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Count Me In ...

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Count Me In …

Kathy Oliver

Disease registries have come a very long way since the 1660s when a Londoner called John Graunt – a prosperous haberdasher by trade – analysed decades of mortality data and literally invented the science of medical registries.

In Graunt's time, the focus was on bubonic plague and the effects that scourge had on the population's mortality.

Today, and for a rare disease like a brain tumour, relevant health information collected in national registries and then shared internationally can help ensure accurate analysis of a range of important data.

Primary brain tumours are relatively rare. There are many different types, and currently some countries register only primary malignant brain tumours but do not record benign or low-grade brain tumours.

This discrepancy promoted a UK-based patient organisation, Brain Tumour UK, to launch a 2009 campaign, "Register my tumour, recognise me", which sought to include the thousands of missing, unregistered brain tumour patients in the UK's official health statistics[1].

The importance of registries for all brain tumours is also noted in the Brain Tumour Patients' Charter of Rights: *"I have the right to ask that my brain tumour is properly registered in my country's cancer registration records, whether it is benign or malignant"*[2].

Also in 2009, the Council of the European Union announced its "Recommendation on an Action in the Field of Rare Diseases" whereby national plans and strategies for responding to rare diseases should be created in each member state by 2013. The importance of registries for rare diseases like brain tumours was recognised in the recommendation[3].

If we are to understand this fearsome cancer we need to establish methods for pooling consistent data that has been collected by local registries so that we can create an international collaborative brain tumour registry. A first step would be to link local registries and establish limited inter-operability. Over time, the move to internationally standardised datasets and consistent data collection could hopefully be achieved.

Real-World Patient Registries

"Real-world patient registries" – another type of databank but different from population- and hospital-based registries – can provide pragmatic answers to many important questions about a disease trajectory.

While there is currently no consistent definition of a "real-world patient registry", the term is generally used to refer to data which is dictated by patient experience, namely patient-reported outcomes. Thus, it is an observational attempt to collect information which is then analysed.

Of course, real-world patient registries must also satisfy the same stringent requirements that population- or hospital-based registries do in terms of accuracy, data protection, timeliness, accessibility, good leadership, and well-developed consent mechanisms.

Real-world patient registries can help determine the effectiveness of a therapy post-approval based on reported outcomes from a much larger, far more diverse patient population than is normally available through traditional clinical trials. A brain tumour clinical trial, for example, may only test a therapy on fewer than a thousand people. But a real-world patient registry might keep track of the first 5000 or 10,000 people using the therapy post-authorisation and in everyday life.

Real-world patient registries can also be used for surveillance, flagging up unexpected adverse events in the wider population. They can highlight inequities and inefficiencies in healthcare systems, planning, and resource allocation.

Real-world patient registries can help monitor adherence to guidelines and enhance the quality of patient care because these types of registries track – on a self-reported patient-by-patient basis – exactly how the patient feels about his medical and supportive care.

These registries can also highlight the use of combinations of standard therapies and complementary therapies, as well as record time to diagnosis (thus addressing issues of late diagnosis) and other factors.

Real-world patient registries might even allow us to look at new ways of using existing therapies for new indications and in new combinations.

An Example

One example of a real-world patient registry spanning all brain tumours is the internet-based facility operated by the Musella Foundation in the United States.

Established in 1999, this is a self-reporting registry of brain tumour patients around the world (but mostly from the US) which records and tracks treatments and outcomes of individuals (currently > 800 people) who register online and update their records monthly.

Patients submit pathology and MRI reports; data is anonymised and a consent form is required. Participants may view online anonymised data from other patients and an interactive map reveals where patients are located and geographic trends in treatment[4].

The success of real-world patient registries relies heavily on people religiously submitting their data and on the efficiencies offered by new technology. On the downside, patients who are elderly or who have no easy access to technological wizardry (as in many of the less developed countries) may not be able to actively participate in a real-world patient registry because of its reliance on high tech.

Four centuries have passed since John Graunt chronicled the devastation of bubonic plague in his scientific pamphlet known popularly and simply as "Observations"[5]. Graunt, were he alive today, might be surprised at some of the current innovative ways that registry data is being collected and used.

For those whose lives have been touched by a brain tumour, real-world patient registries can play a vital role in patient empowerment and involvement in their own healthcare as well as hopefully achieving improved outcomes.

Notes:

1. Brain Tumour UK. http://www.braintumouruk.org.uk/sites/default/files/register_tumours_web_ed.pdf [accessed March 10, 2012].
2. International Brain Tumour Alliance (IBTA). http://www.theibta.org/RightsCharter.htm [accessed March 10, 2012].
3. The Council of the European Union. Council Recommendation of 8 June 2009 on an action in the field of rare diseases. http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF [accessed March 11, 2012].
4. The Musella Foundation. www.virtualtrials.com [accessed March 11, 2012].
5. Graunt J. Observations. http://www.actuaries.org.uk/research-and-resources/documents/john-graunts-observations-foreword-bernard-benjamin [accessed March 9, 2012].

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