

Case Study - Patient Advocate Stories

David Snelson

Patient advocate, use MY data

In common with a number of older people I have three chronic conditions requiring monitoring and, in some cases, treatment.



The majority of my blood tests are done by my GP and me to monitor trends. I use my GP Practice's Patient Access system but have also signed up to the NHS data app which shows much the same information. But two of the three consultants I see regularly are at the Royal Surrey Hospital (RSH), Guildford. They do not see my blood test data on their computer system. Now when I attend their clinics, I hand them my iPad logged into Patient Access. They can then see the test results and the graphical trend analysis available in Patient Access (which is not available in the equivalent NHS App).

Patient support groups use the phrase 'Smart Patients get Smart Care' and I make sure I am one of those - but I do feel for those who don't know how to utilise the system.

Another flaw in this workaround system that I employ, is that not every data point is in Patient Access. So, I often also refer to my own Excel spreadsheet which contains every data point I know of. But I hold also data points from four sources over twelve years; East Surrey Hospital (via Gatwick Spire), Swan Surgery, QA Hospital and Centre Hospitalier Universitaire de Grenoble (though I recognise that merging the latter data set would be taking the pursuit of excellence too far!)

This is an issue that has bugged me for a while and I'm pleased to discover that the NHS is working on the problem. However, the weakness, seen from a patient perspective, is that these are very geographically limited and don't cater for the realities of a patient life which, in my case at least, result in test results data from a variety of sources outside Hampshire.

The only solution to this problem (setting aside the foreign data) is for the NHS to adopt an integrated nationwide approach. Through my membership of use MY data I hope to do my bit to make this happen.



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

**<http://www.usemydata.org/stories5.shtml>
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“The only source of data is the patient”

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