

Data Access and Discovery event, February 2022 – Data Use Registers

Questions from the webinar:

Will this information to the public include 'negative/ undetermined' research results?

Absolutely, 'negative' or 'null' research outputs are just as valuable as 'positive' outputs and we would encourage full transparency in this respect.

A paper recently published showed that women suffered much greater side effects from chemotherapy and immunological treatments for cancer, than men. Treatment results should therefore be analysed to discover differences. Will such analyses be encouraged, or preferably mandated?

Whilst we are not in the position to mandate specific types of research, establishing a standard for data use registers will enable better analysis of how datasets are being used and for what purposes (through the aggregation of data uses across multiple data custodians). This may help funders address any gaps and prioritise underserved areas of research.

Are the data use registers and standards just for NHS data providers or will Universities etc. sign up?

The recommendations for a data use register standard apply to all data custodians responsible for the safe storage, sharing and processing of data. In some instances, this will be the university.

Will this standard improve transparency around data sharing agreements or other memoranda of understanding across various organisations?

We hope so. Whilst we are aware that there may be legitimate cases where publication of a data use register entry is delayed or kept private, this should be the exception, not the rule. Access requests that have been agreed under the terms of a non-disclosure agreement may make up some of these cases. However, in the spirit of transparency, we would encourage data custodians to disclose the number and type of organisations that fall within this category. Decisions to delay publication should, as far as possible, be reviewed by lay representatives to test for reasonableness.

Would it be worth Trusts and universities incorporating completing a data use register entry, linked in with the research governance side and the GDPR checks for new projects? Collating this for older studies that have been running for many years is likely to be more challenging.

We appreciate that curating legacy data uses for very old studies or projects could be time consuming and unrealistic. However, we would encourage organisations to make publicly available as many data uses as possible. Alliance member organisations are encouraged to capture at least the seven minimum data elements recommended for data uses (Recommendation 4). Therefore, to reduce time and effort we would highly recommend considering integration of data access approval processes with the publication of data use registers. The Innovation Gateway provides an example of this integration. Custodians using the Gateway data access management system will benefit from automatic creation of a data uses following approval of a data access request application.

An 'end date' specified in the Patient Information Sheet might be useful too. Participants are sometimes informed that 'the results will be published', but they are not told When or where.

Whilst we cannot comment on changes required to patient information sheets or the communication between research teams and participants, we think data use registers have the potential to close the loop on the impact of data uses, by including where possible the link to research outputs and findings, as they become available.