

Case Study – Patient Advocate Stories



Nicole Larkin

Patient advocate, use MY data

I think that the process of sharing the data just makes everything better.

I've just recently had my five year check-up. It was really nice that they spent the time to go back to the data from day one - to show me how everything had progressed, what had changed, and where I had improved. It was disappointing that there was a period when I had private treatment and they had no idea what had gone on at that stage. But that was good to see that there was a lot of information together in one place, and they could actually take me from the journey from day one to now.

A lot of people worry about data going to companies that are going to use it for making drugs, but that's good because they are making drugs to improve treatment.



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.”