



Patients in Wales to take control of medical records

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London

The NHS in Wales has moved closer to adopting a privately developed, online health records system designed to put patients in control of their personal information and care.

The system, called Patients Know Best, has been awarded a national framework contract by the Welsh government. It allows patients with smartphones and other devices to organise their personal records in an internet based account, add information, and share it with others, including hospitals and GPs.

The interactive platform was developed by a for profit, Cambridge based software company, also called Patients Know Best, which is backed by venture capital investors and already has contracts with NHS organisations in England.¹

Abertawe Bro Morgannwg University Health Board established the national framework after carrying out “successful” pilot schemes. It is investing around £350 000 (€398 000; \$445 000) over two years and will evaluate whether the system improves outcomes and patient experience, and delivers cost savings and efficiencies. The evaluation will involve 70 000 adults attending Princess of Wales hospital and community teams in Bridgend.

Hamish Laing, the board’s executive medical director, told the *BMJ*, “We’re not the first country to use the system, but we’re the first country that has a country-wide framework for it. Other parts of NHS Wales could buy into it, if it’s successful.”

Patients Know Best lets patients record their own symptoms and track them, connect to devices such as glucose monitoring equipment; receive and store results, letters, and appointments; and co-create care plans. Other features include secure remote messaging, video consultations, and the ability to conduct virtual clinics.

Laing said, “We and others can put information into the account and the patient then becomes the data controller. They can choose to share it with whomever they wish.”

He said this helped to tackle current challenges around data sharing between different parts of the NHS.

Mohammad Al-Ubaydli, chief executive and founder of Patients Know Best, said the system improved on those that were centrally filed or managed by NHS organisations. “It combines

the best features of the institutional systems, the specialty based systems, and the patient entered systems, but it’s all in a record which is joined up,” he said.

He said it was Europe’s first national framework for a patient held medical record.

“No other country has gone down this route. Previous government efforts have all focused on a regionally locked or institutionally locked approach to patient portals,” he told the *BMJ*.

The national framework has been approved by Vaughan Gething, Wales’s cabinet secretary for health and social care.

Laing, who is also the board’s director of information and innovation, said it would take a few months to complete the integration and staff preparations for the deployment.

Al-Ubaydli said Patients Know Best, whose chairman is former *BMJ* editor Richard Smith, operated a “social enterprise business model.”

“The profits go back into the company. We put our all money back into developing the product.”

He said that patients could be confident that the data was secure. “We can’t sell the data, we can’t advertise the data, we can’t even get to the data. The data are owned by patients and they’re encrypted for them, so we just get paid for the services, for securely hosting that information for them and carrying out the instructions of the patient.”

NHS Wales has begun a national roll-out of Patients Know Best to people aged 16-24 with diabetes.

A Welsh government spokesman said, “The NHS uses strategic national frameworks to enter into appropriate contracts for digital and technology products and services, some of which will be from private providers.”

¹ Patients Know Best. www.patientsknowbest.com/about-us.html.

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