategy was broken down into three steps. First, we combined relevant search terms for identifying current research articles in the respective countries in MEDLINE via PubMed and Google Scholar:

(health OR healthcare OR clinical OR medical) AND (information exchange OR data sharing OR data exchange OR information sharing OR interoperability) AND (United States OR Germany OR United Kingdom OR England OR NHS OR Israel OR Portugal)

Second, we researched the official websites of the respective health authorities for additional resources (e.g., strategy papers, government reports, policy documents or

other information on current legislation). Third, we complemented the search with additional grey literature based on leads from the sources found in the first two steps. Furthermore, to contrast the state of HIE between the selected countries along comparable dimensions, we used the identified literature alongside complementary sources to classify: 1) the level of EHR adoption in acute care organizations (as an essential prerequisite for HIE); 2) the overall HIE maturity; 3) the level of HIE centralization; and 4) level of incentivization for HIE as either “low”, “moderate”, or “high” for each country (Table 1). We then summarized our findings across these international contexts to create a synthesized set of lessons learned, as well as areas for future study and research.

3 Results

3.1 Health Information Exchange – The Concept, The Verb, the Noun

As discussed in the introduction, the goal of HIE sounds simple – all health information should be available to the appropriate users (patients, clinicians, public health agencies, etc.) whenever necessary, regardless of where that data was generated. However, operationalizing this idea requires consideration of many socio-technical issues, e.g., What data should be shared with whom? What specific data elements? Who should access the data? How should data be ac-

cessed? Should the patients opt-in to data sharing, or should they be enrolled by default with the ability to opt-out? What standards and processes should be used to capture and transfer data and to ensure data privacy and security? These difficult questions, and many more, illustrate the complexity in turning HIE from an idea into a reality. HIE can therefore represent a wide array of electronic data sharing – ranging from sending flat PDF files via secure email to semantic interoperability, where standardized, structured, machine-readable data elements are transferred and integrated directly into the receiving organization’s EHR without manual intervention [10, 11]. HIE can be a “push”, where a health system or provider sends patient data to another provider during a transition of care, or a “pull”, where the receiving system queries for any patient data available from other providers.

The term “HIE” is frequently used as both a verb and a noun [12, 13]. HIE the *verb* refers to the act of data transfer, sharing data between two health care organizations, of which there are many possible technical approaches and mechanisms of data exchange. HIE the *noun*, however, most frequently refers to an organization that is facilitating the data transfer, sometimes known as health information exchange organizations (HIOs). They are most often vendor-neutral, compared to the vendor-mediated tools that connect organizations using the same EHR vendor [14], and HIOs provide technical capability and governance frameworks for data exchange [15, 16]. In the United States

Table 1 Dimensions of Health Information Exchange Across Five Nations.

	Electronic Health Record Adoption in Acute Care Organizations	Overall Health Information Exchange Maturity	Level of Health Information Exchange Centralization	Incentives for Health Information Exchange
United States	High [21]	Moderate [27]	Low [14]	Moderate [27]
Germany	Moderate [52,104]	Low [49,52]	High [17]	Moderate [105]
The United Kingdom	High [58,106]	Moderate to High [7,61,107]	High [7,55]	Moderate to High [7,108]
Israel	High [72,109,110]	High [6,71,111]	Moderate [54,71,112]	High [71,112,113]
Portugal	High [87,114]	Moderate to High [79,80,82]	Moderate to High [81,82]	Moderate to High [83,84,93]

(US), for example, these organizations can be non-profit or for-profit, based in a specific geography (e.g., state or local) or national, and may be based on a specific framework designed to streamline data exchange across different platforms and technology vendors such as Carequality, and some HIEs are a “network-of-networks” that link several other HIEs together, while in Germany the gematik, a national eHealth organization, provides similar services but with a much broader mandate to set policy, standards, and governance relative to regional US HIOs [17, 18].

