

Information & Guidance

for

use MY data

Members & Associate Members

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Purpose of this document

This document is intended to provide information and guidance for [use MY data's](#) Members and Associate Members. It contains the principles which are at the heart of [use MY data](#), details of the position of [use MY data](#) in areas of data policy and has general guidelines.

Structure of [use MY data](#)

Our Membership comprises:

- **Members** - patient advocates who are either patients, relatives or carers
- **Associate Members** - clinicians, researchers, charity workers, academics, public and commercial sector workers, who are united by their support for our work.

We are **patient-led** - only our Members make the decisions about the work of [use MY data](#).

Our **Executive Group**, comprising a small number of [use MY data](#) Members, guides the Secretariat on all aspects of [use MY data's](#) work, on behalf of the Members. Information about the Executive Group, including profiles and meeting notes are published on our website [here](#).

Our **Secretariat** takes forward the work of [use MY data](#), on behalf of the Members. The Secretariat comprises a small team and these are the only funded roles within [use MY data](#).

Status and funders

[use MY data](#) is the only independent UK movement of patients, relatives and carers focussed on the use of patient data to save lives and improve outcomes. Our independence enables our Membership to speak freely.

We are extremely grateful to present and past funders. We have never been influenced or steered by our funders - they have all given us free reign to use the funding as we see fit, through non-restricted grants. We have funding for the Secretariat roles and to support our projects and events, including covering the costs of Members' attendance.

Funding information is published on our website - [Funding page](#).

We are registered as a company limited by guarantee in England and Wales (14425977).

Secretariat support for [use MY data](#) Members

Members can contact the Secretariat for help about patient data matters - enquiries, requests for information and support are welcomed. All Members of the Secretariat will strive to help. Please make initial contact via alison@usemydata.org.uk.

The Secretariat hosts regular Members' **Education Sessions**. These are on a specific patient data topic, chosen by Members. The format is a short talk, followed by lots of time for questions, answers and discussion. Numbers are limited to ensure the sessions are interactive, with places prioritised for Members and Associate Members welcome to attend if space permits. The library of past recordings are published on our website [here](#).

The core purpose of [use MY data](#)

[use MY data](#) is the only UK independent movement of patients, relatives and carers focussed on the use of patient data. Our independence enables our Membership to **speak freely**. We have freedom to **set our own agenda** and work programme. We have a **clear set of data principles** which we encourage others to follow. We have a principle of **positive engagement** with all.

Our vision

- Every patient in the UK willingly giving their data to support medical research and their own care

Our mission

- To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data for research and improving healthcare

Our aims

- To promote the responsible and accountable use of data to improve health and health research, and to help to remove barriers preventing this
- To highlight the benefits of using patient data for our individual health and for our communities
- To help to ensure patient data is used to create and support an NHS that is better for all
- To advocate for robust and transparent safeguarding of data, which is clearly communicated to patients and the public
- To provide balance as a trusted voice in patient data, highlighting aspirations and concerns around the use of patient data
- To act as a critical friend and sounding board to organisations who want to collect, store and use patient data to benefit society
- To build knowledge and expertise for patients, families and carers to help them play a more active and informed role in discussions and decisions about patient data

"use MY data to help others and help me"

What [use MY data](#) does not do

- We do not hold patient data
 - We do not endorse specific organisations
 - We do not support specific bids or proposals
 - We do not stray outside the patient data field
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The position of [use MY data](#) on patient data matters

Members and Associate Members are encouraged to promote [use MY data](#) and highlight our work wherever possible. When taking part in either informal or formal conversations and meetings about patient data, Members and Associate Members are encouraged to identify themselves as being part of [use MY data](#). This helps to raise [use MY data's](#) profile and opens the way for interested parties to engage with us.

As Members and Associate Members of [use MY data](#) you may be asked for the position/view of [use MY data](#) on patient data issues and matters. This might be in an informal chat, at a formal meeting, when speaking on behalf of [use MY data](#) at an event or representing [use MY data](#) on a group or project.

We have position statements and principles, written by Members. These are published on our website - [Position Statements](#). In addition to these and our core vision, mission and aims, the following guidance should help to address enquiries about our position.

