

Information & Guidance

for

use MY data

Associate Members

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## Purpose of this document

This document is intended to provide information and guidance for associate members of [use MY data](#).

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 general guidelines for associate members.

Appendices document the history and evolution of [use MY data](#) and information about funding.

The guidance has been written by [use MY data's](#) Secretariat and is updated regularly. If you have any queries about the content or require further information, please contact the Coordinator. We would welcome suggestions for additional content for the document.

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## 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. They are united by an interest in sharing healthcare data to improve patient outcomes under appropriate levels of consent, security and privacy.

Our **Advisory Group** advises the Secretariat on all aspects of [use MY data's](#) work. The Advisory Group comprises [use MY data](#) members and there are currently eight members on the Group. Members of the Advisory Group have joined via an open-call system, made to all Members.

Our **Secretariat** supports the work of [use MY data](#). The Secretariat comprises a Coordinator, Expert Data Adviser and Events & Website Manager. All of the Secretariat roles are funded on a part-time basis and these are the only funded roles within [use MY data](#).

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## Secretariat structure

At any time, [use MY data](#) associate members can contact the Secretariat with enquiries or requests for information:

- Alison Stone - Coordinator - [alison@usemydata.org.uk](mailto:alison@usemydata.org.uk)
  - Chris Carrigan - Expert Data Adviser - [chris@usemydata.org.uk](mailto:chris@usemydata.org.uk)
  - Emily Boldison - Events & Website Manager - [emily@usemydata.org.uk](mailto:emily@usemydata.org.uk)
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## The core purpose of use MY data

**use MY data** is the only independent movement of patients, relatives and carers concerned with 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
- For a small organisation we are very influential and **regularly punch above our weight**
- Our principle of **positive engagement** works well
- We are **UK focused**

## Vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

## Mission statement

**use MY data** is a movement of patients, carers and relatives.

**use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

**use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

**use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

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## 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

use MY data members are often asked for their position / perspective of use MY data on patient data issues and matters. This might be in an informal one to one chat or a formal meeting, when speaking on behalf of use MY data at an event or representing use MY data on a group or project.

In addition to our vision and mission statement, the following guidance should help to address enquiries about our position, both for our members and associate members.

- **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**  
We bring together different views on data usage and ensure that all members have a voice and are represented. Within our membership there are polarised views on the uses 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 the data being used outweigh the risks.

Some members are more protective and may actually have opted 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 patient data. The views of other people's willingness to share, or not share, must be respected. Our role is to ensure that people are furnished with the facts about data. 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.

We strive to ensure that all members have a voice and are represented. We aim to provide leadership and guidance but never coercion. For instance, we will coordinate views and thoughts from members to provide responses to national consultations. The response will be a direct collation of those views and will represent all angles which have been raised. Nothing will be added other than what our members have said, or what has already been agreed within the principles of use MY data.

- **Recognising the use of patient data**

The patient data citation was conceived and developed by the patients and carers in the [use MY data](#) movement. 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.

Similarly, following the success of the patient data citation, and following a joint project with the Medicines Discovery Catapult and Incisive Health, we have developed a patient tissue citation. We will be working with stakeholders to promote the citation and push for widespread adoption.

- **Improving access to data for research**

Obtaining patient data for use in meaningful clinical research is expensive, time-consuming and stymied by a conservative, risk-aware culture among the controllers/guardians of the data. With this in mind, everyone has a part to play. We need to push for a change in culture and understand the incentives which influence the data controllers

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

Data which is not used will not affect outcomes. The usage of data, safely, openly and transparently is our key focus.

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

### What is Transparency?

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 needs
- Assessable - is checkable/provides sufficient detail
- Being as pro-active with 'bad news' as with 'good news'
- Being timely with communication.

## Resources & supporting materials

We have a range of materials that you can use to help promote **use MY data**.

If you would like printed copies of the resources please contact the Coordinator, who will arrange for printing and postage to you.

## Website resources

Our website has a range of resources, which it can be useful to direct people to.

Some key items:

- Patient data citation information <http://www.usemydata.org/citation.shtml>
- Patient advocate case studies <http://www.usemydata.org/casestudies.php>
- Patient advocate video library <http://www.usemydata.org/videos.php>
- Workshop summaries <http://www.usemydata.org/events.php>
- Responses to consultations <http://www.usemydata.org/publications.php>



### Patient advocate video stories

A key aim of use MY data is to give a forum for patients, advocates and carers to have more of a voice in how data is used. These short video messages are from members, and are all freely available for reuse. All we would ask is that you reference use MY data members as the source. You may also be interested in the written member case studies and short quotations.



## Slide template

We have a standard PowerPoint template which can be used when representing [use MY data](#) at conferences/meetings.

The Coordinator keeps the most up-to-date copy of this and will email the template to you on request.

The template is in a wide screen format (16.9). If you require another format the Secretariat can provide this.

If you would like input from the Secretariat to create a slide-set for a presentation you are giving on behalf of [use MY data](#), please contact the Coordinator.