Finally, the terms HIE and interoperability are often used interchangeably. However, they are distinct concepts – HIE involves any health data transfer, in any format, whereas interoperability refers specifically to the exchange of structured data elements. In this way, sending scanned paper files in PDF form electronically would represent HIE, but not interoperability, whereas data that was sent in a machine readable format and integrated into the receiving provider’s EHR would be described as interoperability [19].

3.2 The State of International Health Information Exchange: a study of five case nations

3.2.1 The United States of America

Following the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009, acute care hospitals and primary care physician offices in the U.S. rapidly adopted EHRs in response to federal incentives included in the Meaningful Use (MU) program [1, 20, 21]. While not as directly incentivized with payments to the same level as EHR adoption, a variety of public policies have focused on encouraging interoperability and HIE within US health care delivery organizations. Most directly, HITECH included several subsidies and grant programs to fund the creation, expansion, and operation of HIOs, often operating at the state or local level, to build HIE infrastructure. Several MU requirements in the later stages of the program directly incentivized at least some level of data sharing, such as requiring a certain pro-

portion of patient care transitions to outside organizations have summary of care records sent electronically, and the EHR certification program to attest to MU ensured that EHR products were able to send and receive data electronically. These requirements have been expanded by the Centers for Medicare and Medicaid Services (CMS) Promoting Interoperability program [22]. Several policy initiatives have attempted to promote HIE adoption and use through aligning the financial incentives of care delivery organizations with data sharing, such as the proliferation of value-based payment models including bundled payments or Accountable Care Organizations (ACOs) that reward providers for reducing population-level utilization and spending [23]. These types of value-based payment reforms were intended to overcome the misaligned financial incentives in the fee-for-service payment model for care delivery in the US, and which provides no financial incentive to use HIE to avoid redundant or unnecessary services [19, 24].

Despite the wide range of policy incentives targeted at encouraging HIE, the state of interoperability (within and across the health care delivery eco-system) in the US varies. The US Office of the National Coordinator for Health Information Technology (ONC) tracks hospital interoperability using four domains of: 1) finding/querying for data; 2) sending data electronically; 3) receiving data electronically; and 4) integrating outside data into the EHR without manual intervention [25, 26]. Reflecting the structure of the MU certification requirements, as of 2018, the ability to send data electronically is nearly ubiquitous, with nearly 90% of hospitals reporting they often or routinely send patient summary of care records electronically. In contrast, fewer than two-thirds of US hospitals report being able to integrate outside data into their EHR, and less than half (45.4%) reported engaging in all four ONC’s interoperability domains [27]. Research has also found that hospitals and public health agencies lack bi-directional interoperability, which caused significant issues aggregating population-level data in the early days of the COVID-19 pandemic [5, 28, 29]. While interoperability has made progress over the past several years [30, 31], it has been significantly slower than EHR

adoption [1, 21]. Ambulatory physician offices report even lower levels of interoperability or HIE engagement, as they often lack the organizational resources such as a full-time information technology staff to build and maintain HIE connections [32], though national-level data for these organizations is less detailed [33].

The current state of HIE and interoperability in the US is a patchwork of connectivity without a centralized national HIE approach, and whether a patient’s data follows them as they transition across care providers is determined more by whether their organizations are on the same EHR vendor or participate in the same method of HIE. Significant heterogeneity in state policy for HIE, including different approaches to governance, financial support, data privacy and patient consent laws (opt-in vs opt-out), also contributes to variation in interoperable data exchange in the US [34, 35]. Many organizations report participating in multiple different modalities of sharing patient data, such as vendor (EHR)-based systems [36] as well as regional HIEs and national HIE networks [37]. Interoperability between acute care providers and other health care organizations, including long-term care facilities or public health agencies, is also limited and uneven across the country [5, 38]. These results are the reflection of the somewhat scattered policy environment, with few prescriptive requirements and many diffuse and weak incentives to share data without a comprehensive path towards national-level interoperability. The value-based payment models to align financial incentives for data sharing were only modestly successful, with ACO hospitals sharing data with more types of partners, but with a lower overall volume of records exchanged relative to non-ACO participants [39, 40], and the lack of HIE infrastructure has presented a significant barrier for ambulatory practices participating in population health management programs [41].

