

Case Study- Patient Advocate Stories

Margaret Johnson
Patient advocate, use MY data



I'm absolutely passionate that our information should be used. My son died from leukaemia and without the information about him and his cancer we're not going to make any progress at all.

It is absolutely vital that every piece of information is used and in his case of course it was childhood cancer and without the numbers, what are we going to do?

It's just that people don't understand what they are signing (when opting out of data being used). We need to get this message across to people because it's so so important.



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."