Dame Fiona Caldicott - Reflections from use MY data

It was with great sadness that we heard about the passing of Dame Fiona Caldicott. We send our sincerest condolences to her family, friends and colleagues.

Dame Fiona has left a huge legacy and we would like to highlight the impact of her work on use MY data.

use MY data is a patient-led movement, focused on promoting the use of patient data for societal benefit, therefore engagement with the National Data Guardian and team has been a priority for us. As a result, since the foundation of use MY data, we have had a close relationship with Dame Fiona.

Dame Fiona’s work advocating “to ensure no surprises for patients and service users, so they can have clear expectations about how and why their confidential information is used, and what choices they have about this” has been important and significant for our work.

Our engagement with Dame Fiona has included attending interactive workshops, contributing to consultations, sharing a speaking platform at a national conference, recently (and perhaps most notably) our work advocating for the National Data Guardian’s panel to include patient voices. As a result, Dame Fiona decided to include two patient/public representatives on her panel, with use MY data being offered a place for the first patient to be appointed, an opportunity which we took with appreciation.

At all times in our engagement, Dame Fiona was patient, courteous and receptive to ideas and views from the patient community.

Dame Fiona’s death leaves such a huge void and we will greatly miss her presence. We do hope that knowledge of the importance of Dame Fiona’s work and the positive impact on patients and the NHS will be of some comfort to her family, friends and colleagues.

Alison Stone
Coordinator, use MY data
“The sentiments [in the tribute written by John Carvel] reflect my own experiences collaborating with her for use MY data and also more recently on the accessible information project.

I found her kind, open and respectful, unconditionally inviting and encouraging our patient voice.”

Paul Charlton,  
Member, use MY data

Currently, I am looking at artificial intelligence and taking part in a couple of research projects providing input from a patient and public viewpoint. This is very new to me and there is much to learn. Dame Fiona’s report, ‘Review of Data Security, Consent, and Opt-Outs’ published in 2016, is a valuable reference work, as it enables me to keep grounded and better assess the benefits and value of AI systems in tandem with the data they use.

So her work goes on, giving safety, security, and confidence in use of their data to the ordinary person. Quite an achievement.

Jacqui Gath  
Member, use MY data

I met Dame Fiona at an event, which I attended as a use MY data Member. I spoke with Dame Fiona to ask for help with a concern and she took my phone number. I thought that was the end of the conversation, but sometime later Dame Fiona called me to follow-up. Although Dame Fiona was unable to help directly with my concern, I appreciated that she did look into my request and followed up to let me know.

Clive King  
Member, use MY data

I knew Dame Fiona from my work as Chair of IGARD (Independent Group Advising on the Release of Data) and as part of the work that I do for use MY data. She was always helpful, supportive and most importantly she listened to what people thought, whether they were a member of the public, a patient or senior civil servant, treating each equally.

The work that Fiona has done through the years has fundamentally changed the way that the NHS manages data about its patients and, most importantly, uses that information to drive research into better care and treatments for people. As well as her pioneering and inspirational work to develop and embed the Caldicott principles for safeguarding patient data, Fiona always recognised that there was an equal need to be able to use the data to save lives. For this, and many other reasons, we all owe her a great debt. Her legacy will live on and her work will undoubtedly save more lives in future.

My heartfelt sympathy goes out to all Fiona’s family and friends.

Chris Carrigan  
Expert Data Adviser, use MY data