Future Considerations & Strategy: In 2016, Congress passed the 21st Century Cures Act (Cures), which included several provisions to improve patient access to data as well as interoperability between provider organizations. Cures provides a framework for HIE in the US, including provisions

such as outlawing “information blocking”, the practice of intentionally and knowingly blocking patient data access by health information technology developers or health care provider organizations [8], as well as updates to the ONC EHR certification criteria to mandate the use of standardized application programming interfaces (APIs) that facilitate patient access to their own health data and HIE using a common set of standards known as Fast Healthcare Interoperability Resources (FHIR) [42]. Further, the act outlined the Trusted Exchange Framework and Common Agreement (TEFCA), a voluntary technology and governance model that seeks to streamline the exchange of patient data across the multiple fragmented HIO networks that exist in the US, reducing the need for provider organizations to participate in multiple HIE networks [43]. Rulemaking for the Cures Act was finalized in 2021, with information blocking and FHIR API requirements now in place, and the first several organizations designated as Qualified Health Information Networks (QHINs) in the TEFCA framework were named in early 2023 with plans to go live within the next year [44,45]. This more prescriptive framework represents a departure from previous efforts focused on aligning financial incentives, and will hopefully deliver significant improvements to interoperability in the US.

3.2.2 Germany

Germany initiated the development of a dedicated infrastructure for HIE, called the telematics infrastructure (TI), for the statutory health insurance (SHI) system in 2004. The TI uses an opt-in patient consent model that also requires the patients provide their clinician with a physical card that authorizes access and changes to the data stored in the TI. This was followed, however, by a prolonged timeframe of disagreements and mutual obstruction among the main shareholders of the national organization that was made responsible for the development of the TI (the so-called *gematik*) [46]. The ensuing stalemate was said to be driven by a mix of poor federal governance, lack of a strategy, lack of consensus-building, excessive data protection concerns on the part of the physician associations, and miss-aligned fi-

nancial incentives which severely hampered progress towards widespread HIE practices [46–50]. From 2016 on, renewed legislative efforts were made to implement the TI and to subsequently specify how data ought to be exchanged through a central EHR system that utilizes the TI. Also, the federal ministry of health intervened in 2019 and took over the majority shares of the *gematik* to be able to undercut further deadlocks between the main parties (particularly the National Association of SHI Funds, the National Association of SHI Physicians, and the German Hospital Federation).

As part of the latest legislative initiatives, the National Association of SHI Physicians was made exclusively responsible for specifying syntactic and semantic standards for exchanging health information via the central EHR system. Although this recently resulted in an increased focus on international standards (e.g., FHIR, SNOMED CT, and LOINC), Germany's HIE capabilities remain at a low level. While all German EHRs are now required to be interoperable with the TI infrastructure [51], a survey from 2017 showed that only a fraction of German hospitals are able to regularly exchange data with other providers or the patients electronically [49]. More recent data corroborate these findings [52] – and note poor HIE between physicians in ambulatory care settings and low adoption rates of the central EHR by patients [17, 53]. However, the central EHR system and related components are still being developed and the current government has committed to switching from an opt-in to an opt-out principle for all members of the SHI, thus hoping to significantly increase HIE engagement. Still, Germany is generally considered to perform worse in HIE as compared to the US, England, Portugal and Israel [6, 54].

