

Case Study - Patient Advocate Stories

Tom Haswell* Patient Advocate, use MY data

I'm quite happy for my data to be used in any way they wish, whether it's identifiable or not.



More data could have been taken from me, more tissue samples, blood samples, whatever tests they may have wanted to do, to find out if there was something there that made that treatment so effective when it was not expected to be as effective as it was.

I am quite happy and would have been all these years, to volunteer myself if it had been asked, to give information and for it to be generally published. I'm not particular about it being hidden. Like I say my journey through cancer is well documented and well known, so I have no qualms about it being identifiable or unidentifiable, I have no problems with that at all.

* It is with great sadness that we update this case study, with the information that Tom died suddenly at home, on 27 November 2020. Tom was a founder Member of use MY data and instrumental in deciding our direction/strategy, including the need for a Patient Data Citation.

Tom brought much enthusiasm, and always a smile, to his work campaigning for patient data to be used to save lives and improve outcomes for others. We would like to acknowledge Tom's total dedication to making a difference to the next generation of patients. We will greatly miss Tom's presence and involvement.



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"