

Case Study - Patient Advocate Stories

Christine Allmark Patient Advocate, use MY data

Data is important to research because it is the experience of the patient's pathway, the patient's journey, what happens to them during their diagnosis, treatment and post treatment and their subsequent progress through life for however long or short that may be.



This information is vital to researchers because they will know what the real experience is of the patients. So, this information should be known to the researchers and all those involved, in order to properly shape treatments and policy which is accurate and matches the experience of the patients on the actual side of the treatment pathway itself.

One problem is that the primary care may use one data system, secondary care may use another. That incompatibility can be a cause of concern. So, there is no direct communication sometimes between the GP and the patient's specialist in the hospital. So, if this was a seamless transfer process, the patient's journey through care from the initial diagnosis, treatment and subsequently, would be much smoother.



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"