Future Considerations & Strategy: Germany's previous “hands-off” approach to facilitating HIE can hardly be classified as strategic. And with few exceptions, neither the health insurance companies nor the various providers or the state governments developed HIE systems themselves from the ‘bottom-up’. To cope with the resulting inadequacies, the federal ministry of health started intervening through numerous leg-

islative initiatives, especially after a change in leadership in 2018. These were primarily concerned with further developing the TI as a single, centralized HIE system and the central EHR system as well as a comprehensive financial incentive program for hospitals that, among others, aims at the widespread adoption of patient portals to exchange data with the patients and other providers. From an organizational viewpoint, clearer lines of responsibilities were instituted within the self-governing bodies (e.g., the physician's association was made solely responsible for defining standards to be used in the central EHR and the health insurance companies for providing the EHR to their beneficiaries). Additionally, a decree was issued in 2021 to create a governance structure for ensuring universal interoperability with the so-called Interop Council at the center and binding directives for providers and vendors to adhere to certain standards. However, some of these initiatives were criticized as being reactive rather than proactive, partly disconnected from one another and at risk of creating parallel HIE structures. Hence, calls for a coherent strategy followed, which the current federal ministry has taken up and is expected to announce in 2023.

3.2.3 The United Kingdom

The English National Health Service (NHS) has had a long and checkered history of building its HIE capabilities [55]. Capitalizing on its centralized make-up and control, the NHS has focused on defining and propagating technical and data standards as early as 1992. Significant investments were made early on which led to the incremental establishment of a connectivity framework, comprising the Health and Social Care Network, the “NHS Spine”, as well as various other central and local services for enabling HIE [7, 55]. Current rules for data sharing in the United Kingdom (UK) use an implied consent (or explicit ‘opt-out’) model for direct patient care purposes [56]. The NHS's strategic approach has often been characterized as largely coming from the ‘top-down’ [55, 57]. Particularly the much-discussed National Programme for Information Technology (NPfIT) from 2003 exhibited high degrees of central control. It

attracted a lot of criticism and is said to have failed partly because of this high degree of centrality [57]. Still, the NPfIT contributed fundamentally to the connectivity framework in its current form. The NHS subsequently moved on to allow for more local variation in their following strategies, thus shifting towards what has been characterized as a ‘middle-out’ approach [55].

The NHS’s early commitment to HIE, together with a convoluted interplay of policy and technology changes over time has resulted in a rather complex ecosystem of patient health records [58]. Perhaps most importantly, Summary Care Records (SCRs) containing basic patient information such as medications and allergies are available and used by almost all general practitioners via the NHS Spine digitally and this functionality is required for EHRs [59], and more comprehensive shared records are increasingly being adopted by local NHS organizations and systems. The increase in shared records partly results from more recent initiatives – particularly the Information Governance Framework for Integrated Health [60]. However, despite the NHS’s relatively advanced stage of HIE adoption [7], data sharing and interoperability challenges remain – particularly with regard to the EHR vendor specificity of HIE systems in place as well as information exchange with and between hospitals [58, 61]. While a recent study by Watkins *et al.* shows that the use and user satisfaction with an EHR vendor-specific solution is quite high, another study by Warren *et al.* points to substantial misalignments and information exchange barriers that remain between hospital trusts that use different HIE solutions [58, 62].

Future Considerations & Strategy: The NHS continues to actively adjust and adapt its HIE strategy from a rather central angle while explicitly leaving room for variations by local NHS authorities and systems. Most recently, this finds expression in its 2022 “data saves lives” strategy and in the substantial reforms of its governance structure [63]. These activities might best be summarized as the ambition to consolidate, advance, and capitalize on its HIE capabilities. As a principal challenge in delivering universal interoperability still lies in the fragmentation

of responsibilities for the HIE infrastructure [61], the NHS plans to consolidate the previously separated public bodies NHS Digital, NHSX and NHS Improvement under one roof in 2023 – that of NHS England to form a centralized, single HIE system. This consolidation is also reflected in the data strategy’s premise itself, which views HIE not as an isolated matter, but rather as an integral part of a wider and more far-reaching data strategy. It thereby, among other things, aims at giving patients greater control over their data and creating secure data environments for research. From a technical viewpoint, the strategy commits to enhancing the usage of international standards (particularly in the form of UK-wide HL7 FHIR Profiles), the usage of cloud services, and services to centrally find and retrieve records from the various systems. In terms of advancements, it aims to extend the types of data exchanged such as health information from wearables and, crucially, social care data. Lastly, the strategy also sketches out further steps to better harness health data for research, promote the application of AI technologies in reference to the Topol review [64], and steps to continue to work towards establishing a learning health system – thus capitalizing on its current and anticipated HIE capabilities [65]. These activities reflect an integrated, holistic policy approach and a structured governance framework to integrate care pathways across siloed responsibilities to encourage health information technology-based innovation [66].