- **Transparency is essential**
Knowing that intentions / planned activities / appropriate governance and accountability are in place, at the earliest stage, is critical to confidence in the use of patient data. Please see the fuller section on transparency below.
- **Patient involvement at the earliest stage**
There should be patient involvement at the earliest stage of projects / initiatives to do with patient data. Co-development is ideal.
- **Good communications**
These are essential for any patient data project - good projects will fail with bad communications.
- **All Members have a voice**
[use MY data](#) works to ensure that patient voices on the use of patient data are heard. We lobby for the patient voice to be included in all discussions about patient data. If you find details of patient data events without patients on the agenda, please let the Secretariat know. The Secretariat will then, via a strategy of positive engagement, contact the organisation and work to have the patient voice included.

As part of the Secretariat's work, striving to ensure that the voices of Members are heard, the Secretariat coordinates [use MY data](#) responses to national consultations on patient data, directly incorporating the views of Members. All responses are a direct collation of Members' views and represent all of the angles which have been raised. Other than Members' words and supporting information already agreed within [use MY data's](#) principles and position statements, nothing will be added.

- **Members have different perspectives on the use of their data**
[use MY data](#) Members have different perspectives on the use of patient data. Some Members wish for all of their data to be used for research and do not mind if their identifiable data is revealed in the course of this - the benefits of their data being used outweighs the risks. Some Members are more protective and may actually have decided to opt out (either in the past or currently) of their data being used for research/planning. While there are diverse views, our Members are united in wanting data to be used to improve outcomes and save lives and for the patient voice to be heard in relation to this.

As a movement, we know people bring different views about their willingness to share their patient data. The views of people's willingness to share, or not share, must be respected. Our role is to ensure that people are furnished with the facts. Our guiding principle must be that, once someone has the information available on which they can make an informed decision, the actual decision is personal to them and should be respected.

- **Recognising the use of patient data**

The patient data citation was conceived and developed by Members of [use MY data](#), as one of the earliest actions - 'This work uses data provided by patients and collected by the NHS as part of their care and support'. It has been widely adopted by data and research organisations and recommended for adoption by the major research funders in the UK. We would encourage everyone who uses patient data to adopt and promote the citation.

We worked on the project **The Issue with Tissue**, with the Medicines Discovery Catapult and Incisive Health and, as part of this, [use MY data](#) developed a patient tissue citation - 'This research was possible only because patients have donated their tissue'.

- **Improving access to data for research**

Obtaining patient data for use in clinical research is expensive, time-consuming and stymied by a conservative, risk-aware culture among the controllers/guardians of the data. A culture change is needed, to enable researchers to access patient data, in a timelier and simpler way.

- **Patient data should be used to save lives and improve outcomes**

The use of patient data - safely, openly and transparently - is our key focus. We also strive to highlight areas where patient data is not being used but should be - when data is not used, lives that could be saved are lost.

Transparency - [use MY data's](#) guiding principles

Transparency should underpin everything and is essential if the trust and support of patients and the public is to be maintained and developed.

Transparency means operating in such a way that it is easy for others to see what actions are performed. In a nutshell - **Say what you do, do what you say.**

Our guiding principles for transparency:

- **Accessible** - easy access to information
 - **Understandable** - the right language for the audience
 - **Relevant** - addresses audience concerns
 - **Useable** - in a form that meets the audience's need
 - **Assessable** - information is checkable/provides sufficient detail, not just bland PR
 - **Being as pro-active with 'bad news' as with 'good news'**
 - **Being timely with communication.**
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What is the difference between consent and opt-out?

Put simply, consent means giving very specific permission for something to happen with your data. If you are on a clinical trial, everything is done using this type of explicit consent from you. The consent you give basically says “the researcher can use my data for this, and nothing more”.

However, lots of data is routinely collected about your health and care - when you go to your GP, attend appointments, have tests, a diagnosis or treatment. This is often called ‘real world data’ and is collected as part of treating you. If researchers want to use real world data for other purposes (not for your care), they need to go through other legal gateways (not consent), to gain access.

In England, patients can request a National Data Opt-out (commonly called the ‘opt-out’). The opt-out stops the disclosure of your confidential patient information for purposes beyond your direct care across the health and care system in England, unless an exemption has been granted.

The exemptions to which the opt-out will not be applied are listed [here](#).

For research and planning where anonymised data is used (so that you cannot be directly identified), the opt-out does not apply.

All health and adult social care organisations must, by law, share information with each other about patients they are caring for directly, to improve the care provided. Consent is not needed for this.

Resources & supporting materials

We have a range of materials that you can use to help promote [use MY data](#).

