Case Study – Patient Advocate Stories

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Patient Advocate, use MY data

It could be a game of scrabble: acute leukaemia, aspergillosis, bronchiectasis, dyspnoea, pseudomonas aeruginosa, m-kansasii, hearing loss, meibomitis, osteo-arthritis. These are some of my past and current medical conditions.

A lot of data is associated with hospitalisations, lengthy treatments and tests of all kinds. A mountain of data which I have never expected care settings to be able to share, let alone manage effectively.

It has always been my understanding that in order to cope with the burden of disease, I had to ensure that all those involved in my care had comprehensive, up-to-date and full access to all those aspects of my medical diagnoses, treatments and outcomes. Why risk a health care professional working under pressure [dire conditions across secondary and primary care existed well before the pandemic] and making an inappropriate decision because s/he did not easily access my medical history and key touch points?

So yes, sharing my data started from a very ‘selfish’ basis: let me provide you with all that you need to be in a position to make the best treatment and/or referral decision. But a ten-month long hospitalisation illustrated the benefits of international clinical research and data sharing, as I was the recipient of all those millions of people across the globe who had contributed their data to the advancement of treatment protocols for blood cancers.

Whether for direct care, global health clinical and services research or population management planning sharing and contributing one’s data is [should be] a basic citizen engagement and social commitment.

How to share? There is more to data usage and value than the context-limited GP held records. Given the high proportion of older patients developing long term conditions and being affected by multi-morbidities, a very wide plethora of health and social care professionals are increasingly conducting assessments, providing various types of prescriptions and recommendations. Equally, with increasingly transient populations, the number of care settings and care providers is growing exponentially.

Once there is a will to share, there is a need for a suitable, flexible and portable tool. To date, the anywhere, anytime Personal Health Record [as developing in the UK with Connecting Nottinghamshire, Care Information Exchange in London, and other regions] is the most versatile and safe tool to allow me to share my data with literally anyone, anywhere, anytime, as well as forming a constant monitoring process during bouts of illness or specific and time-controlled study projects.

We are building an online library, where the patient voice is heard direct, talking about the rewards of using their data

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"The only source of data is the patient"

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