3.2.4 Israel

HIE structures and practices in Israel have been closely tied to the structure of the country’s healthcare system [67]. Within their universal national health insurance system, each Israeli citizen is a member of one of the four not-for-profit Health Maintenance Organizations through which they receive both insurance and care. While the Ministry of Health (MoH) is responsible for overarching policy, regulation, planning, budgeting, etc., the HMOs have been relatively independent in the way they design their healthcare services. The competition among them as well as their integrated accountability for the patients across various care settings is

said to have facilitated innovation-seeking strategies from the bottom-up, including the adoption of HIE solutions within the HMOs [54, 67]. The largest of the four HMOs, ‘Clalit’ (which covers roughly 52% of the population and exhibits the highest degree of vertical integration from primary to tertiary care services), was an early adopter of an HIE system called OFEK – a distributed system that enabled the retrieval of basic patient information from any kind of local EHR system through a specific interface, with patients automatically enrolled with an opt-out option [68, 69]. Although the system was found to create local benefits in terms of reduced test ordering and nearly all Israeli EHRs were interoperable within HMOs [70], information exchange outside the HMOs remained insufficient and patient access to their medical data is still rather limited for many citizens [6]. In light of these limitations, the MoH started taking on a more active role to promote widespread HIE. This was first expressed by adopting OFEK as a single centralized HIE system to be used on a national level across all service providers by 2014 [70, 71]. Subsequently, the MoH also published a digital health strategy in 2018 in which HIE was recognized as a foundational strategic element [71, 72]. Correspondingly, OFEK was further developed and eventually upgraded to a new version with more comprehensive and advanced functionalities, called EITAN. The implementation of EITAN was supported by a financial incentive program for the adopting organizations and designed as an opt-out system to ensure widespread use [71, 73].

Most Israeli healthcare organizations have now adopted EITAN. Similar to its predecessor OFEK, EITAN uses a decentralized architecture: clinical data are stored in local databases within the provider organizations based on a nationally consented clinical dataset. These databases operate using a proprietary and detailed mapping of clinical data elements into a semantic interoperability standard, and receive their data from the organization’s EHR and are connected through a national HIE network which has its hub at the MoH [74]. Thus, patient data can be shared and accessed by authorized personnel in all provider organizations. However, due to the usage of varying HIE

solutions in conjunction with different local EHR systems over time, challenges remain concerning the consistent use of standards and terminologies [71, 75]. Furthermore, Itzhaki *et al.* recently found that many ward nurses, contact nurses (who are responsible for care coordination across providers), and patients are still unaware of EITAN which impedes its effective use [76]. Additionally, there is a nascent but growing community emphasizing the use of HL7 FHIR standards in Israel, including the MoH, which launched the first FHIR-based projects in 2021 [75]. But despite these drawbacks, Israel's HIE capabilities are viewed as rather advanced as compared to many other developed countries [54, 72].

Future Considerations & Strategy: The MoH continues to actively support the adoption and further development of its nationwide HIE solution EITAN based on a public-private partnership [72, 77]. Thus, local-level HIE innovations within the HMOs have largely given way to more centralized strategic planning and execution by the MoH to promote coherence across health system silos. For example, this is currently reflected in efforts to improve the interoperability and accessibility of clinical information for advanced data analytic services by pursuing the widespread implementation of HL7 FHIR [75]. Despite this tendency for more centralized planning in many regards, the MoH still aims to facilitate bottom-up innovation based on their past successes by, for example, providing funding for digital health services such as third-party clinical decision support tools that utilize data from the HIE network [72, 78]. Going forward, it is also expected to aim for enhanced patient access to their medical data through mobile, personal health record solutions [71] – thereby making further progress in realizing the paradigm shift towards more personalized medicine.

