

Case Study – Patient Advocate Stories

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Patient advocate, use MY data



There's a lot of misinformation out there. But what's important is that we continue to develop research and we continue to develop treatments for patients, and the only way to do that is through research and through gaining access to appropriate data that is actually going to change policies, change operational systems, and change treatment for patients.

There's a big need for the media, for different outlets, to publish information responsibly and not to generalise and not to go overboard on issues that actually are misinformation for people.

There are always potential problems that can come from collecting data and privacy, but there are so many measures in place to prevent that from happening. So, I think you have to trust the people that have the data; they know what they're doing and if you can (and we should) then I think a lot of good can come from that.



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.”