

Case Study – Patient Advocate Stories

Margaret Ticehurst
Patient advocate, use MY data



My experience of cancer was obviously made a lot better by the fact thousands and thousands of people have given willingly of their data so that all the research could be done. So, instead of having radical mastectomies as was happening a hundred years ago, my cancer was dealt with relatively painlessly.

What's so special about my data?! I think that everybody should give of it willingly. It's a bit like saying after our death our organs can't be used... of course they can, and they should be. So why are we so special that our data has to be put in a safe and never looked at?



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.”