3.2.5 Portugal

Portugal's national HIE strategy has gone through several transitions since its foundation in the 1990s. If in the late 90s and early 2000s, the Portugal eHealth ecosystem was recognized as being the most advanced for its time, i.e. being one of the first countries

to implement nationwide unique health identification, it has been lacking the same propelling drive since the early 2000s. The prevalent idea until the early 2000s was monolithic solutions that, in theory, would cover most of the institutions' Health Informatics necessities. However, the 2010s brought a different perspective to the Portuguese landscape.

This happened for mainly two reasons, SONHO as a mandatory software and LIGHT (Local Interoperability Gateway for Healthcare). SONHO is a public admission-discharge-transfer (ADT) health information system (HIS) and in 2013 all public hospitals were forced by law to migrate their current solutions to it [79]. This software is the base for registering administrative and demographic data and was first built in the early 90s. Even though it has passed through several iterations and improvements, the core is still very similar to its original one (based on Oracle 8). The second reason is an infrastructure called LIGHT which functions like a broker that is used to communicate health information from the state-provided software (i.e., SONHO) to third parties and is highly based on the HL7 version 2 standard [80]. This was a significant paradigm shift as this gateway provided the state-owned HIS the ability to connect with third parties. All this software and infrastructure is provided by SPMS, a state-owned enterprise, which is the governmental branch and the center of public eHealth policies, infrastructure, acting as regulator and HIS developer. This centralized top-down initiative was meant to enable better, faster interoperability progress, though it may come at the cost of innovation as private technology developers are unable to find a market in Portugal [81], and may explain why many large information technology companies do not have a significant presence in the country as Portugal's health information software systems are based on public, state-owned systems.

Due to the mandatory migration, virtually all public hospitals have the same basis for administrative data input and different health information systems for the clinical data (some public and some private). Private care delivery organizations are free to choose which health information software to use and now are not part of the HIE structure

[82]. The data stored in public software is exchanged through the RSE (“Registo Saúde Eletrónico” – Portuguese for Electronic Health Record) [83]. From its inception, the RSE was designed to act as an aggregator of health data, with a similar structure to a hybrid federated approach having three different layers of information, ranging from local to shared/centralized data. In the middle layer, rests interoperability with existing systems. The catalog of data available at the moment in the RSE is difficult to collect and aggregate, but the high-level national goal is to provide access to general information about medication, diagnosis, demographic data, procedures, vaccination, and laboratory exams in the shared layer [84]. While the definition of full interoperability is constantly being updated, a major barrier to completion is physical hardware, where it is estimated that the public sector has between 25% and 50% of the necessary computer equipment across care delivery and public health agencies [85].

Future Considerations & Strategy: The current focus of the MoH is applying eHealth efforts supporting the patients, namely telemedicine and personal smartphone applications. Key points from Portugal's scene from 2021-2022 were the telemedicine support for its HIS. In 2019, the Portuguese MoH introduced PENTS (National Strategic Telehealth Plan), with an aim to provide access to telehealth across the country [86], with a focus on chronic illnesses [87]. Further, SNS24 – the personal app provided by SPMS has received several updates over the last two years, and can now be used by patients to access key health information due to connection with RSE. Vaccines, prescriptions, referrals, teleconsultations, allergies, and sick leaves are some of the possible information to view in the app [88]. These two points are defined by the national strategy for the Health Information Ecosystem 2020 which is focused on three aspects: governance and strategy alignment; improvement of human resources' competencies and technological upgrades [89, 90]. Finally, Portugal faces several future challenges which have yet to be addressed in a formal way. Data security is a growing issue, with several hospitals having been attacked by ransomware hackers

