Mental health outcomes – PDCN services

Frequently asked questions

Introduction

This information leaflet gives a overview of why, how, and when we ask those seen within our services to answer a range of questions about mental health and wellbeing.

For the reasons outlined below, it's really important for us to get feedback directly from you. We'd like to thank you for taking the time and making the effort to engage with us on this.

Why are Essex Partnership University NHS Foundation Trust (EPUT) asking questions about mental health/wellbeing and collecting OMs?

In order to understand the effects of the treatment we provide, we recognise that it's vital for us to hear directly from those that we support.

The responses that you give to the questions we ask help us to assess how you, as an individual, may be responding to the treatment provided. Your health professional may use this information to support the work you do together.

Being able to measure these effects helps us to get a clearer picture of 'what works for who' and benchmark our overall impact as a service. It also influences the case we can make for NHS mental health service provision.

Whenever we make this case and present the data, *it will always be fully anonymised.* We would therefore please ask you to answer the questions as honestly as you can.

How will my data be kept secure?

The security of your data is our top priority. In order to implement this OM initiative, our processes have been through a full Data Protection Impact Assessment (DPIA) process. This has involved these processes being scrutinised and approved by EPUT's Information Governance specialists.

To access the Privacy Policy which gives full details of how we process your data, as well as your rights under General Data Protection Regulations (GDPR), please visit: https://eput.nhs.uk/privacy-policy/

How are the Trust collecting OMs?

We want to be able to collect your responses digitally. Feedback we've received from EPUT's Service Development Collaborative group of patients suggests that digital questionnaires may be most convenient for people to engage with.

Links to the questionnaires will be sent by SMS to the mobile number listed on your record.

Importantly, by reducing our reliance on hard-copy paper records, digital questionnaires help us to be more efficient whilst also protecting the security of your data. Reducing paper usage through a ‘digital-first’ approach is also a central aim of the NHS as a whole.

We do appreciate that in certain circumstances, people may struggle to engage digitally. We really want to hear from everyone, so if you are not able to respond to the digital questionnaires, you can let us know and we can explore alternative options.

When will I be asked to complete OM questionnaires?

We will be sending out links and asking you to complete these questions roughly once a quarter.

At the beginning and end of treatment, we ask a larger number of questions (the ‘FULL quota’). This greater level of detail helps us to develop a fuller picture of your mental health and wellbeing ‘before’ and ‘after’ treatment. A smaller number of questions will be asked quarterly for people who are actively in-treatment (the ‘BRIEF quota’). The schedule is outlined in more detail below:

1. **Pre-treatment (sent shortly before treatment begins. If there has been an assessment phase as part of your journey, this quota of questions may be asked twice: once pre-assessment, and then again pre-treatment):** FULL quota (68 questions)
2. **In-treatment (sent quarterly during treatment):** BRIEF quota (26 questions)
3. **End of treatment (sent shortly after completion):** FULL quota (68 questions)
4. **Post-treatment (one quarter after completion):** FREE TEXT quota (7 open questions inviting reflection)
5. **Post-treatment (two quarters after completion):** FULL quota (68 questions)

What questionnaires will I be asked to complete?

We have selected validated and evidence-based OM tools. These mainly consist of versions of the ‘Clinical Outcomes in Routine Evaluation’ (CORE) questionnaire, the ‘Recovering Quality of Life’ (ReQoL) questionnaire, and the DIALOG questionnaire.

These questionnaires are widely-used in similar services and settings, which helps us with our bench-marking. The vast majority of questions will invite multiple-choice responses.

For full details on these questionnaires, as well as links to the research that underpins their usage in mental health services, please see details provided further down this document.

Where can I find out more?

If you’ve any further questions about this that you don’t feel are addressed by the information provided, you can get in touch with EPUT on 0300 123 0808 and leave your message with the Psychotherapy South-East Admin Team.

Please request for your message to be passed to the Outcome Measures Team and a member of our group will address your query.

What specific surveys will I be sent and at which stage in my journey?

