Personalised Medicine for All: Our Patient and Research Data Statement

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Process of co-creation: crafting a data use promise with our patients

The words crafted below represent a direct collaboration between researchers and patients in co-creating a new patient data promise for new Christie data-related research. It details the approach to real world data combined with the GM Integrated Care Record for the benefit of cancer patients in Manchester by optimising their care and offering new treatments based on the research-driven insights.

The data promise was created through work with leads of the Digital Cancer Centre and real-world evidence research teams (Professors Corinne Faivre-Finn Niels Peek, Robert Bristow alongside Dr Sinéad Savage of the MCRC strategic team).

It was then reviewed by the Christie IT team and Caldicott Guardian committee, before finally being presented to a patient forum on 25.08.2021 for feedback, editing and final drafting.

Below is the patient data promise to all cancer patients that represents the ongoing collaboration between researchers and patients.

A partnership founded by

Our Patient and Research Data Statement

The Manchester Cancer Research Centre is a collaboration between the University of Manchester, The Christie NHS Foundation Trust, and Cancer Research UK. Our ambition at the Manchester Cancer Research Centre is to build on the historical successes of data science in Manchester to use patient data in a safe and secure way to look at new and innovative ways to improve patient outcomes. This will be accomplished through best practice related to the patients in our research programmes, with strict security measures applied for all our studies in order to protect patient's confidentiality.

We believe we can create a world leading approach to transforming cancer diagnosis and treatment for all patients, by using a holistic **"Cancer Precision Medicine for All"** approach; rather than just focussing on a few selected groups of patients. Patients are critical collaborators needed to succeed in this vision to achieve world-leading research and cancer care for both themselves and for the future cancer patients.

What is Cancer Patient Data?

Cancer patient data is information collected about individual patients throughout their medical journey. It can be collected by healthcare professionals, such as doctors, nurses, or physiotherapists.

It covers a range of information, including age, gender, ethnicity, medication, family history, diagnosis, treatment details and results from blood tests or imaging scans. It can also be collected by the patients themselves, such as using the web-based questionnaire "My Christie, My Health". This system uploads the symptoms, quality of life and experience of patients directly to central and secure data storage at the Christie for use by both clinicians and patients to make clinical decisions together.

Some patient data that is not directly related to cancer may be stored outside the Christie NHS Foundation Trust, such as in Primary Care records from your GPs or at different Trusts around Manchester. It is possible to incorporate such data to add valuable information to the analyses of patient outcomes.

Why do we collect cancer patient data?

The primary reason cancer patient data is collected is to continue to improve individual cancer care, including the diagnosis, treatment and monitoring of cancer. We believe that understanding the whole patient is important for our clinical programmes to ensure best and individualised cancer care is provided to each and every one of our patients.

Cancer patient data can be collected when a patient is on a clinical trial. But clinical trials, by their design, do not allow all cancer patients to take part. This may be due to the patient's disease characteristics or patients having multiple other diseases that could affect the trial study. So with data delivered through clinical trials, we only have the opportunity to study a small and selected group of patients, i.e. typically younger and fitter patients.

As a complementary approach, through approved research programmes, we can analyse cancer patient data from all patients during every day clinical practice (i.e. in the "Real World"). This is also called Real World Data. We can use this to answer research questions to benefit all patients. Through the [Manchester Cancer Research Centre](), we aim to take the renowned excellent cancer care provision in the North West to the next level, with clinicians from The Christie NHS Foundation Trust collaborating with scientists from the University of Manchester and other NHS Trusts to develop future and improved care for patients at the local and national level.

What do we want to use cancer patient data for?

While an individual's real world data can be used to tell us about their specific cancer journey, the pooling and studying of multiple patients' data together can

be used to generate broader insights, which are useful to improve the care of cancer patients in general.

In addition to improving individual care, studying the relationships between different types of patient data can enable clinicians and scientists to work together with patients and develop best treatment(s) for the individual patient. Very few cancer centres in the world use **this holistic approach to the study of patient data** to change treatment.

Combining data from different sources, such as data on other diseases (called co-morbidities), other medications, early and late effects of cancer treatments, or family history and genetic make-up, will allow us to reach the goal of improving the outcome of cancer patients together.

How is cancer patient data protected?

Both [The Christie NHS Foundation Trust](#) and the [University of Manchester](#) comply with all NHS and legal requirements such as standards set out in the UK Data Protection Act when processing patient data, further details on their websites.

Your patient data will be used to support your direct care. You can decide to stop being part of an MCRC data programme at any time via the [NHS-wide system](#), without giving a reason. This will not impact data being used to support your direct care. As each programme undergoes approval, your status is verified before your data is used for a project.

At times, we may collaborate with selected commercial partners as part of approved research programmes. It sometimes has an added value that we share some specific data with commercial partners. This will ensure our research creates the maximum benefit to current and future patients. These partners will go through the same approvals as our academic partners to ensure the correct security measures are in place, and to ensure the research is in the patient and public's best interests. Before any external partners are allowed

access to data through a [secure data environment](), it will be anonymised or pseudonymised to protect patient identity.

Conclusion

The Manchester Cancer Research Centre wants to use patient data in a safe and secure way to look at new and innovative ways to improve patient outcomes. It's important that we are using data from all patients, rather than just focussing on selected groups of patients.

If you are happy with the information in this document, you do not need to take any further steps.

If you would like to learn more about patient data and how it can be used, the organisation [Understanding Patient Data]() has some excellent resources.

If you would like to opt out of having your patient data used for research purposes, you can do so via the [NHS-wide system.]()

Glossary

Anonymised

Any information that would make you identifiable has been removed from the data.

Pseudonymised

Your identifiable information has been replaced with an alternative identifier, such as a random number, that is not related to your information. Someone will hold a key to re-identify you, but without this key, the data is anonymous. This is sometimes required, for example if data from two different hospitals is being brought together, the data needs to be correctly matched.

Real World Data

The cancer patient data collected for all patients as part of their routine care, as opposed to clinical trial data, which generally only include selected groups of patients.