

Review of Informed Choice for Cancer Registration by Cancer Research UK and Macmillan Cancer Support

Response from use MY data

In the context of the National Data Guardian's overarching review of the management of health and social care data, Cancer Research UK and Macmillan Cancer Support offered to review how people with cancer in England can be better informed about how their data is used in cancer registration.

use MY data members welcome the publication of the review, and relay their thanks to the teams at both Cancer Research UK and Macmillan Cancer Support for their hard work on this complex subject.

use MY data welcomes many of the report's recommendations about raising awareness of the importance of registration and data. We strongly agree with the principle that people should be informed about cancer registration, including how the collected data is used and the benefits of this use.

In view of cancer being a disease that will strike half the population, we would encourage further consultation to include looking at the option of cancer as a notifiable disease, and thus making registration mandatory. This would not exclude or preclude many of the recommendations in this report. use MY data therefore encourages the review team to consider this urgently and would be happy to contribute to this discussion.

Some members reflected that the questions that were asked during the review, particularly during the online survey, had the potential to skew responses and felt that more needed to be heard about the benefits of using patient data.

use MY data supports the safe, transparent and optimal use of data for the benefit of patients, both current and future.

***"The type of treatment that I had depended so much on the data of patients
who went before me."***

"If nothing else comes out of this diagnosis let it be to save some-one's life."