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## What You Don't Know Won't Hurt You

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# What You Don't Know Won't Hurt You ...

Kathy Oliver

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... or will it?

Each year, 200,000 people worldwide develop a primary malignant brain tumour.

Although there are no statistics to show it, some of these people – as well as some of the tens of thousands of others who are diagnosed annually with low-grade, benign, and metastatic brain tumours – will want to know everything about their disease. The big picture, the truth, and nothing but the truth.

Others won't want to know.

In their paper on “psychosocial and supportive-care needs in high-grade glioma”, the authors Catt, Chalmers and Fallowfield state: “*Active information seeking is an integral part of coping strategies for both patient and their relatives*” [1].

It is the strong belief of some brain tumour patients, caregivers, and advocates that patients must have as much information as possible about their disease, its genetic characteristics, existing treatments, and emerging experimental approaches if they are to make truly informed choices about their care.

What you don't know can hurt you, they argue.

A fledgling pilot project in Britain has the potential to arm brain tumour patients with an unprecedented level of knowledge. It is a patient information portal which will give patients free access to data about their care held by the UK National Brain Tumour Registry (UK NBTR).

Dr Jem Rashbass, director of the UK NBTR, said: “The approach we propose will be incremental and designed to strengthen the relationship and deliver considerable benefits for both patients and their clinical teams. A key element of the brain tumour registry pilot will be to ensure that the technology, processes, and systems can easily be scaled to cover all cancer sites.”

Relying heavily on health information technology (“HIT” is “*increasingly viewed as the most promising tool for improving the overall quality, safety and efficiency of the health delivery system*” [2]), this potentially transformative project will give brain tumour patients pioneering access to aspects of their datasets.

These datasets generally include full-text pathology, multi-disciplinary team data, Patient Administration System information (“PAS” data relates to hospital stays and activity), and some imaging. There is also data on radiotherapy, PET-CT

imaging, vital status from the Office for National Statistics, and, from 2012, national chemotherapy data.

The pilot has the support of the National Brain Tumour Registry itself, the UK National Cancer Intelligence Network (NCIN), clinical groups, and a number of charities representing the UK brain tumour patient community.

The project's steering group recognises that the initiative is not without controversy for it contains possible risks as well as benefits for patients who choose to participate.

Among the benefits are: upholding an individual's rights to access their own healthcare data; empowering patients to take a more active role in their treatments and care, thus improving patient experience; driving up data quality and context (patients will be able to see, question, and comment on their own data); patients being better prepared to discuss their care with their clinicians; and the opportunity to contribute to the registry longer-term information about their brain tumour journeys which has the potential to improve not only treatment but quality of survivorship as well.

So it will not only be a case of asking what your brain tumour registry can do for you as the patient, but what you can also do for your brain tumour registry.

Among the risks are: fear and anxiety potentially inflicted upon patients by obtaining information which they may not easily understand or be able to appropriately interpret; the effects that patients being privy to this information may have on the clinician-patient relationship; and the potential for compromised security of personal data. The steering group recognises that in order to allay any fear and anxiety for the patient, most users of the portal will require information to be accompanied by professional interpretation so that medical terminology and data impact is correctly understood.

At the heart of this pilot programme are 2 important notions. The first is recognising patient ownership of their own medical data. The second is the notion of personal choice, a tenet which is enshrined in the UK NHS (National Health Service) Constitution [3]. It will be completely up to a brain tumour patient to choose whether he or she wishes to access their data on the brain tumour registry.

This innovative project is one of a number of emerging initiatives that focus on and support patients who wish to become experts in their own care.

Another such initiative – not brain tumour-specific but from which people with brain tumours can benefit – is the “European Patients Academy on Therapeutic Innovation” (EUPATI);

<http://www.patientsacademy.eu>). Launching in spring 2012 by a consortium of 30 partners led by patient organisations, this is a multi-million Euro programme which aims to educate patient advocates and the lay public about personalised and predictive medicine, design and conduct of clinical trials, drug safety, risk/benefit assessment, pharmaco-economics, and drug development. EUPATI will provide educational material in 6 European languages targeting 11 European countries [4].

Patient portals for rich but hitherto un-mined sources of data such as brain tumour registries, together with the opportunity to benefit from educational programmes such as EUPATI, have the potential to transform the brain tumour journey's landscape.

#### References:

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