

Meaningful Measures' Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® data share policy

1.0 Who are Meaningful Measures Ltd?

We are a company who own Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® 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.

2.0 What data security standards are in place at Meaningful Measures Ltd?

Meaningful Measures Ltd are compliant 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 (the company also holds Cyber Plus Certification) and Dr Marie Polley has 15 years' experience sitting on research ethics committees.

3.0 Why is some of the Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® data shared with Meaningful Measures Ltd?

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. These data sets which are anonymised are enabling us to inform people such as NHS commissioners on how to make services more aligned to concerns and symptoms. To generate these databases, the licence agreement for a practitioner or organisation to use our tools includes an anonymised data share clause.

4.0 What happens to the anonymised datasets?

Meaningful Measures Ltd uses the data they collect for our internal analysis. The data we receive from you are analysed to get a deeper understanding of the concerns and symptoms 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 people but describe broad categories. No organisations will be identified in the reports or scientific papers, without prior consent (sometimes we co-author papers on a specific topic with an organisation).

We also use the anonymised concerns data to create coding frameworks that provide a scientifically rigorous approach to analysing Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® data for our customers. Again, no individuals or organisations are named in these frameworks - [for example](#).

Anonymised concerns from specific cohorts may be shared with researchers who want to compare their results to ours. Again, no organisations or individuals would be identifiable in this process.

5.0 How can I communicate this data share process with my clients who complete Measure Yourself Concerns and Wellbeing® or Measure Yourself Medical Outcome Profile®?

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 Ltd operates the licence for MYCaW®/MYMOP® and collects anonymised and non-identifiable data 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 Ltd, for more information see the website: www.meaningfulmeasures.co.uk”

6.0 How long will my data be stored for?

Data will be processed into the coding frameworks and then automatically deleted after seven years, unless there is a specific agreement to keep it for longer.

7.0 How are Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® administered and data collected?

There are 2 ways in which Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® are administered and the data collected which have slightly different implications on general data protection.

i) administration of the tools via a practitioner or organisation using a paper-based copy or their own quality assured digitised version of the tools. Data gathered by this route is controlled by the practitioner or organisation that collects it. This data is

likely to contain personal or sensitive information hence the practitioner or organisation is required to adhere to GDPR.

ii) administration of the tools via the Meaningful Measures Ltd digital portal, where data collected automatically accrues to the database on this portal. Data gathered by this route is controlled by the organisation who gathers it, hence they are a data controller of data that is likely to contain personal or sensitive data. They are therefore required to adhere to GDPR.

7.1 Administration of the tools via a practitioner or organisation using a paper-based copy or their own quality assured digitised version of the tools.

After 1 year we ask for the practitioner or organisation to share with anonymised data as details below. Meaningful Measures Ltd therefore becomes a data processor in this scenario.

- Fully anonymised Measure Yourself Concerns and Wellbeing® Concerns data (words written)/ Measure Yourself Medical Outcome Profile® symptom and activity data (words written)
- Measure Yourself Concerns and Wellbeing® concerns scores (numbers) /Measure Yourself Medical Outcome Profile® 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).

By only receiving anonymised data, the data does not fall into the ‘sensitive or personal’ category and this removes the requirement for the data to be governed by GDPR which is part of the Data Protection Act (2018).

How is this 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.
- In the event that a file contains a lot of identifying information this will immediately be destroyed and we will ask the client to clean the file and resend it to us.
- Files are password protected and securely stored on Meaningful Measures cloud storage. Anonymised data handling and storage is fully compliant with 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 this data with Meaningful Measures?

Meaningful Measures can provide an excel sheet to add data onto with pre labelled columns. The data will be shared with Meaningful Measures at the end of 12 months' of Measure Yourself Concerns and Wellbeing® or Measure Yourself Medical Outcome Profile® licence use. You will be given instructions on how to securely provide us with your anonymised data.

7.2 Administration of the tools via the Meaningful Measures Ltd digital portal, where data collected automatically accrues to the database on this portal.

The Meaningful Measures Ltd digital portal allows you to send links to clients to fill in the tools and create your own repository of data.

The digital portal is accessed via the Meaningful Measures Ltd website and you sign in with your designated unique details.

Who can access the data that is collected?

- **If you are a sole practitioner** you will have access to a Measure Yourself Concerns and Wellbeing® or Measure Yourself Medical Outcome

Profile®dataset along with demographic information for each client as they complete the tools. You can view data per client and as a dataset of all your clients. You will be able to download a .csv file with all the client data on and therefore when doing so you become a data controller and are required to adhere to GDPR.

- **If you are part of a team of people accessing the portal**, then there are options for each person to see the whole client database or just the clients each person is managing themselves. As above, each person will be a data controller for their own dataset if they download the data, and anyone who can view all the data collected by the whole team within an organisation will be a data controller for the whole dataset (if downloaded). Adherence to GDPR (2018) is, therefore, managed accordingly by each organisation.
- **If you oversee a research project where multiple people will be collecting Measure Yourself Concerns and Wellbeing® or Measure Yourself Medical Outcome Profile® data from different organisations:** The level of access to data is set up at the beginning of the licence process. Everybody will have access to the data contributed from their clients on a dashboard and as a downloadable csv file. A data manager or research manager is likely to have access to data from all the clients across a team of practitioners on a dashboard and as a downloadable .csv file. This file can identify which person/practitioner has supplied the client data. Adherence to GDPR (2018) is managed accordingly when data is downloaded as a .csv file.
- **Meaningful Measures Ltd has super-admin access to the digital portal.** On a daily basis the parameters of the portal have been set that only anonymised data can be viewed by Meaningful Measures Ltd staff. No demographic data, therefore, is accessible to Meaningful Measures Ltd staff. We can, however, see concerns, symptoms, activity data, corresponding scores and wellbeing scores which appear as anonymised data. This data

will be used to generate an anonymised dataset of concerns and symptoms for the Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® tools. Meaningful Measures Ltd acts as a data processor in this scenario.

- **Meaningful Measures Ltd owns the digital portal and has the right to access the whole dataset you are collecting.** We do not foresee having to do this unless we are served with a legal request such as a freedom of information request, which we have to take action on, or permission is granted by an organisation who require technical support. To enable us to access the whole dataset containing identifiable information, we will have to notify and pay the company that designed and hosts the digital portal servers to action this request. Meaningful Measures Ltd acts as a data controller in this scenario and will adhere to all DPA(2018) and GDPR requirements.
- **The digital portal for Measure Yourself Concerns and Wellbeing® and Measure Yourself Medical Outcome Profile® is designed by [Amperative \(formally Worthers\)](#) who also host the servers for our portal.**

Data collected via the digital portal is shared with [Amperative](#) (formally Worthers) as a sub-processor of the digital portal data. You can read more about their [data security processes here](#).

How do I share this data with Meaningful Measures Ltd if I am using their digital portal?

Whilst an anonymised data share is part of your licence requirement, you do not need to do anything as Meaningful Measure Staff will be able to download anonymised data directly from the portal. Please note that anonymised data is separate to demographic data which we avoid viewing or downloading.

**For further information on our data share policy please email
marie@meaningfulmeasures.co.uk**

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