

## Standards for engagement with external bodies

use MY data welcomes engagement with external bodies (organisations and individuals). Initial engagement is usually undertaken by the Secretariat, on behalf of use MY data's Members.

These standards will guide the Secretariat in their engagement work and are based upon the established principles, values and position statements of use MY data, created by Members.

- 1) All engagement work with external bodies is undertaken on behalf of use MY data Members and will support the <u>Vision and mission statement</u> of use MY data. Engagement must be related to, and supportive of, the benefits of using patient data (generally, routinely collected patient data).
- 2) a. Engagement must be in line with use MY data's <u>Transparency Principles</u> which underpin all of use MY data's work. The Secretariat will ensure the external body is aware of, and willing to adhere to, the principles.
  - **b.** A condition of engaging with use MY data is that Members will be informed about the work and that use MY data will declare the engagement publicly (via the website as a minimum). If the external body will not meet this condition, engagement cannot be undertaken.
- 3) The Secretariat will draw attention to use MY data's position statements on the use of patient data. They will specifically emphasise the principles detailed within the position statement <a href="Expectations of organisations which use our patient data">Expectations of organisations which use our patient data</a> and use these principles to guide the engagement individual choice, societal benefit, patient voice, transparency, security and ascertain whether the engagement would be in line with these.
- 4) use MY data does not endorse any organisation, product or service and this must be made clear at the outset of all engagement discussions.
- 5) The Secretariat will ensure that the external body is aware of use MY data's strategy of positive engagement.
- 6) The Secretariat will draw attention to the <u>Patient Data Citation</u> created by use MY data Members, to emphasise that patients are the source of the data used for research and analysis. The Secretariat will encourage the external body to promote and use the Citation, as appropriate.
- 7) a) The Secretariat will ensure that the Executive Group is aware of engagement work being undertaken on behalf of use MY data. This may be via consultation beforehand or updating afterwards (depending on the nature/stage of the engagement).
  - **b)** The Secretariat will ensure that Members are informed of any formal engagement work that use MY data undertakes.
- 8) Engagement work will only be undertaken if it is within use MY data's resource capacity, in terms of the Secretariat's time, use MY data's work programme and funding. If the engagement is desirable but is outside of current resource capacity then, with the agreement of the Executive Group, the Secretariat may propose a charging/funding structure to enable obtaining additional personnel, to carry out the engagement work.