In addition to questions about your details, you will be asked:

<u>FULL quota (sent pre-assessment if applicable; pre-treatment; end of treatment; and two quarters after treatment has been completed)</u>

- **CORE-OM (stands for 'Clinical Outcomes in Routine Evaluation – Outcome Measures'):** 34 multiple choice questions
- **ReQoL-20 (stands for 'Recovering Quality of Life'):** 20 multiple choice questions
- **DIALOG:** 11 multiple choice questions

<u>BRIEF quota (sent quarterly in-treatment)</u>

- **CORE-10:** 10 multiple choice questions
- **ReQoL-10:** 10 multiple choice questions
- **Additional service specific questions:** 3 questions; multiple choice and free text

<u>EXPERIENCE quota (sent one quarter after treatment has been completed)</u>

- **Invitation to reflect on experience:** 5 questions; multiple choice and free text

What happens if I state that I or someone else is at risk in my responses to the questions?

It is very important to note that the collection of this data is for evaluation purposes only. If you are reporting risk, it is vital that this is done via the normal clinical channels and that established safety plans are followed. EPUT cannot guarantee that information reported via this survey will be available to clinicians within the timeframe that may be necessary to provide suitable support.

How can I access the digital surveys?

Links will be sent to you on SMS. These will go to the mobile number listed on your patient record.

Will the links to the surveys expire?

Whilst the links do not have an expiry, we would request that you please complete the questionnaires as soon as you are able to after you have received the link, ideally within 1 week.

Can I save and return to the surveys later?

Yes, you can save and return.

Can I answer the questions on different devices?

Yes, the message will go to your mobile phone number and can be opened on a smart phone. The link can also be copied and accessed on other devices, e.g. desktop computers.

Who will have access to my responses to the questions?

No one outside of the NHS will have access to this data. Administrative staff for the Service you're seen in will upload this to your individual patient record. Once this task has been done, the clinician you're working with have access to your responses. NHS service managers will also be able to access the data. Everyone that does is bound by a strict code of information governance conduct.

What if I am distressed by the questions asked?

Completion of these surveys is not mandatory. If you do not feel able to engage with them, this will not impact the availability of treatment. If you feel distressed by any of the questions posed, the first step would be to discuss these with a clinician you are working with. If you are not able to do so and require mental health support, you can dial 111 - option 2. The Action Line webpages also contain lots of helpful information on a wide range of mental health related matters: https://www.bbc.co.uk/actionline/. For information on how to seek urgent support from the EPUT in case of crisis, see: https://www.eput.nhs.uk/in-crisis/.

Why is there some repetition of questions?

You may notice some repetition in the wording of questions across the surveys that we're asking you to complete. This repetition is an effect of using this range of questionnaires, all of which are fully validated. Whilst the questions may look similar, all of your responses are helpful to us.

How can I give my feedback if I cannot answer the digital questionnaires?

If you feel able to, we would generally ask you to answer digitally. This route is the most secure as at no stage does it involve the completion of patient-identifiable results sheets. This said, if you don't feel able to engage digitally, alternative options can be made available. You can speak to your clinician about this or respond to the SMS messages indicating that you would like to explore this.

What should I do if I struggle with reading and/or writing?

These surveys are not mandatory. If you struggle with reading and/or writing, however would still like the opportunity to complete the surveys, speak with your clinician. Alternative ways of completing the surveys can be made available, which your assigned clinician may be in a position to support you with completing.

Can I get a translation of the questionnaires into languages other than English?

We appreciate that English may not be your first language. There are many tools freely available on the internet for translating the survey if you would prefer to read the questions in another language. If this is the case for you, we would advise translating the text before you've indicated your responses, so as to best ensure your privacy.

How long will my data be retained for?

The data will be securely held, complete with unique identifiers, for a period of 10 years. This is to ensure that, should the person be re-referred, their previous OMs can be meaningfully reviewed. Following this period, and assuming no further contact from the patient, all data will be redacted, including any identifying information, and retained in perpetuity in this fully anonymised form to enable ongoing monitoring of service development and in pursuit of continued measurable improvement.

