FOSTERING A DIGITALLY ENABLED healthcare system through health information exchange

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EXECUTIVE SUMMARY

The fragmented nature of South Africa's health system negatively impacts both the cost and quality of healthcare, and impedes the introduction of universal healthcare for the entire South African population.

This has raised concerns among leaders and policymakers alike, including the Competition Commission's Health Market Inquiry (HMI) panel whose recommendations include the need for innovations that increase efficiencies in healthcare delivery and funding; greater transparency on health outcomes; less fragmentation; and a move towards care coordination (CCSA, 2019). Aligned to these recommendations, the South African government also recognises the importance of digitisation in improving access to quality healthcare in its National Digital Health Strategy (NDoH, 2019).

The CareConnect Health Information Exchange (HIE) has been developed over the past two years to respond to the above imperatives. Founded jointly by six South African healthcare organisations, the HIE enables the sharing of rich patient health information, thereby enabling fragmented systems to exchange and use the information to support healthcare professionals. From August 2021 to December 2022, 4.7 million consented patient records had already been added to this HIE and 94.5 million 'transactions', i.e. an exchange of information within the HIE, including updates of patient demographic and clinical data, had taken place.

In this paper, we firstly present the background to HIEs and the value they provide to the various ecosystems they operate in. Secondly, we share key lessons learned in developing the CareConnect HIE, specifically in collaborating with six large healthcare organisations. Thirdly, use cases are shared on the value of HIE to both the private and public health sectors. Lastly, we provide insight into the HIE roadmap from both a clinical and technology perspective.

INTRODUCTION

South Africa's healthcare system is marked by a high degree of fragmentation caused by a variety of factors, including geographic disparities, income inequality, a two-tier health system, a siloed approach to patient care and a lack of care coordination between different stakeholders. This fragmentation creates challenges for both patients and providers and affects both the costs and quality of healthcare delivery.

In its final report (CCSA, 2019), the Competition Commission's HMI panel made recommendations related to factors that affected efficiencies and competition within the sector, several of which could be resolved by Health Information Exchange (HIE). These include:

- Moving away from a fee-for-service model of reimbursement towards alternative reimbursement models
 to contain expenditure and encourage value-based contracting. Data would be needed from the HIE to
 assist in measuring the clinical effectiveness of these new models.
- A single data repository, such as the HIE, to collect timely and reliable information for both the private and public health sectors.
- The need for a platform for providers, patients and all other stakeholders in the provision of healthcare to generate patient-centred and scientifically robust and standardised information on health outcomes.
- Increased multidisciplinary team-based care, which would directly benefit from providing and supplying data to the HIE to support coordination of care.
- Investing in innovative forms of care and reaffirming/strengthening the care co-ordinator role of GPs. The HIE allows GPs a complete clinical view of their patient's journey.

The case for a HIE

Because it is seen as such an important mechanism for improving the efficiency and effectiveness of health-care delivery (Payne et al, 2019; HealthIT.gov, 2023), HIEs have become a priority on many health policy agendas for governments around the world. They are already common in the most advanced health systems globally, such as China, England, India, Scotland, Switzerland and the United States (Payne et al, 2019).

Research has shown that the electronic exchange of clinical information is vital to improving healthcare quality, safety and patient outcomes in the following manners:

- Improved quality of care: Improved healthcare quality and health outcomes by reducing medication and medical errors (Payne et al, 2019; HealthIT.gov, 2023).
- Improving efficiency: Improving efficiencies by reducing unnecessary tests and ensuring that those involved in the patient's care have access to the same information (HealthIT.gov, 2023).
- Streamlining administration: Reducing administrative costs by reducing paperwork and making many administrative tasks simpler and more efficient (HealthIT.gov, 2023).
- Engaging patients: Enabling patients to be involved in their own healthcare, reducing paperwork and time spent briefing health service providers on their medical histories (HealthIT.gov, 2023).
- Supporting community and public health: Coordination with and supporting public health officials to improve community and public health (HealthIT.gov, 2023).

To address fragmentation and other obstacles plaguing the system, which later became the focus of the HMI, in 2016 six South African private health sector organisations, Netcare, Momentum Health, Mediclinic, Medscheme, Life Healthcare and Discovery Health, came together to explore the possibility of creating a coordinated health information management system, which could ultimately become an independent health utility for the entire health sector.

