

Cancer patients offered access to their treatment records by a new online information portal

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Cancer Research UK, the National Cancer Registration Service (NCRS) and brain tumour support charity, brainstrust, have teamed up to offer cancer patients easy access to their treatment records after early research reveals how patients respond to having their details available online.

At the end of a pilot study in March this year, 88 patients had asked for access to their records and 50 had used the new system to view them.

The study began in November 2013 for [brain tumour](#) patients. These patients were told about the portal during consultations, in letters posted to them before clinics and with leaflets in information packs.

In July 2014 this was extended to other [cancer](#) types with eleven clinical teams across England offering the portal to patients with melanoma, brain, colorectal, prostate and kidney cancer.

The portal allows patients to look at reports on samples of their tumour as well as details of their hospital visits and treatments and any other records held about them by the NCRS.

As well as potentially helping patients to understand their own diagnosis, it also allows patients to flag up if something is missing or incorrect in their records to help improve the accuracy and quality of the data the NCRS holds.

The portal has a 'quality of life' section where patients can fill in questionnaires to help track different factors such as fatigue. There is also space for patients to add their own notes, keep a list of contacts and directory of links to helpful information about support, treatment, clinical trials and research.

But while patients were generally in favour of the portal, clinicians were more cautious.

They were concerned that, "it may heighten a patient's anxiety about their condition" and "patients may interpret reports they see via the portal differently to how it has been presented to them".

They also found it to be "one more thing" to do on top of a busy workload and access to up-to-date computers in clinics was often a problem. But all of the eleven clinical teams who helped with the pilot recognised the potential advantages of offering the portal to patients.

The partnership is working towards making cancer registry records available to users of [Patients Know Best](#) – a company that manages patient-controlled medical records – by the end of 2015.

Patients have to provide their name, address, NHS number, date of birth and details of their GP and consultant to request access to their records. Staff use these details to locate, check and positively match their records.

Patients are then informed that their records are ready. To fully activate their account and view their information, patients then need to contact their Clinical Nurse Specialist (CNS) to verify their identity.

The nurse then activates the accounts by telephoning the National Cancer Registration Service and providing a PIN code shown to the patient when their records are retrieved and the CNS's own code. Once their account is activated, the patient can access their NCRS records at any time through the portal.

Records are not shared with anyone other than the patient and their medical team and remain completely confidential.

Michael Chapman, Cancer Research UK's project director for the Cancer Patient Portal, said: "We've shown that patients would like to use the portal but we need to work on how this can be offered to a much larger number. Our pilot has only involved a small number of patients, but eventually we would like every cancer patient in England and across the UK to be able to access their own cancer registry record if they

choose. This will help restore a small amount of control into the seemingly uncontrollable experience that is cancer."

Will Jones, director of development at Brainstrust, said: "We know that access to relevant, personalised information is a significant contributing factor to helping people with a brain tumour better understand their situation. This understanding is most important in helping our patients and carers feel less afraid, less isolated and more in control. We are delighted to see the Patient Portal being offered to more people as a result of our expanding collaboration of engaged and committed experts who recognise the significance of information in the battle against cancer. "

Dr Jem Rashbass, interim cancer lead for Public Health England, said: "The National Cancer Registration Service in Public Health England is delighted to be working with CR-UK and Patients Know Best to help any patient who wishes to have secure access to their own records held by the National Cancer Registration Service in England."

Dr Mohammad Al-Ubaydli, founder and chief executive of Patients Know Best said: "The NCRS registry is unique in the world in the quality and coverage of data for research. Cancer Research UK's support of this work is yet another example of how they advance research to support the care of patients with cancer. Patients Know Best is proud to be the first patient portal to provide its patients with access to NCRS data so they can see and understand all the information about their health. We also know from previous research that 92 per cent of our patients want to make their data available to researchers so we expect that they will want to contribute additional data to the NCRS registry - further advancing cancer research."

Provided by Cancer Research UK

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