Meaningful Measures' MYCaW and MYMOP data share policy and procedure

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Who are Meaningful Measures?

We are a company who support the use of MYCaW and MYMOP and carry out research, evaluation and audit using these tools. The company directors, Dr. Marie Polley and Dr. Helen Seers have developed these tools over the past 15 years and are highly trained and experienced researchers.

What data security standards are in place at Meaningful Measures?

Meaningful Measures hold compliance with the NHS' Data Security Protection Toolkit standard https://www.dsptoolkit.nhs.uk/ which ensures high standards in policy and practice in terms of data handling and processing. Both Directors have also completed NHS Cybersecurity training and Dr Marie Polley has 15 years' experience sitting on research ethics committees.

Why do Meaningful Measures want my data?

Over the past 10 years we know that a proportion of the issues people want support with are often unrecorded and unrecognised, or not given priority in consultations. Often these concerns are non-medical.

Meaningful Measures uses fully anonymised MYCaW concerns or the MYMOP symptom and activity returned via the license agreement to create larger anonymised data sets.

By using only anonymised concerns/symptoms/activities, there is no way that any individual data can be traced back to a person or an organisation. This removes the data from the 'sensitive or personal' data category and removes the need for the data to be governed by GDPR.

What happens to the anonymised datasets?

Firstly, Meaningful Measures will **not** share your data with any third parties, it is solely for our internal analysis.

The anonymised data we receive from you is analysed to get a deeper understanding of the issues that cohorts are seeking support with when they access services for help. The larger the dataset, the more confidence we can have in the patterns being seen in the analysis.

We may publish reports or scientific papers to help share the aggregated findings with the research community to bring more attention to the unmet needs in the population. Any published findings do not refer to individual concerns, symptoms or activities, but describe broad categories. Neither will any organisations be identified in the reports or scientific papers, without prior consent.

We also use the anonymised data to create coding frameworks that provide a scientifically rigorous approach to analysing MYCaW and MYMOP data for our customers. Again, no individuals or organisations are named in these frameworks.

What data needs to be shared with Meaningful Measures?

- Fully anonymised MYCaW Concerns data (words written)/ MYMOP symptom and activity data (words written)
- MYCaW concerns scores (numbers) /MYMOP symptom and activity scores (numbers)
- Wellbeing scores (numbers)
- A summary of the service demographics – not actual raw data, but just overall average service user profile (eg. the average service user for this data set is a female, aged between 45-55 years, and diagnosed with cancer).

How is the data handled and stored?

Data received is checked to remove any potential identifiers that may have been accidentally left in (eg. a name, date, location, identifiable scenario) – any initial files with identifiers in are immediately destroyed.

Files are password protected and securely stored on Meaningful Measures cloud storage. Anonymised data handling and storage is fully compliant within GDPR regulations and the Data Protection Act (2018), even though it does not contain any identifiers, cannot be linked to any individuals and is therefore not sensitive or personal data anymore.

How do I share the data with Meaningful Measures?

Written concerns you provide and remove all personal identifiers (any names/ details that could identify a person, date or location). Meaningful Measures can provide an excel sheet to add data onto with pre labelled columns. The data will be shared with Meaningful Measures at end of 12 months' of MYCaW licence use. You will be given a secure link to upload your data to ensure data is not transmitted via email.

How can I communicate about this data share with my clients filling in the MYCaW/MYMOP?

The following statement can be added to your client information sheet / data share agreement.

"We use a questionnaire called MYCaW/ MYMOP in our data collection. Meaningful Measures operates the licence for MYCaW/MYMOP and collects anonymised and non-identifiable data from all users around the world to create a database of anonymised concerns/symptoms/activities. This data collection helps organisations understand people' needs. Your MYCaW/MYMOP data will be fully anonymised and sent securely ONLY to Meaningful Measures, for more information see their website: www.meaningfulmeasures.co.uk"

How long will my data be stored for?

Data will be processed into the coding frameworks and then automatically deleted after seven years.

Meaningful Measures Ltd Data Share