

AI & Robotics Implementation and Pitfalls

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The Patient Is the DATA

With the advent of digital technology in healthcare, data has become an essential component of modern healthcare delivery. The availability of patient data is crucial for providing quality care, managing patient privacy and safety, and promoting patient engagement. However, data silos and the lack of interoperability between healthcare systems have made it difficult to access patient data across the entire healthcare ecosystem. Using a quote from the CEO of Health House, Isabelle François: “In the future a hospital will not be brick and mortar, where you go for treatment and then home. Instead, a hospital will be an integrated healthcare entity that together with General Practitioners, Home Caregivers coordinate and work together to give the best possible assistance to the patient. An example of such is the Sheba Medical Centre in Israel where this close collaboration already exists”.

To attain this at scale, a unified access to all data of a patient across the entire system is needed.



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key points

- Unified Access must be able to integrate data from multiple sources, including hospitals, general practitioners, first and second line healthcare workers, as well as the patient and their relatives.
- To achieve a healthcare ecosystem based on prevention and minimised stays in hospitals, we need to ensure that all elements of our health are available.

Unified Access to All Relevant Patient Data

Currently, a semblance of availability exists due to the use of Electronical Medical Records (EMR/EHR) kept by the hospitals and the existence of a Generalised Medical Record (GMR) kept by the GP.

A unified information system would enable healthcare providers to access a patient’s medical records from any healthcare facility or provider, however no such information system exists consistently across the ecosystem; this would improve patient care by providing a comprehensive view of a patient’s health history, current medical conditions, and ongoing treatments. The system would also facilitate communication between healthcare providers, allowing for better coordination of care and reduce the likelihood of medical errors. The system would allow patients and their families to access their medical records securely, providing them

with greater control over their healthcare. Patients could easily access their records, track their progress, and communicate with their healthcare provider.

Garbage in, Garbage out

This credo of Digital applies to Digital Health as well! So, before we discuss how and why to share data, we need to be certain that the data is clear, concise, complete and correct! Recent studies by Deloitte as well as other reputed institutions raise concern that data in the EMR’s is not to be completely trusted as being correct and/or complete. This stands for a large percentage of the accumulated information. In order to tackle this, we need to ensure that the current data is surveyed, compared and corrected where needed, otherwise chaos will ensue!



Security and Privacy

Security and privacy are critical considerations in any accessible system. Healthcare providers must

patient consent rather than working through indirect channels.

A distributed universal Unified Access governing all patient data would allow access across the entire healthcare system unchaining the information that is required to open the doors of the future

adhere to strict regulations governing the storage, transmission, and use of patient data, including GDPR and government regulations on local, regional, federal and EU level. Healthcare providers must ensure that patient data is securely stored and transmitted, using encryption and other security measures.

To ensure privacy, patients must have control over who can access what part of their medical records. Patients must be able to authorise access to their records, and healthcare providers must ensure that only authorised individuals can access the records. Patients must also have the right to view their records and ask to correct any errors. The most efficient way to achieve this is through a federated authority access system, where the final say lies with the patient achieved through a non-technical control mechanism.

Access to Different Sources

Unified Access must be able to integrate data from multiple sources, including hospitals, general practitioners, first and second line healthcare workers, as well as the patient and their relatives. This requires the use of standardised data formats and communication protocols to ensure that data can be shared seamlessly between different systems. The system must be designed to accommodate the needs of different healthcare providers, including those with varying levels of technical expertise.

Access to Data for Not Just Primary Use but Also Secondary Use

To make the system affordable and healthcare more efficient we do not just need to facilitate better connection between doctor and patient, but we need to allow the entire healthcare ecosystem to better communicate and share information. Clinical studies and research need access to data; ideally, unrestricted access but within clearly defined rules, obtaining direct

Benefits

The system would offer several benefits, including:

1. Improved patient care: Unrestricted Access to patient data can help healthcare providers make better-informed decisions by providing them with a complete picture of a patient's health. This can help to improve patient outcomes and reduce the risk of adverse events. Having one overview access to the medical history, ongoing treatments, and care plans, as well as potential access to the IoT and personal data provided by social and auxiliary systems would show a more complete picture.
2. Enhanced communication and coordination between healthcare providers can reduce the likelihood of medical errors.
3. Improved patient engagement: Unified Access to patient data can also help to improve patient engagement by giving patients greater control over their health information. Patients can access their data, review it for accuracy, and share it with other healthcare providers as they see fit.
4. Improved efficiency and cost savings by reducing the need for duplicate tests and procedures. This will reduce time to treat and any potential error which in itself will enhance the patient's trust with their doctor and treatment.
5. Use interoperable systems and standards: Through the use of standards, such as FHIR and HL7, the system for accessing patient data warrants interoperability and can work with existing systems. Key to success is that no existing system needs to be changed or replaced.
6. Patients MUST have control over their data: Patients should have control over their data, including the ability to review it for accuracy and share it with other healthcare providers as they see fit. This can be achieved through the use of patient portals or other tools that give patients access to their health information.