Any hard-copy questionnaires will be securely disposed of once the data has been transcribed into the OM database. This transcription process and secure disposal will be undertaken as soon as is reasonably permissible.

Where can I access the Privacy Notice?

Please visit: https://www.eput.nhs.uk/about/compliance-and-assurance/privacy/

What if I don't respond to the survey?

Access to treatment is not conditional on engagement, however we very much appreciate you sharing your responses as it helps enormously with data oversight and continuous improvement.

How can I access the responses that I feed back?

We're currently working on creating a report for patients that they'll be able to access at the end of their treatment. This work is currently in progress.

How can I ask questions about this?

Your first port of call would be to talk to your assigned clinician. If for some reason you are unable to do this, you can contact the Trust's Contact Centre and request for someone from the outcome measure group to get in touch. To relay this message, please go via the Psychotherapy South-East Essex Admin Team.

What is the evidence underpinning the usage of these surveys?

All the measurement tools that we're using are widely-used, well-established, and recommended for use in mental health settings. As a result, they are helpful is supporting benchmarking.

Below are references to a range of research papers that underpin the usage of the CORE and ReQoL:

CORE:

Evans, C., Mellor-Clark, J., Margison, F., Barkham, M., Audin, K., Connell, J., & McGrath, G. (2000). CORE: Clinical Outcomes in Routine Evaluation. *Journal of Mental Health, 9*(3), 247–255. http://doi.org/10.1080/jmh.9.3.247.255.

Gave the rationale and development of the CORE-OM.

Evans, C., Connell, J., Barkham, M., Margison, F., McGrath, G., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: Psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry, 180*(JAN.), 51–60. http://doi.org/10.1192/bjp.180.1.51.

First and still the most extensive psychometric exploration of the CORE-OM in English in UK clinical and non-clinical samples of convenience.

Connell, J., Barkham, M., Stiles, W. B., Twigg, E., Singleton, N., Evans, O., & Miles, J. N. V. (2007). Distribution of CORE-OM scores in a general population, clinical cut-off points and comparison with the CIS-R. *British Journal of Psychiatry, 190*, 69–74. http://doi.org/10.1192/bjp.bp.105.017657

Gives the first fairly representative UK non-clinical population sample data albeit censored by CIS-R interviews. Uses the "Clinical Score" which is 10x the mean item score in the previous reference.

Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., Mellor-Clark, J., Richards, D., Unsworth, G. & Evans, C. (2012). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research*, 1–11. http://doi.org/10.1080/14733145.2012.729069.

Introduced the CORE-10 with some UK psychometric exploration

ReQoL:

Keetharuth, A., Brazier, J., Connell, J., Bjorner, J., Carlton, J., Taylor Buck, E., Ricketts, T., McKendrick, K., Browne, J., Croudace, T., & Barkham, M. (2018). Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties. *The British Journal of Psychiatry, 212*(1). https://doi.org/10.1192/bjp.2017.10

Main paper outlining the development of the device.

Keetharuth, A.D., Rowen, D., Bjorner, J., & Brazier, J. (2020). Estimating a Preference-Based Index for mental health from the Recovering Quality of Life (ReQoL) measure: Valuation of ReQoL-UI. *Value in Health*. https://doi.org/10.1016/j.jval.2020.10.012

Paper detailing how clinical outcomes can be used to generate health economic insight.

DIALOG

Priebe, S., Golden, E., Mccabe, R., & Reininghaus, U. (2012). Patient-reported outcome data generated in a clinical intervention in community mental health care-psychometric properties. *BMC Psychiatry, 12*, 113. http://www.biomedcentral.com/1471-244X/12/113

Paper investigating the psychometric properties of DIALOG and finding them to be strong.

Mosler, F., Priebe, S. & Bird, V. (2020). Routine measurement of satisfaction with life and treatment aspects in mental health patients – the DIALOG scale in East London. *BMC Health Services Research, 20,* 1020. https://doi.org/10.1186/s12913-020-05840-z

Paper examining the implementation of DIALOG as a routine patient outcome measure, finding that patients in mental healthcare services were “fairly satisfied” in both life and treatment aspects with improvements seen over time.