over the last few years and the strategy to respond to this matter is still being formalized [91]. Several workgroups were created, but a clear guideline or approach is yet to be determined. Further, patient consent processes remain an ongoing area of development in Portugal – currently, many patients engage in a two-step consent process where they consent for their inclusion and for each use of medical services for some features (such as e-prescribing), but for other features such as the use of HIE for clinical care by providers, implied consent (or an opt-out consent model) is the norm, while the patient-facing portals have stricter consent requirements [92]. Experts rated “Inadequate or inconsistent approaches to patient consent” as a major barrier to interoperability in Portugal in 2020 [93]. Additionally, data quality issues remain problematic – researchers have found large discrepancies in reconciling different electronic referral records in Portuguese hospitals [94]. Keeping in mind that evidence generated from data is the basis of clinical practice, ensuring quality and accuracy standards is key to going further into digital adoption and fulfillment of national strategies around the world.

4 Discussion

While deriving generalizable insights from the case studies of the health systems presented here is difficult, given the unique legislative and regulatory, policy, and health care delivery environments in each, our study contributes to our understanding of how policy shapes HIE adoption and use by identifying several commonalities across our five focal nations. First, successful national HIE requires some level of central strategic planning and involvement, irrespective of health system type. As Payne et al. noted in their paper comparing HIE internationally, *“in countries that have successfully achieved HIE, or are on course to do so, the impetus came from government and the change was galvanized with economic incentives to health care providers”* [7]. Despite operating within different payment and care delivery environments, both Israel and Portugal have more advanced HIE capabilities than the US,

in part due to the emphasis placed on data exchange by a national-level policy. However, centralization is not a guarantee of complete success without adversity – the UK NHS has, and continues to, experienced challenges in their HIE strategy despite the extremely high level of organizational centralization in the UK. However, “bottom-up” innovation and early adoption can spur important progress, such as the adoption of early HIE systems by Israel’s largest HMO, Clalit, which provided a blueprint for national adoption. The US may soon experience a similar process – despite the relatively “hands-off” nature of their early HIE strategy, several pockets of successful HIE did develop, which serve as a model for a new strategy following the 21st Century Cures Act focusing on APIs, FHIR standards, and penalties for information blocking.

The variation in HIE policy and success across varying nations reflects the multiple challenges of HIE, including aligning financial incentives for adoption and use, technical challenges, governance choices, and integration of outside data into clinical workflows. If the only serious impediment to broad interoperability were financial incentives, the UK NHS would have had a simple time achieving robust HIE. Similarly, while HIE is far from robust in the US, it is likely more advanced than the German system despite featuring an even more decentralized, competitive, and market-oriented care delivery system. Socio-technical challenges around setting standards, generating awareness of the HIE and encouraging adoption without burdening clinician and patient users, and building governance models with broad acceptance that are flexible enough to adapt to changing technological and social needs are common across our case study nations.

While there is no clear “best” overarching HIE strategy, multiple approaches may be effective in facilitating robust interoperable data exchange. For example, it may be that a “middle-out” system, defined by Price *et al.* as centralized leadership with strong public-private collaboration and more local control by individual care delivery organizations similar to the current strategy in the UK, may provide a balanced approach to these challenges, preserving local innovation around

issues like workflow integration by private vendors and health care organizations while setting national-level interoperability incentives, standards, and governance frameworks [55]. Similarly, heavily centralized approaches may be successful, as Israel’s increasing centralization has shown. However, the early experience of the US during the HITECH era illustrates the difficulty of achieving broad, robust interoperability with a heavily decentralized policy framework – even with significant effort to build EHR infrastructure and align financial incentives. Each system must recognize the importance and centrality of the patients – from giving them the final say in the ability to opt-out of data sharing such as in Israel to enabling them to access all their clinical data in the US, any national HIE strategy must work to ensure patients’ changing needs are being met. Policymakers may wish to focus on creating integrated care structures that maximize incentives to share data while simultaneously ensuring there is a national-level interoperability strategy that makes data exchange a priority, with prescriptive guidance around standards and governance. At the same time, these strategies need to be adaptable to an ever-changing world, and researchers should carefully monitor and evaluate HIE progress to inform policymakers and allow them to be flexible in their approach. Finally, ensuring awareness among users (e.g. clinicians, patients, payers, public health agencies, etc.) and supporting actual use of HIE is critical to move from encouraging building interoperable data exchange to maximizing the potential of HIE to improve health and care delivery.

