



The Care Information Exchange - the largest shared patient portal program in the UK

In 2015, Patients Know Best (PKB) teamed up with NHS healthcare providers in North West London to roll out the 'Care Information Exchange' (CIE) – a single patient portal hosting the records of over 2.3 million people living in North West London.

Accessing data anywhere, anytime

Funded by the Imperial College Healthcare Charity and powered PKB, the Care Information Exchange is a true patient portal. Unlike hospital or GP portals which tie the patient to a single institution, CIE allows patients to access their health record from anywhere in the world and share it with any institution, professional family member or carer wherever they are to ensure their care is always coordinated most effectively.

CIE collects data from hospitals and GP practices in the area, and 15 other hospitals outside of North West London including Birmingham, Bristol, Liverpool, Manchester, Scotland and Wales. By using an Application Programming Interface (API) to display data in local medical systems, it enables hospital clinicians to see data about their patients who may also have been treated elsewhere in the country.

Andy Kinnear, Chief Information Officer from Connecting Care – a similar program developed in Bristol, is particularly supportive of this model as it allows patients who travel between Bristol and North West London for tertiary care to easily share their data. He said: "It's great that all data is truly available to the NHS via open APIs. But more than that, there is a consent layer that allows patients to express their preference on being contacted, taking part in research and sharing with friends and family that actually care for them. We have already had professionals in Bristol access data from London, and vice-versa."

Driving productivity and better outcomes for patients

For patients like Paul who was diagnosed with HIV, the Care Information Exchange allows him to be better informed and take control of his care. He said: "I'm treated for my HIV in Chelsea and Westminster, other conditions across London, and my GP in Wandsworth. So, really, I am the central repository of all the global information about me. I once took my iPad to Guy's for a consultation there. I was just about to be sent off for a whole raft of blood tests so I said: "Well, actually, you can see my results on here." The clinician took my iPad and I think the only words she said to me in the next 10 minutes was, "this is fantastic!"

For Nancy, a patient at the intestinal failure unit at St Mark's Hospital in Harrow, CIE is a way to monitor her health more easily. Fed intravenously on artificial nutrition, it is important for Nancy to monitor and coordinate her care with the multiple teams that look after her. She said: "I suffer from low potassium so I often have blood tests to check my potassium levels. So if I have a blood test, I go into CIE. I'll see if it's low or high then I'll use this to identify how much more medication I need to take and if it's significantly low, then the hospital will also see it and let me know if I need to be admitted into the hospital to get more potassium."



Kevin Jarrold
Chief Information Officer
Imperial, Chelsea & Westminster
NHS Foundation Trusts

“
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A system that allows data to move with patients

Designing a system that allows patients to access their health information whenever they need it was particularly important for Kevin Jarrold, Chief Information Officer at Imperial, Chelsea and Westminster NHS Foundation Trusts. He said: "We architected CIE so the data follows the patient wherever they are in the world. Our providers look after NHS patients from all over the UK in their national centres of excellence. And London patients change residence and provider every year much more often than in the rest of the UK. We chose a patient portal that allows patients to share with any provider, and with open read-write APIs to integrate with any provider."

Sanjay Gautama, Chair of North West London Information Governance Steering Group, added: "Patient-controlled data sharing is the right way to join up health and social care, and to consent, patients to contribute data for research."

Enabling access at scale

CIE was the first to introduce 'mass registration', enabling people to sign up and access their health record at scale and with speed in a number of ways; either by speaking to a member of staff; by using the kiosk check-in screen commonly found in waiting rooms during their outpatient appointment; or by letter of invitation to their home.

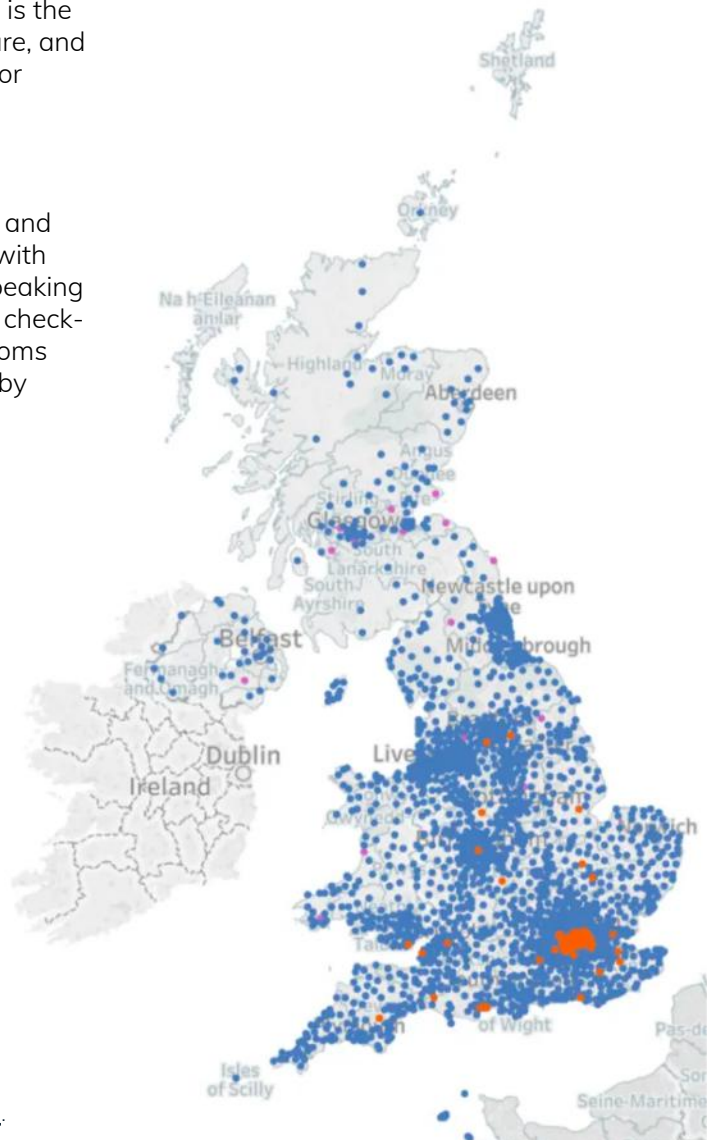
The Care Information Exchange is the first population-level roll out and the largest shared record patient-portal program across the UK, hosting the health records of over 2.3 million people in North West London. The patients are from all across the UK including every country, island and health board.

This approach proved to be a great success at Imperial College Healthcare NHS Trust where kiosk registration signed up over 3,000 patients in the first month alone with over 70 completing registration every day. As the process is automated, it means no staff time is taken up to verify the identity of patients.

A rich source data for more effective care

Since February 2018, CIE switched on GP integration for EMIS in the region and also shared community and GP data from SystemOne. But it's not just institutions that can add data to CIE, patients can also enter their own data. For example, patients can add information about their symptoms from multiple sclerosis, renal and oncology.

So far, more than 10,000 patients have registered with CIE and 31% have consented to share data for research purposes.



For more information about Patients Know Best, check out www.patientsknowbest.com.

To read the full case study, see <https://patientsknowbest.com/2019/10/21/care-information-exchange-the-largest-shared-patient-portal-program-in-the-uk/>