7. Enhanced research: Unified Access to patient data can help to advance medical research by providing researchers with access to a larger pool of data. This can lead to new insights and discoveries that can improve patient care.

Concerns

We need to keep in mind that such system would also raise several concerns, including:

1. Security risks: The more accessible data is stored, the greater the risk of a data breach. It is important to ensure that patient data is stored securely and that access is limited to authorised individuals.
2. Technical challenges: Creating a unified system for accessing patient data can be technically challenging, especially if data is stored in multiple locations or in different formats. It is important to ensure that the system is interoperable and can work with existing systems.
3. Privacy concerns: Patients may be concerned about who has access to their health information and how it is being used. It is important to ensure that patients have control over their data and their privacy is protected.
4. Resistance to change: Some healthcare providers may be resistant to adopting a new system, requiring significant education and training.
5. Legal and regulatory challenges: There may be legal and regulatory challenges to creating a unified system for accessing patient data, especially if data is being shared across different organisations or jurisdictions. It is important to ensure that the system is compliant with relevant laws and regulations.
6. The system would have to be rightsized from the start as any fundamental change afterwards would come at a considerable cost. This does not mean the system needs to be largely oversized from the beginning, but must be architected for growth from the start!

Recommendations for Achieving Unified Access to Patient Data

To achieve Unified Access to patient data while addressing the benefits and concerns outlined above, the following recommendations should be considered:

- o device an umbrella system. This can be defined as a system that does not tax the current investment in people, training, installed base or knowledge required to access and operate it. Every facility currently using EMR/GMR should NOT require any extensive retraining to use the additional information awarded by a unified access sharing.

- o Ensure that we start with healthy data instead of data that has not been verified to be correct and in the right fields. A unified access will only work if and when the data is correct and in the correct location in the original system. Unfortunately, we do not start from a clean slate, so knowing the source system has clean data will warrant reliable and trustworthy sharing. The patient will have a key role in supervising correctness of data up to a certain level.
- o Give patients control over their data: Patients should have control over their data, including the ability to review it for accuracy and share it with other healthcare providers as they see fit. This can be achieved through the use of patient portals or other tools that give patients access to their health information.
- o Ensure that patient data is accessed securely: It is important to ensure that patient data is accessed securely and that access is limited to authorised individuals. This can be achieved using encryption, access controls, and other security measures. In case of secondary use extra measures such as anonymisation and synthetisation need to be covered.
- o Use interoperable systems: It is important to ensure that the system for accessing patient data is interoperable and can work with existing systems. This can be achieved through the use of standards such as HL7 or FHIR...
- o Comply with relevant laws and regulations: It is important to ensure that the system for accessing patient data is compliant with relevant laws and regulations, such as European Health Data Space (EHDS), Health Data Authority (HDA), i-HD and GDPR. This can be achieved using legal and regulatory experts, as well as working with governments.
- o We might consider decoupling the current bond between data and diagnosis as there seems to be an “intellectual property issue” with the latter.
- o Supplementing medical data with situational data (e.g. (non-medical) wearables, ...) will allow a more complete image of the patient and their ailments.

Conclusion

A distributed universal Unified Access governing all patient data would allow access across the entire healthcare system unchaining the information that is required to open the doors of the future. To achieve a healthcare ecosystem based on prevention and minimised stays in hospitals, we need to ensure that



all elements of our health are available. This means that first and second line healthcare professionals require patient information currently stored in silos and undetermined places, but also allows patients and loved ones to contribute with additional information. Just as a patients' life does not revolve around an illness, data is not limited to strict medical observation and instead can be obtained from wearables and personal observation from people around the patient.

To able unrestricted movement of people around the globe, our healthcare data needs to be as easily available as our passport and just as trusted, and if we want this to be true, we better start at the local level but with the end goal in mind!
Plan globally, execute locally!

Conflict of Interest

None. ■

disclaimer

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