

Additional questions to the panel Q&A that we didn't have time to answer during October's Data Access and Discovery webinar (13 October 2022).

How do you assess if the dataset has platinum metadata? Is there a minimal metadata requirement for datasets at submission.

The metadata richness score relates to the amount of information available about a dataset, not to its quality. Learn more about how the score is calculated [here](#). As a minimum, the required fields to onboard a dataset to the Gateway are as follows: identifier; version, revisions; issued; modified; summary, accessibility; and observations.

Regarding data summary notebooks, are these "free text" data?

No, the data summary notebooks do not contain free text data. The notebooks are a mixture of code and outputs. The notebooks have a standard format and there is one for each dataset in the NHS Digital TRE for England. The outputs provided are batch summaries for the datasets (showing how batches for the given dataset change over time in terms of number of records and patients), data coverage plots, variable completeness summaries and a linkage summary that shows how the dataset links and overlaps with other key datasets (i.e. what % of patients in the vaccinations dataset are also in primary care data).

There is a sea of current registers, bioresources, etc. that charities hold or have funded – can these be brought into the Medli app? Also, are you offering a data linkage service between users providing PROMS and their health records?

From the conversations we have had to date it looks like Medli is a useful tool for registries and charities alike. We haven't as yet migrated the data from an existing registry into Medli. We are more than happy to run a discovery session with any registry to assess the work involved in moving their existing data into Medli. We are in advanced discussions and have built a prototype integration with a third party which would give Medli users access to their own health records.

How does it (the BRIAN app/Medli) work in terms of access to and use of the data collected?

Both the BRIAN and Medli apps contain a 'How we use your data' section accessible via the lefthand navigation. A more in-depth account of how data is used is contained within the Privacy Policy and Terms and Conditions section of each of the apps.

Each of the apps provide the capacity to share data with carers and health care professionals (HCPs). The person setting up the share can determine which portions of their account are to be shared, whether to grant read or write access and for how long that access should be granted. HCPs or carers can access each of the accounts they have been granted access to, via the Medli app or Webapp. In BRIAN, this access is only available via the Webapp.

Both BRIAN and Medli contain a feature called Perceived Quality of Life (PQOL) alerting, which allows a healthcare team to set a threshold across a series of QOL dimension, such as physical and emotional wellbeing etc., whereby the team could elect to receive an alert if the score recorded by any one of their patients falls below that threshold. Each dimension can have its own threshold.

Both BRIAN and Medli contain a feature called 'Thin Link' (TL) which allows a person leading a trial or study to:

1. Set their trial or study up in BRIAN / Medli
2. Create participant groups
3. Create a reference code per group
4. Select data fields to be released from BRIAN / Medli to the study per group
5. Specify the frequency at which data should be released
6. Create or upload Patient Information Sheets (PIS) per group
7. Create or upload consents required per group
8. Specify supporting documentation or evidence to be provided by each applicant
9. Specify signatures to be provided per applicant

Once the TL groups have been submitted and approved by the BRIAN or Medli Data Access Boards, the TL group codes can be used by group participants, to interact with 6) through 9) above, to confirm their participation in the trial. If, for example, it transpires at a later date, that additional data fields are required then participant group consenting can simply be rerun, digitally.

Patients who sign up to Medli can affiliate to multiple charities. Medli shares the data input by patients and carers with each of the charities to which they affiliate via the Medli Analytics Portal (MAP). Each data type and the method and controls governing how it is shared, are laid out in the Medli Data Protection Impact Assessment (DPIA). It is not viable to include all of that detail within this answer, but we would be more than happy to explain the Medli and BRIAN DPIAs to anyone who wishes to pursue this discussion further.

Is Medli available for health care providers?

The power of Medli is connectivity across the healthcare sector, so we are open to scheduling some time to discuss the specifics of how health care providers could benefit from the platform. Please reach out to andrew@medlihealth.com

What are the opportunities for collaborations in academia? Or are you only working with specific charities at the moment.

Medli is designed to enable collaboration so more than happy to schedule some time to explore opportunities in academia. Please reach out to andrew@medlihealth.com

End.

