

# Do patients know best?



by

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A look at the platform that's putting medical information in the hands of patients

Software that empowers patients to be active participants in their healthcare looks set to be the next leap in the industry's growing focus on patient centricity. Patients Know Best (PKB), which allows patients to access their own medical records at any time and share them with any health professional, is one such platform, and is currently taking the healthcare world by storm, with a slew of awards to its name and a growing userbase across the country.

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But although PKB's vice-president of business development Lloyd Humphreys describes it as a disruptive technology, the actual concept behind PKB is intuitive enough to make you wonder why there aren't more platforms like it in the healthcare industry.

"Today, where all of our information is available to us, healthcare is the only area where your own information is not available at the push of a button," Humphreys says. "Patients need to become active members of their own health and care, and we need to involve everybody in their network."

He adds: "PKB overcomes a lot of the problems that healthcare providers currently face in terms of sharing information about a patient across different organisations or different geographies. Anyone with an account is able to walk into any healthcare organisation, whether that organisation actively uses PKB or not, and invite a professional in to see their record via email. They can not only see that information that's come from all the different places the patient has visited, but they're also able to communicate directly with those professionals."

This kind of access can facilitate connections that would have been far more cumbersome in the past.

"A really nice example is a patient who was on a Caribbean cruise, who had a flare up in her Crohn's and needed treatment immediately," says Humphreys. "She walked into the local hospital, invited the professional into PKB and connected that professional with a consultant at Luton and Dunstable. They were able to coordinate the treatment, prescribe the right medication, and that patient was able to get back on the boat and carry on with her cruise. That's the simplicity of being able to coordinate across geographies."

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This can be particularly useful for rare diseases, as Humphreys emphasises with the example of children with short bowel syndrome from Great Ormond Street Hospital, where PKB got started. "These are very rare, very complicated patients, and when they're discharged from Great Ormond Street they go back to their local GPs and their local hospital, who don't really know how to deal with them. If mum uses PKB it means that when she turns up to the emergency room the doctor can act on the information held in the medical records because it has come direct from Great Ormond Street."

PKB taps into a wider trend of patient centricity and personalised treatment in healthcare that is currently at the forefront of the industry, but Humphreys says that the cultural change required to fully integrate projects like this may still be slow to come.

"Instigating cultural change has been a challenge. Patient ownership of information is a relatively new phenomena, and yet it now permeates every sort of policy, from the Fiver Year Forward View to Personalised Health and Care 2020. What we wanted to do was actually look at how we shift the culture from a patriarchal model of healthcare delivery – as the doctor says, the patient does – to a much more collaborative approach where both the patient and the doctor are working together around shared information and collaborating around one record. It requires a mindset shift for both doctors and patients; that patriarchal model has been propagated by both groups."

*For more on PKB and other innovations entering the NHS, see our July/August issue, out this month*