Case Study – Patient Advocate Stories

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Patient Advocate, use MY data

Data that goes out from cancer registries doesn't really have identifiable data on – it doesn't have your name, address, or that sort of thing on and therefore I have absolutely no qualms for it being used.

There is a certain part of the population that you will never influence. They will automatically say no – I don't want to belong to this club, as it were. But I think if it is discussed, explained, there is somebody else that perhaps has a bit more knowledge that they can talk to.

I did hear that somebody actually spoke to the Director and came away saying "*You can have my data, no problem, because this is what you do with it and it is for the public's benefit*".

Talk to people about it - somebody who knows!

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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