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## Additional materials

- Two-page overview of [use MY data](#)
  - Trifold flyer overview
  - Business cards
  - Data Citation postcards
  - Data Citation stickers
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### 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.

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

### DONATE YOUR DATA

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

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](mailto:donateyourdata@ncin.org.uk)

## 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

And a key message emerged: Every day lost is another person dying.

The Working Group discussed practical ways forward. Most felt that the name 'Donate Your Data' was not accurate - as cancer patients said their data had been taken, 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 Data Citation and further details about its development are here - <http://www.usemydata.org/citation.shtml>
- 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.

The image shows a meeting agenda for 'Donate Your Data - Working Group meeting' held on 29 July 2015 from 11:15 to 15:00 in Room 232D (Boardrooms, 2nd Floor, Stipon House, 80 London Road, SE1 6LH). The agenda is structured as follows:

Time	Topic	Facilitator
11:15-11:25	1) Welcome & introductions	Chris
11:25-11:30	2) Typical data review	All
11:35-11:50	3) Aims and methods of the project <ul style="list-style-type: none"><li>• Overview of the aims and methods</li><li>• Feedback from the working group on whether the aims and methods are acceptable</li></ul>	Michael
11:55-12:30	4) Areas to address - part 1 <ul style="list-style-type: none"><li>• Recruitment</li><li>• Involvement in data release</li><li>• Communications</li><li>• Advocacy</li></ul>	Group work
12:35-13:15	Lunch	
13:15-14:00	5) Areas to address - part 2 <ul style="list-style-type: none"><li>• Subgroup feedback &amp; discussion</li></ul>	All
14:00-14:30	6) Proposed meeting & events <ul style="list-style-type: none"><li>• Data workshop - 29 September</li><li>• NCRN Cancer Conference session - 01 to 04 November</li><li>• British Against Cancer session - 08 December</li></ul>	Adrian
14:30-15:00	7) Summary of the meeting, with closing questions and remarks	Chris



## use MY data evolves

From its beginnings in 2015, **use MY data** has evolved through a rolling programme of engagement and communications. We host at least two patient data workshops each year, alongside a programme of campaigns, networking, and presence at national events. We are increasingly being asked to 1) advise other organisations about patient engagement and 2) engage with organisations who hold patient data.

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### Development of the Coordinating Group / Advisory Group

**January 2016** - following consultation in late 2015, a formal Coordinating Group was created. Up to this point, **use MY data** was coordinated by representatives from Cancer Research UK and the National Cancer Intelligence Network.

Applications to join the Coordinating Group were opened to the **use MY data** membership - both members and associate members. The result was the expansion of the Coordinating Group to:

#### Patient advocates

Helen Bulbeck, Brainstrust  
John Marsh  
Ann Muir  
John Reeve  
John Rouse  
Richard Stephens, NCRI Consumer Forum  
Maggie Wilcox, Independent Cancer Patients' Voice

#### Charity / partner organisations

Michael Chapman, Cancer Research UK  
Rose Gray, Cancer Research UK  
Julie Flynn, Macmillan Cancer Support  
Jane Lyons, Cancer52  
Jessica Mai Sims, UKCRC Tissue Directory and Coordination Centre  
James Thorneycroft, The Brain Tumour Charity  
Fatimah Vali, Macmillan Cancer Support

#### National Cancer Intelligence Network

Chris Carrigan  
Alison Stone

Work of this Group was carried out via email.

**April 2017** - The Coordinating Group felt that definition of **use MY data's** aims was required. A meeting was convened at which our mission statement and aims were drafted. Although these have been tweaked slightly since this point, they remain essentially the same.

**2017** - Decision taken that the Coordinating Group should comprise members only, rather than a mixture of members and associate members. This was to ensure that [use MY data](#) would be truly driven by patients, relatives, carers.

**2018 onwards** - In addition to work via email, the Coordinating Group began to meet in person regularly, with meetings being set at quarterly from 2019 onwards.

**July 2018** - The Coordinating Group members felt that attendance at the meeting was too low and considered whether membership should be expanded. The Coordinator put things in motion to expand the Group, seeking applications from within the membership. Applications were reviewed at the October 2018 meeting and new members accepted.

**October 2018** - The current purpose of the Coordinating Group was discussed, as members felt that its remit was now as an Advisory Group, not a Coordinating Group. The name no longer reflected their role and also detracted from the role of the Coordinator. The decision was taken to change the name to Advisory Group.

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### Wider membership

[use MY data](#) began as movement for cancer patients, relatives and carers. In the early stages of development, the Coordinating Group felt that membership should be expanded to include all patients, relatives and carers. Our remit was adjusted accordingly.

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### **Status and funders**

**use MY data** is an independent movement of patients, relatives and carers. We are the only independent patient movement focussed on patient data. Our independence enables our membership to speak freely.

**use MY data** is not a charity and does not have a legal status at present.

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 do as we see fit with their funding, 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.

Information about all of our funders, current and previous, is published on our website here - <http://www.usemydata.org/funders.shtml>

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