Case Study – Patient Advocate Stories

Barrie Leyshon

Patient Advocate, use MY data

Without data, I know that we'd still be living in the dark ages.

I believe it's up to each and every one of us to realise that and to be willing to give data.

A lot of people are frightened of giving data; there's a lot of bad press about data, and that's a big problem we've got to combat.

I know far more about throat cancer than my GP does. I think it's up to the patients that have gone through the system – we are the ones that have to teach the GPs. GPs are ok about the technical medical side, but not so much about the long-term effects.

Is the patient voice heard enough so that we learn from patient's experience? To be honest, no. There are a lot of GPs and doctors who tend to hoard the data – they don't like giving it out. I know that my GP wasn't aware of what happened to data.

I was diagnosed with throat cancer 11 years ago. I knew nothing about medical data then. It's very difficult for me to find out even now, how many patients get head and neck cancer. I've been on all sorts of sites to find out and nobody has been able to tell me. One nurse thinks it is between about nine and ten thousand in total, but there is no central register of how many laryngectomies there are.

What things do you think should be happening with patient data? As a double cancer patient, throat cancer and colon cancer, I take a number of medications. When I went for the colon cancer, the nurses weren't aware of what medication I needed to have with me or when I take it.

They had very little data about me. If I was to be admitted as an emergency, they wouldn't have any data with which to treat me. As an example, if they have to put a mask on me, they can't fit it over my mouth and nose – it has to go over my throat.

When I went I for my colon operation a few years ago, there was a plastic package under my bed. When I asked what it was I was told it was "for the laryngectomees". I opened it up and had two questions:

1) what did the nurses know about it – nothing, &
2) it wasn't about laryngectomees – it was about head and neck cancer, which covers a lot.

No nurse or doctor in that ward, that may be experts on colon cancers, none of them were aware of what problems I could have [as a former head and neck cancer patient]. For instance, it meant that they could not put a mask over my face for the anesthetic.

Do we gather enough good quality data about patient experience, and do we use it enough? In some cases, it's too general for it to be of any use, but that's my opinion. As a patient, I think most cancer patients tend to think in specifics.

I want people to realise how important it is to be able to use our data, and not be frightened, because there's more general data out on the web about each one of us, than the "medical stuff". People don't realise that.

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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