

Case Study - Patient Advocate Stories

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Patient Advocate, use MY data



I'm afraid I have a very biased opinion on the issues of data and data sharing for health research.

I'm a great fan of things like having the data stored in some sort of central repository or unified IT system, and then having the gatekeeper access methods to control it.

If that is legitimate, ethically approved medical research then I see absolutely no problem with that happening, and it is how we have made all the advances that we've made so far.



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”

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