Ways of Working

for the

use MY data

Advisory Group & Secretariat

The unique selling point of use MY data

use MY data is the only independent movement of patients, relatives and carers focussed on the use of patient data.

We are unique in being entirely led by our Members. Our Members define our priorities, actions and activities, through our Advisory Group.

The role of the Secretariat

The Secretariat undertakes roles which could be associated with both an Executive and a Secretariat function. This is reflective of the size and nature of the organisation and is also another way in which we are different from traditional organisations.

The Secretariat takes forward the work of **use MY data** by delivering organisational objectives which promote the work of **use MY data**. At all times, the Secretariat acts on behalf of **use MY data's** Members and promotes and protects **use MY data's** reputation.

In order to achieve this, the Secretariat comprises three roles. While these are distinct roles, the holders work very much as a team, communicating regularly via email and meeting weekly.

Coordinator – 0.64 whole time equivalent
· Manages Membership activity
· Manages Advisory Group Membership and coordinates Advisory Group and Secretariat meetings
· Communications lead
· Main point of contact for internal and external engagement

Expert Data Adviser – 0.30 whole time equivalent
· Provides expert data advice to Members and, on occasion, to external stakeholders
· Coordinates responses to patient data consultations
· Engagement with external stakeholders

Events and Website Manager – 0.20 whole time equivalent
· Manages our events programme and delivers all events
· Updates and maintains the website

The role of the Advisory Group and how it intersects with the Secretariat

The Advisory Group's role is to represent the Members of **use MY data** and advise the Secretariat on behalf of the Members. This advisory work is undertaken via regular liaison with the Secretariat, communicating through emails and meetings, ensuring that an audit trail of advice sought and received by the Secretariat is maintained.

The Secretariat can act autonomously on behalf of **use MY data**. While the Secretariat has autonomy, there are occasions when it necessarily seeks the advice, input and support of the Advisory Group. The Secretariat liaises regularly with the Advisory Group to update, inform and consult, as appropriate.

What it means to be an Advisory Group Member

Advisory Group Members have a valuable role in:
- Acting on behalf of Members, to promote the work and values of **use MY data**

- Participating in regular communications with the Secretariat, via emails and meetings

- Responding to Secretariat requests for advice

- Acting as champions for **use MY data** in their own networks and forming channels of communication to and from those networks.

Categories of communication between the Advisory Group and the Secretariat

In order to make the most efficient use of the Advisory Group's time, communications fall into four categories. The Secretariat makes the category clear in any communication.

Advisory Group Members recognise that their roles and remits as individuals are to offer a range of views and perspectives, and thus consensus will not always be possible or even desirable. If a consensus is not achieved, the Secretariat will usually go forward with the majority view.

The categories of communication:

- **Inform**
  The Advisory Group receives details from the Secretariat for information purposes only. with no specific action required from the Advisory Group.

  Example: Circulating information received from NHSX.

- **Contribute**
  The Secretariat asks Advisory Group Members to respond and contribute to a piece of work. A reasonable deadline to respond by will be given, with the understanding that after the date has passed, the Secretariat will proceed with the work. In the event that no responses are received, the Secretariat will send a chaser email to the Advisory Group, with an extension for responses.

  Example: Responding to a consultation from the National Data Guardian.

- **Develop**
  The Secretariat will request input from the Advisory Group Members to the development of a piece of work. A reasonable deadline to respond by will be given. The agreed number of responses is desirable, but if responses are not received, the Secretariat will proceed with the consensus of responses received by the given date. In the event that no responses are received, the Secretariat will send a chaser email to the Advisory Group, with an extension for responses.

  Example: Beta-testing a new website page.

- **Support**
  The Secretariat asks the Advisory Group to support an item, for which the agreed number of responses will be required. A reasonable deadline to respond by will be given. The Secretariat will not proceed until support has been given. Support from at least 50% of the Advisory Group will be required before proceeding with an item for which support has been sought. In the event that no responses are received, the Secretariat will send a chaser email to the Advisory Group, with an extension for responses.

  This approach is designed to ensure the Secretariat is confident that it has the Advisory Group's support for its work. This will ensure that work will progress, rather than risk delay or failure to complete by abstention.

  Example: Deciding whether or not **use MY data** should join/promote another organisation's project.

Advisory Group meetings

Frequency and format
The Advisory Group and the Secretariat meet virtually once a month. Meetings are generally scheduled for one hour and cover a single topic. Prior to COVID-19, meetings were quarterly and in person.

Quorum
The minimum number of Advisory Group Members needed for a meeting to be quorate is 50%. Having a quorum means that decisions can be made at meetings, although most work of the Advisory Group takes place via email.

Membership of the Advisory Group

The number of Members within the Group can range from a minimum of six to a maximum of ten.

Advisory Group Members sit on the Group for an initial term of three years.

This can be renewed once by mutual agreement between the Member and the Secretariat (i.e. without reapplication), making Membership a maximum of six years.

Recruitment of new Members of the Advisory Group is done via an open call system to Members. The process is facilitated by the Secretariat. Applications are assessed by the Secretariat.

Ad hoc vacancies are advertised to the Membership within six months of the vacancy occurring. Ideally, planned vacancies (i.e. vacancies by rotation) are advertised six months ahead of them occurring.

As a result of illness or other short-term difficulties of Advisory Group Members, the Secretariat may also recruit (by appropriate methods) temporary Members of the Advisory Group e.g. for a single issue or a particular meeting. Such temporary appointments will have their rationale and terms made clear to all Advisory Group Members and, where practical, will be items for the Secretariat to seek advice in advance.