Key items:

- [Patient Data Citation](#)
 - [Position Statements & Calls to Action](#)
 - [Patient Advocate case studies](#)
 - [Patient Advocate Video Library](#)
 - [use MY data event outputs](#)
 - [Consultation responses](#).
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Appendix

DONATE YOUR DATA

PLEASE HELP US TO TURN YOUR DATA INTO THE BEST OUTCOMES FOR FUTURE CANCER PATIENTS

The history and evolution of use MY data

Beginnings - Donate Your Data

use MY data began on 09 June 2015 at the National Cancer Intelligence Network conference, in Belfast.

If you'd like to register your support for the idea of cancer patients being able to donate their data for analysis and ethically approved research, then please sign up below. You can also express your interest in being part of the working group that helps to develop the idea. We will use your contact details to keep you informed about progress and won't share these with anyone else.

If you would like time to consider this before signing up, or if you have further questions please email donateyourdata@ncin.org.uk

In response to concerns about how the proposed Care.data programme was causing cancer research to stop, patients, carers and relatives gathered together, over a lunch time session. The session was jointly hosted by Cancer52, Cancer Research UK and the National Cancer Intelligence Network.

Its focus was on how current cancer patients could help turn their data into the best outcomes for future cancer patients. 'Donate your data' was proposed - an organisation where patients would willingly give their data for this purpose.

The patients attending the session showed unanimous support for the concept of donating their data. Some specific comments & questions:

- "Good examples of proper use and benefit" needed - to help the public understand
- Need information on the impact of not doing research, as well as knowing impact of what has been done
- "Patients don't realise their data is not being used" and "assume their data is being used in right way"
- The general public don't understand the value of the data, in the way that cancer patients do. Need the public to understand the bigger picture and how they could be affected in the future.
- Currently information is not written by patients - this is needed.

Next stage - Donate Your Data changes to use MY data

A follow-up meeting was arranged, which took place in London on 29 July 2015. This comprised delegates from the 09 June session, along with representatives from the Brain Tumour Charity, Cancer52, Cancer Research UK, Macmillan Cancer Support and the National Cancer Intelligence Network,

Key themes and results from the workshop were reviewed:

- Patients should be in charge of their data, because their data is a gift
- Transparency is essential
- Patients trust patients (not the Government)
- This is not about opt-in/out - it is about data usage

A key message emerged: **Every day lost is another person dying.**

Donate Your Data		
Agenda		
Title of meeting	Donate Your Data - Working Group meeting	
Date	29 July, 2015	
Time	11:15 to 15:00	
Venue	Room 232D (Boardroom), 2 nd Floor, Skipton House 80 London Road, SE1 6LH	
Timings		
1115-1125	1) Welcome & introductions	Chris
1125-1135	2) Topical data issues	All
1135-1150	3) Aims and methods of the project <ul style="list-style-type: none">• Overview of the aims and methods• Feedback from the working group on whether the aims and methods are acceptable	Michael
1150-1235	4) Areas to address – part 1 <ul style="list-style-type: none">• Recruitment• Involvement in data release• Communications• Advocacy	Group work
1235-1315	Lunch	
1315-1400	5) Areas to address – part 2 <ul style="list-style-type: none">• Subgroup feedback & discussion	All
1400-1430	6) Proposed meeting & events <ul style="list-style-type: none">• Data workshop – 29 September• NCR1 Cancer Conference session – 01 to 04 November• Britain Against Cancer session – 08 December	Allison
1430-1500	7) Summary of the meeting, with closing questions and remarks	Chris

The Working Group discussed practical ways forward. Most felt that the name 'Donate Your Data' was not accurate - the data of cancer patients is taken, rather than donated - and the focus should therefore be on how their data would/could be used. Further work, post-meeting led to the name change to [use MY data](#).

Some of the key decisions and actions that emerged from the meeting were:

- Host a public workshop on patient data issues in the Autumn of 2015
- Encourage the practice of publications stating that the work was only possible because of the use of patient data - this led to the Patient Data Citation
- To have a UK focus
- Provide a set of examples of 'what data does', highlighting where uses of data have changed practice
- Not have a hierarchy or corporate structure.



Evolving as an organisation

[use MY data](#) began as movement for cancer patients, relatives and carers. In the early stages of the movement, Members felt that patients, relatives and carers from all disease areas/health conditions should be included. Our remit was adjusted accordingly.

[use MY data](#) has evolved through a rolling programme of engagement and communications. We host patient data workshops which are open to all, alongside a programme of campaigns, networking, and presence at national events. We engage with organisations who hold patient data and advise organisations about patient engagement.
