

Case Study - Patient Advocate Stories

Margaret Grayson **Patient Advocate, use MY data**



Data - that small word with massive importance.

I share data on a personal level.

You see I am a statistic, but behind my Northern Ireland health & social care number, I am Margaret Grayson - a person.

Talking to clinicians and researchers I want to acknowledge your part in audit, in expert analysis, monitoring patterns of patient care that drives improvement in that care, that asks the right research questions that effects outcomes.

Asking the right questions of the data available for me has meant finding the right surgery technique for my mastectomy, the right combination of drugs for my chemotherapy, the dose fractions and technique in radiotherapy, the right aromatase inhibitor that I took this morning and have done for the last eleven years and some answers on the long-term effects of living with cancer, lymphoedema for example.

I believe that as a patient I have a responsibility to the rest of society in permitting my data to be used, but I also have the right to ask clinicians and researchers, or perhaps rather demand, that my data is used, remove the barriers, use for purposes of audit, comparison, research, ask questions and find answers for me and all the other patients like me.

I want that data to be used in ethical research.

I want you to be careful with data Margaret, but I don't want data Margaret to be looked in a box, padlocked, probably triple padlocked, as access to data Margaret is becoming more & more difficult.

I know the legislators among you will say they are protecting real Margaret, but can I ask you are you protecting Margaret or yourself.



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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