

use MY data – ABPI Agreement

Terms of Reference July 2022

1. Context

The Association of the British Pharmaceutical Industry (ABPI) and use MY data are establishing a relationship between their organisations. The purpose of the relationship is to enable the ABPI to work with use MY data's Advisory Group to create a test bed for messaging and approach. This will inform the ABPI's multi-year engagement programme to build public confidence in industry use of health data for research purposes.

A synopsis of this programme is included and should be read in conjunction with these Terms of Reference.

The ABPI respects the position of use MY data as an independent patient movement and will make public the relationship, including details of any funding provided.

2. Nature of the engagement

use MY data's Advisory Group will operate as an 'ideas test bed', offering opinions and ideas on the ABPI programme without directly advising the ABPI.

This will take the form of providing input into content and approach during the early phases of the programme. This is likely to require 1-2 hours input per month until Q4 2022, with an agreement that the ABPI may ask for additional help for more intensive pieces of work such as workshops and seminars in 2023.

In all cases, the ABPI commits to giving use MY data at least 2 weeks' turnaround time on a schedule of asks for comment on content, and a longer lead time for more intensive involvement/participation in events.

3. Confidentiality

Members of use MY data's Advisory Group agree to hold in confidence all matters discussed under the terms of this relationship.

4. Route for input

All use MY data Advisory Group Members' input to the ABPI programme will be co-ordinated via use MY data's Secretariat. However, the ABPI will manage all supporting logistics involved in obtaining input so as not to place an additional burden on the Secretariat.

Mindful of Advisory Group Members' time, most interactions will be virtual; however, subject to agreement and availability, some interaction (eg workshops) may be face to face in a central London venue. The ABPI will cover any reasonable travel costs associated with face to face meetings in addition to the reimbursement set out below.

5. Duration of this agreement

This agreement will run from 1st July 2022 until the end of 2023 at which point both parties will review it and consider whether or not to extend the relationship.

6. Reimbursement

use MY data Advisory Group Members will be reimbursed for their time following use MY data's honoraria policy to recover pass-through costs for the patient daily rates, which range from £50 per half day to £150 for a full day.

Costs for use MY data's Secretariat time will be £400-£500 per day.

Appendix

About use MY data www.useMYdata.org.uk

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 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.

Our mission

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

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
- We work to bring a patient voice to all conversations about patient data. We have developed the Patient Data Citation, which acknowledges that patients are the source of the data.
- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- We provide learning resources for patient advocates on patient data issues, including: - Hosting events for patients and the public, focussing on patient data topics - a library of resources of data security, consent - narratives from individuals about the value of collecting and using patient data.
- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

About the ABPI

www.abpi.org.uk

The ABPI is a trade association representing the research-based pharmaceutical companies which invent and develop most of the prescription medicines and vaccines used by healthcare professionals every day. The ABPI exists to make the UK the best place in the world to develop the medicines and vaccines of the future. Our members supply cutting edge treatments that improve and save the lives of millions of people. We work in partnership with Government and the NHS so patients can get new treatments faster and the NHS can plan how much it spends on medicines.

Our programme to build public trust in industry use of health data for research purposes