

Ways of working for the Executive Group & Secretariat

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The unique selling point 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 to save lives and improve outcomes. Our mission is 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. We are led by our Members - patients, relatives and carers who want their patient data to be used, to support medical research and for their own care.

The role of the Executive Group

Our Executive Group is drawn from use MY data Members. The Executive Group exists to act on behalf of the Members and works to define the priorities, actions and activities of use MY data. The Executive Group sets the strategy and direction for use MY data and monitors progress against the strategy. All of this work is undertaken on behalf of the Members of use MY data. In this role, the Executive Group guides the Secretariat in its work to take forward use MY data's work programme.

Executive Group Members have a valuable role in:

- Acting on behalf of Members, to define the priorities, actions and activities of use MY data
- Acting on behalf of Members, to promote the work and values of use MY data
- Providing guidance and advice to the Secretariat, via participating in regular communications
- Taking a lead in areas of use MY data's work where they have a particular interest or skillset
- Acting as champions for use MY data in other networks they connected with, forming channels of communication to and from use MY data.

Members on the Group have a real interest in using patient data for health and social care research, perhaps with a particular patient data story or experience, whether for good or bad. They see the 'bigger picture' of use MY data and are able to think strategically and work accordingly.

Executive 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.

Executive Group Members have a short profile on use MY data's website. Within this profile, as well as listing relevant groups or networks to which they belong, they are encouraged to highlight their reasons for being part of the Executive Group and indicate areas where they take a lead for use MY data. Conflicts of interest are declared within the profiles, for transparency and the profiles are updated regularly.

The role of the Secretariat

The Secretariat takes forward the work of use MY data by delivering the work programme, on behalf of the Members. At all times, the Secretariat acts on behalf of use MY data's Members and works to promote and protect use MY data's reputation.

The Secretariat comprises four part-time roles. While these are distinct roles, the role holders work very much as a team, communicating regularly via email and meeting weekly. The roles are:

- Head of Programmes & Engagement - 4.0 days per week
 - Data Adviser - 2.5 days per week
 - Communications and Media Lead - 3.0 days per week
 - Administrator - 2.0 days per week.
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How the Executive Group and Secretariat work together

Communications and meetings

The Executive Group and Secretariat undertake their roles via regular liaison. The Secretariat updates, informs and consults with the Executive Group, as appropriate. Liaison is via emails and meetings, in-person and online, for which an audit trail of guidance and advice (sought and received) is maintained.

Executive Group and Secretariat meetings - format and frequency:

- In-person, quarterly, for a full-day (the current location is London)
- Online, three times per year, for 1.0/1.5 hours

If needed, ad hoc meetings may be scheduled between regular meetings. These would be online, for 1.0 hours and generally on a single topic. In addition to the need for the meeting, the scheduling depends on:

- the Secretariat having sufficient time to arrange and support the meetings
- sufficient funding available to offer honoraria to the Executive Group, for their attendance.

The minimum number of Executive Group Members needed for a meeting to be quorate is 50%. Having a quorum ensures that decisions can be made at meetings, if necessary.

Categories of email communication

To make the most efficient use of the Executive Group's time, email communications fall into three categories. The Secretariat makes the category clear in any communication, in the subject heading.

- **For your information**

The Executive Group receives details from the Secretariat for information purposes only and no action is required by the Executive Group.

Example: Circulating an update from the National Data Guardian.

- **Contribution required**

The Secretariat asks Executive Group Members to respond to a specific piece of work and/or request. A reasonable deadline will be given. Support from more than 50% of the Executive Group will be required, to enable the Secretariat to proceed to the next stage. This approach is designed to ensure the Secretariat is confident that it has the Executive Group's views and can take forward (or decline) specific pieces of work. If too few responses are received, the Secretariat will send one chaser email, with a short deadline extension.

Example: Deciding if use MY data should partner with an organisation on a patient data project.

- **Seeking your sign-off**

The Secretariat asks the Executive Group to sign-off an item, which it is highly likely the Executive Group will have had previous sight of. A reasonable deadline will be given. Support from more than 50% of the Executive Group will be required, before sign-off can be taken forward. This approach is designed to ensure the Secretariat is confident that it has the Executive Group's sign-off and can take forward the piece of work to the final stage. If too few responses are received, the Secretariat will send one chaser email, with a short deadline extension.

Example: Signing off the final version of a new Position Statement, written on behalf of the Members.

Response times

Generally, the Secretariat will give a minimum of one calendar week as a deadline for Executive Group responses. On the rare occasions where something urgent arises, and only if there is good reason, the Secretariat may send a request to the Executive Group with a shorter turn-around time. When this happens, the Secretariat will explain the reason for the short time frame and understands that the Executive Group may not be able to respond within the short timeframe.

Chair, Vice Chair and Secretariat liaison

The Secretariat liaises with the Chair and Vice Chair of the Executive Group on a regular basis (generally fortnightly), to provide updates on key strategic items and to seek guidance on pressing topics.

The Chair and Vice Chair may act on behalf of the Executive Group, in areas related to delivery of agreed strategy and work programmes.

Secretariat autonomy

While seeking the guidance and advice of the Executive Group as a default, the Secretariat can and does act autonomously on behalf of use MY data. This is primarily when undertaking scoping work with external organisations or individuals, about potential involvement or engagement work for use MY data.

As part of its work, the Secretariat ensures that external organisations/individuals are aware of, and sign up to, use MY data's [Standards for engagement with external bodies](#). The Standards are based upon the established principles, values and position statements of use MY data, created by Members.
