

Case Study – Patient Advocate Stories



Andy Smith
Patient advocate, use MY data

Because I did work for the National Cancer Registration Service I was able to see that data that I generated. And not only that, I was also able to see how that data was being used for research projects and was being made available to researchers who were actually using my data to improve patient care.

Having seen how my data is used that's why I'm involved with use MY data, because I actually want my data to be used by more researchers. I want more of my data to be captured, particularly my outcomes data, so that my data can be used by researchers to actually figure out why have I recovered, how have I recovered, are there any data that I have generated in my pathway that can help others who are going to come along behind me.



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>
getinvolved@usemydata.org.uk

“The only source of data is the patient.”