

RESHAPING THE CARE MODEL

Enabling patients to understand their own health information to make informed decisions is paramount, says Mohammad Al-Ubaydli, CEO of Patients Know Best

This month, as the global healthcare community gathers at Abu Dhabi Global Health Week, the transformative potential of digital health and AI takes centre stage again.

At Patients Know Best (PKB), we believe this technological revolution is not just about innovation but about fundamentally reshaping the care model by placing the patient at its core.

Our mission is to empower patients to “know best” by ensuring they can own, understand, and use their health information to make informed decisions with their care team.

This approach benefits patients directly and, when enabled by technology, can revolutionise care delivery, especially in resource-constrained environments. We envision patients as equal partners in their health management, and active providers in its delivery. To achieve this, patients need access to their health records, the ability to understand the information, and the means to act on it.

Data as a Cornerstone

PKB has always prioritised securely sharing data with patients, because we recognise data as the foundation for patient engagement and personalised care.

Healthcare systems have increasingly embraced automated data sharing, but patient engagement remains inconsistent. While people like Richard Stephen (see case study), who has kidney disease, demonstrate the potential of active patient involvement, they rely on naturally motivated individuals, both clinicians and patients.

We’re now moving beyond this passive engagement digitally - relying on clinicians working to activate patients - to a new era of automated digital activation of patients. By engaging patients with their data and



intelligently explaining what the data means and what the patient must do next, we can automate activation and reduce the burden on the health system.

A new era of activation

After years of patient registration and data hosting, PKB is poised to deliver meaningful change at scale. We have significantly enhanced our architecture with FHIR, ensuring optimal data handling and we have streamlined interaction for all stakeholders.

By integrating an engaged patient user base with their data and the ability to intelligently support their understanding and action, we can now move to automated patient activation, reducing the burden on stretched healthcare providers.

This approach requires collaborative efforts to define actions based on coded data and to align with the preferences of healthcare providers and health economies. Rules generated by third parties, such as healthcare providers, can automatically prompt patients to take action in specific scenarios. This shift removes the burden of initiation from clinicians, empowering patients as proactive partners in their care.

What lies ahead: clinical trials and medication optimisation

Our immediate focus is on clinical trials, helping to bridge the gap between frustrated patients who are not aware of all their options and organisations struggling with recruitment alongside day to day care. We aim to enable organisations to share trial information with eligible patients via

PKB based on structured known criteria, most notably their diagnosis with our patient-consented approach, ensuring the patient’s data is not shared until they decide they would like to.

The second area of expansion is medication optimisation, such as



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prompting patients to contact their organisation for a medication review. Medicines optimisation introduces the capability to use snomed codes in data held in PKB records to apply rules set by clinicians to prompt automated action and early intervention. For example, if you have gout, and are on Allopurinol, have you had your annual check for urate? This process takes the onus away from clinical teams and within PKB we will prompt patients to take action where it may have been missed. The record will then also allow for changes and optimisations to be tracked and quantified as a result of the notifications.

It’s early days, yet the potential is immense. We are witnessing the dawn of a new era in healthcare, one where technology empowers patients to become active participants in their well-being.

The Patient Perspective: What Really Matters in Digital Health

If you’d like to know more, don’t miss this fireside chat on ‘The Patient Perspective: What Really Matters in Digital Health’ on Thursday 17th April at 11:25am. Steve Gardner will be sitting down with Dr Mohammad Al-Ubaydli to discuss the role of the patient and their involvement in the digital health ecosystem and to share his insights from his new book *Digital Health Records for Governments*.

Case study: Kidney patient, Richard Stephen

Diagnosed with Stage 5 Chronic Kidney Disease in 2019, Richard Stephen faced a stark prognosis, but he was determined to maintain his quality of life and avoid dialysis or a transplant.

Access to his health record on Patients Know Best (PKB) became vital. It empowered him to meticulously track his test results and start research on what was needed to improve them.

This information enabled informed discussions with his healthcare providers and further guided his research. PKB led him to actively manage his condition by tracking his blood pressure, documenting exercise and meal plans and maintaining a library of research documents.

Five years later, Richard has defied expectations by avoiding dialysis and a transplant. He attributes this success to the detailed tracking, and the tools and analysis made possible by PKB, demonstrating the power of patient activation in chronic disease management by comprehensive conservative kidney care.

CONTACT INFORMATION



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