After a successful feasibility study was conducted, a Memorandum of Understanding was signed between the six participants and the CareConnect HIE, a non-profit organisation, was formed. Funding for the development of the CareConnect HIE was provided by the six founding members. During February 2019, a pilot study was conducted with two of the founding members to test and validate the integration, functionality, privacy and security of data required for the initial use cases. The exercise achieved the agreed critical success factors necessary to operate an HIE and clearly demonstrated the potential value of sharing data through an HIE. It also brought to the fore the mutual trust required to ensure that the data being shared are utilised for the correct reasons, i.e. improving health quality, outcomes and efficiencies. This gave rise to the drafting of a Data Use and Reciprocal Support Agreement (DURSA), which establishes the rules of engagement and obligations to which all CareConnect HIE participants agree and sign as a condition of joining the HIE community. It specifies the principles around sharing of data and the permitted purposes for sharing data, i.e. in the interest of improved health quality and outcomes for patients. For example, data security is a key element of the DURSA and each participant needs to ensure sufficient mechanisms to keep data safe.

The data exchanged via the CareConnect HIE environment consists of both demographic and clinical data. In adherence to the POPIA, only consented data are shared and exchanged. The obtaining and managing of consent rests with the participants, who remain the responsible parties and should have the necessary consent management processes and systems. In the case of health facilities, explicit consent is obtained upon admission to the facility. In the case of medical schemes, consent is obtained through their usual member management channels.

KEY ELEMENTS OF THE CARECONNECT HIE

Initially built around five use cases, the CareConnect HIE facilitates the consented sharing of a wide range of information, such as patient medical records, test results, previous hospitalisations and medication lists. The five initial use cases are as follows:

- *Elective admission*, which provides access to a patient's health insurance details and related authorisations required during pre-admission for an elective procedure.
- Emergency visits (conscious patient), which provides access to a patient's demographic and clinical information such as previous hospital visits, historic procedures, historic and active diagnosis, chronic and other current medications.
- *Emergency visits* (unconscious patient), which provides access to a patient's demographic (including contact details) and clinical information as with the conscious patient.
- **Personal detail updates** allow patients to validate and update personal and medical details during a preadmission visit or check-up.
- Revocation of consent.

Using state-of-art technology whereby participants can accurately and securely exchange data using the CareConnect HIE is one of the key building blocks required for the successful implementation of the HIE. As a result, the HIE provides the following value for all participants:

- A unified care record (UCR): A single UCR of a patient that increases in value as more data is added.
 This contains both up-to-date demographic and clinical information, including hospital encounters,
 chronic conditions, medication and information relating to diagnostic testing. This care record assists in
 facilitating coordinated patient care by providing clinicians with a unified view of patient data.
- Master patient index (MPI): Adapted to the South African context, the MPI enables seamless patient
 identity matching across the total patient population, which provides access to up-to-date patient demographic data.
- Data quality management: The CareConnect community obtains value by addressing data quality issues within their own data. Where data can't be matched, or where anomalies are discovered (as in the case of duplicate scheme membership), streamlined processes defined between CareConnect and its members are in place to handle manual worklist items. From August 2021 to November 2022, 45 681 (approximately 1%) of the total patient records have required manual intervention. This process aids participants in addressing data quality issues within their own data sources.
- HL7 (Health Level 7) and FHIR (Fast Healthcare Interoperability Resources 1): A set of international standards used to transfer and share data between various healthcare systems regardless of how it is stored in those systems. Both these standards aim to standardise the messages that are passed between systems, which is what drives the interoperability because everyone is speaking the same language. CareConnect HIE supports these industry-wide integration standards. This provides us with a standard common target data format, transforming information into a usable form. This common format ensures data integrity, accuracy and consistency while clarifying ambiguous meanings and minimising redundant data. It also allows for consistently applying specific business rules. Having these data standardised makes it simpler to govern with a data catalogue that can track things like who owns the data, where it came from, who is allowed to use it and who has used it.
- **Data security:** The HIE is built on local Amazon Web Services self-contained environments. Security and encryption occur at access network, communications, server, operating system and software levels. User-based roles and rights provide an additional layer of security.

Privacy and security of data form the cornerstone of HIE. The CareConnect HIE conforms to both local and international data privacy regulations to ensure that sensitive health information remains protected at all times and will only be accessible to healthcare providers when medically necessary and only with the patient's consent. User-based access permissions are automatically regulated by the HIE, further safeguarding sensitive patient information.