Directions for Future Study, Research and Policy Implications:

While there is a significant and growing literature, there are still many unknowns with respect to HIE. While we provide speculation above regarding how different policy frameworks have influenced the development of HIE in five nations, in many dimensions of HIE we are unable to make direct cross-country comparisons due to a lack of data or published research. Standardized measures of HIE in terms of data exchanged, semantic interoperability, use by frontline clinicians are often not available at the national-level, or only available in aggregate form or with organization-level survey

measures that do not provide granular details of use. Our analysis was limited to holistic, qualitative evaluations of HIE maturity, centralization, and incentives due to this lack of broad, comparable empirical measures, and we supplemented what literature exists with small and single-site studies, policy briefs, and grey literature. To remedy this, we provide a non-exhaustive list of areas for additional future research:

- *Measurement*: Many measures of HIE focus on organization-level adoption, rather than evaluating actual real-world use (e.g., how often data from HIE is used in care delivery, or aggregated into population-level data by public health agencies), especially in studies measuring at a national-level [33, 95]. More granular measurement, including measuring volume of outside records exchanged, viewed, and their influence on the patient and clinician, is the next frontier of HIE measurement. Finally, measuring whether and how clinicians actually use that data when delivering care is critical to improving HIE policy at a national level and implementation at a local level.
- *Impact*: While early modeling studies have predicted significant cost reductions from HIE [3], many empirical studies have found it difficult to identify broad gains in either quality or cost [96]. Additional research, especially studies with robust designs for causal inference, is important to identify the impact of HIE on quality, costs, and the patient experience [97].
- *Workflow*: Given growing concerns over clinician EHR work [98, 99], especially in the US [100], it is critical for HIE to present outside records within existing workflows without exacerbating burden. Early studies show integrating HIE into the standard patient history screen greatly increased clinician views of outside records [101], future research should evaluate how and when to present information from various sources (e.g., other providers; patient reported data; remote monitoring devices) to clinicians across various clinical scenarios and settings (e.g., inpatient, outpatient, emergency; post-acute care; community health providers).
- *Population Health and HIE as “Data Utility”*: While HIE has always held great potential as a data aggregation source

to fuel population-level analytics, the COVID-19 pandemic demonstrated the importance of this information. Several efforts are underway to conceptualize HIEs more broadly as a “data utility”, including using HIE data for more accurate clinical quality measurement, data aggregation for research, and public health analytics [102, 103]. While still a nascent field, following the development of these next-generation efforts and evaluating their effectiveness is critical to guide the next phase of HIE.

HIE research is at an important inflection point – moving past structural measures of adoption to evaluating volume and impact at scale, best practices for integration of data into clinical workflows across a range of scenarios and broadening the spectrum of HIE use cases. Scientific research plays a critical role in the continuous evaluation of HIE to inform the healthcare eco-system (including patients, policymakers and practitioners) of the value of data sharing and avoid potential pitfalls and unintended consequences.

5 Conclusion

Following the digitization of health care delivery, HIE and data interoperability has become increasingly important for delivering high quality care. HIE can reduce costs and duplicative utilization, improve the patient experience, and empower patients with access to their data, and ensure clinicians have access to all relevant information for their patients at the point of care, no matter where that data was generated. While implementing robust national HIE has been a challenge, our case studies highlighting different approaches from five nations suggest some generalizable policy frameworks that balance centralized decision-making around standards and governance but allow for local innovation in technical capability and workflow integration. Future research on HIE should include more detailed measurement of data exchange and use, the impact of interoperability on patients and care delivery organizations and assessing new frontiers of using HIE for public and population health.

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