HIE USE CASES

The increase in patient-consented information on the HIE from 2021 to date, combined with a growing appreciation by stakeholders within the industry, is driving participation in the initiative.

While still in its infancy, participating organisations, including clinicians, in the HIE are already finding value in its use for care coordination, through real-time access to patient records and the single UCR. The HIE is also being utilised by hospital facilities to complement their admission process and reduce paper-based processes through the use of CareConnect's Clinical Viewer and system-to-system interface. Additionally,

hospital groups and administrators have found significant value in the CareConnect MPI for identifying data quality issues and some have also adopted the CareConnect integration standard and methodology for implementing internal integrations and projects.

The next phase of HIE developments, now underway, includes the addition of radiology information. Having a view of radiology reports and images will provide a more comprehensive view of the patient journey and drive further adoption of the HIE and of sharing data. The integration of pathology data is currently being sought, as the more data there are on the HIE the more value it will provide.

Simultaneously, additional use cases are in the process of being developed to provide healthcare providers, funders and future participants of the HIE with a 'richer' set of data in support of their own objectives. New use cases include:

- Discharge summaries, which provide access to a summary of a patient's condition, care received, treatment plans and hospital admissions;
- Adverse reactions, which provide access to any testing and diagnoses, for consistency and accuracy of patient's allergies;
- Obstetrics care, which provides access to a deeper data set around pre- and post-antenatal care, including the patient's labour and delivery information received from GPs and specialists.

The implementation of these use cases would also be of value to the public sector, and National Health Insurance (NHI). South Africa's NHI (Republic of South Africa, 2019) is a proposed system that aims to provide universal healthcare coverage for all citizens. One of the key components of the NHI is the establishment of a comprehensive electronic health record (EHR) system, which would enable the exchange of health information among different healthcare providers. This would allow healthcare providers to access a patient's complete medical history, even if the patient has received care from multiple providers or at different locations.

HIE, which includes a rich EHR in the form of its UCR for each patient, has the potential to significantly improve the efficiency and effectiveness of the healthcare system, as well as the quality of care that patients receive. Overall, the use of HIE as part of South Africa's NHI would help to achieve the goal of universal healthcare coverage by improving the quality, efficiency and effectiveness of the healthcare system.

CONCLUSION

Health data sharing, now more than ever, is a crucial aspect of effective healthcare and benefits everyone: individuals, healthcare systems and global populations. Sharing data can improve patient care by making it more efficient and coordinated, allowing patients to take a more active role in managing their own healthcare journey. Healthcare providers can also use data-sharing to design better diagnostic and care pathways and use resources more efficiently. The potential for medical research is also improved, as data-sharing allows for faster development of new treatments. EHRs, in particular, are useful for healthcare professionals as they allow access to all prescribed medicine, laboratory test reports and a patient's medical history on a single screen, enabling more accurate diagnoses and better care (Data Saves Lives, 2022).

The value of any HIE lies in the quantity and quality of data available to be exchanged. The more data that are added, the more value the HIE will provide to its participants. The CareConnect HIE is still in its infancy (relatively speaking) in terms of the use cases it has developed, so more participants are required to come on board, so as to develop new use cases that further contribute to, among others, quality of care; outcomes; coordination of care; performance-based reimbursements and standardisation.

Critical to the CareConnect HIE is participation by clinicians and their societies, as the HIE will enable analysis, reporting and quality improvement projects to be conducted on de-identified data. Projects relating to perioperative outcomes improvement, obstetrics monitoring, allergies and others are being developed.

Given South Africa's dual health system and the federated approach in terms of autonomous provincial health departments, interoperability and HIE are key to achieving a more cohesive system. To this end, the CareConnect HIE is working with government as a potential capability to address data exchange and standardisation between the various health systems in the interests of improved patient experience, better patient care and a more cohesive system.

HIE platforms like CareConnect, along with their capabilities for transmitting real-time clinical information between participants and their bundled products and services, have the potential to accelerate and scale access to healthcare and spark transformative innovation that meets needs in South Africa's health system. The CareConnect HIE is already having a positive impact on the South African private healthcare system and has the potential to become a catalyst for innovation in both the public and private healthcare systems in South Africa.

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