



**Version 1.0**

# **ADVICE AND GUIDANCE ON WORKING REMOTELY WITH OUTCOME MEASUREMENT AND FEEDBACK QUESTIONNAIRES**

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**Child Outcomes Research Consortium**

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Coronavirus is affecting the way we work and live, changing the demands placed on services and the needs and challenges we face. Many services are adapting to delivering services in new ways: here we share our guidance and advice on working with feedback and outcome measures for services transitioning to working remotely with children, young people and families either online or by phone.

The advice and tips set out here reflect work in progress.

We are actively gathering suggestions, tools, insights and experience that we can share in this area.

Please email us at [corc@annafreud.org](mailto:corc@annafreud.org) or call us at **+44 (0)20 7443 2225** if you are happy to talk to us about:

- what you are doing
- the challenges or issues
- and what you find works well.

Other practitioners and services are keen to learn from your knowledge and experience.



## PRINCIPLES TO BEAR IN MIND

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Measuring and monitoring the outcomes of care is just as important for services delivered remotely as for those delivered face to face. This is part of offering responsive and person-centred care, improving and developing services, and being accountable and transparent.

There is even more of a case for working with feedback where there has been a change in the way support is provided. However you approach this, good practice principles are

- ‘no measurement without meaning’ – know why you are asking, what you are going to do with the information, and explain this clearly
- always acknowledge and respond to the feedback shared through questionnaires
- ask questions as they were designed to be asked – if you adapt an outcome measurement questionnaire, you can’t be confident that it will still be a good tool for measuring what it is supposed to measure.



## APPROACHES TO CAPTURING QUESTIONNAIRE FEEDBACK IN REMOTE PROVISION

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We look at this in terms of three over-arching approaches

1. The questionnaire is **completed at the service user’s end**: the service user will download and complete a questionnaire and send it back to the service (e.g. by email)
2. The service makes a **shared electronic space** available: this might be a portal or platform where measures can be accessed, completed and saved or submitted by the service user, without the service user needing to ‘send’ anything to the service
3. The service user shares their responses to a questionnaire verbally, and these are recorded **by the practitioner** who stores them in the appropriate place in the service’s care record system.

The table below breaks down how these three approaches can work in practice and some of the infrastructure, data protection, back office and practice considerations that you might like to take into consideration in planning your approach.



SPACE WHERE MEASURE IS COMPLETED	AT THE SERVICE USER'S END 	IN A SHARED ELECTRONIC SPACE 	AT THE PRACTITIONER'S END 
			
	<p><i>The service user downloads and completes a questionnaire, and sends it back to the service</i></p>	<p><i>The service owns or creates an electronic space where measures can be accessed, completed and saved without the service user needing to download anything</i></p>	<p><i>The service user shares their response to the questionnaire verbally, and the practitioner records and saves the answers/scores</i></p>
<b>How does this work?</b>	<ul style="list-style-type: none"> <li>Service user is sent the questionnaire directly (e.g. by email) or is sent a link from which they can download a copy</li> <li>The service user might print and complete a hard copy and scan or photograph this</li> <li>The service user might be able to edit the measure in a programme like Microsoft Word or Adobe Acrobat on their computer/ phone</li> <li>The service user returns the questionnaire as an attachment sent on a direct channel (email, WhatsApp).</li> </ul>	<ul style="list-style-type: none"> <li>There are a wide range of platforms available/ in use, with different degrees of functionality, integration with existing care records etc</li> <li>One example is <b>POD</b> a website where staff or clients can login and complete measures online</li> <li>Some services have used online survey tools like SurveyMonkey to capture feedback about service user experience</li> <li>Shared folders in the cloud (akin to GoogleDocs, Dropbox, SharePoint) can also allow a questionnaire to be completed, stored and accessed, by both the service and the service user.</li> </ul>	<ul style="list-style-type: none"> <li>This can be done in any remote working context. It is helpful if video conferencing software has a 'share screen' option so both can view the questionnaire. The blank questionnaire (or a link to it) could also be emailed in advance so both can see the questionnaire being discussed</li> <li>The practitioner records the service users responses. It works well if the practitioner is able to edit the questionnaire live on a shared screen in the session.</li> </ul>
<b>Infrastructure and skills required</b>	<ul style="list-style-type: none"> <li>Depending on the approach the service user may require: Access to internet and electronic device (phone/ laptop/ tablet); printer/ scanner; capacity and skills to save and upload documents on their device; software (e.g. Microsoft Office, Adobe Acrobat).</li> </ul>	<ul style="list-style-type: none"> <li>Access to internet and electronic device (phone/ laptop/ tablet).</li> </ul>	<ul style="list-style-type: none"> <li>Nothing beyond what is needed for the service to be delivered.</li> </ul>
<b>Data protection considerations</b>	<ul style="list-style-type: none"> <li>Is the channel through which the service user returns the completed questionnaire (e.g. email) secure enough?</li> </ul>	<ul style="list-style-type: none"> <li>Security of the shared electronic interface for the storage of sensitive personal data.</li> </ul>	<ul style="list-style-type: none"> <li>None that are additional to the data protection considerations involved in delivering the service itself.</li> </ul>
<b>Back office considerations</b>	<ul style="list-style-type: none"> <li>Will involve data entry and scoring of responses to record these in the care record.</li> </ul>	<ul style="list-style-type: none"> <li>May involve transferring files or data from a shared interface into the patient care record.</li> </ul>	<ul style="list-style-type: none"> <li>Will involve practitioners scoring responses and recording these in the care record (or involving administrators).</li> </ul>
<b>Meaningful measurement</b>	<ul style="list-style-type: none"> <li>If an administrator is involved in this process, arrangements should ensure that the practitioner can access the questionnaire responses in a timely way to discuss them with the service user.</li> </ul>	<ul style="list-style-type: none"> <li>The practitioner needs to be sufficiently confident/ supported with the system to access the questionnaire responses - so that feedback can be discussed with the service user.</li> </ul>	<ul style="list-style-type: none"> <li>Provides a natural opportunity to reflect together on responses (see page 8— Helpful tips and practical pointers 2: filling in a questionnaire together, verbally).</li> </ul>



## HELPFUL TIPS AND PRACTICAL POINTERS 1: VERSIONS OF QUESTIONNAIRES THAT CAN BE EDITED BY PRACTITIONERS OR SERVICE USERS

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### If you have access to PDF versions of the questionnaire you want to use:

- The free Adobe Acrobat Reader does have commenting tools that allow you to add, circle or highlight text and then save the PDF with these 'comments'
- If you are a practitioner going through the questionnaire verbally online and can share screen, we feel it works well for the child or young person to be able to see you edit the questionnaire as you go through it
- The questionnaire can also be edited this way at the service user's end, although do experiment with this yourself to check its suitability for those you work with - not everyone will find this equally user-friendly and practice or advice may help.

### Microsoft office formats, e.g. word, excel

If you are considering reproducing the questionnaire in another format, please bear in mind possible copyright considerations, and the research findings about how questionnaire responses might be influenced by particular contexts or formats – both discussed below.



## COPYRIGHT CONSIDERATIONS

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If the copyright for a measure is held by a measure developer (or other party), specific terms of use may have been set, for example regarding the purposes for which the measure is used or the ways in which it is reproduced. If you are thinking about reproducing or modifying a questionnaire – for example so it can be completed in a particular electronic format – you should check whether this is compatible with the terms of use.

In response to the impact of coronavirus, some developers are taking a more flexible approach: where we have information about this we have highlighted it in our section on 'specific measures' below, as well as putting details on the page for the relevant measure in our [measures hub](#), which signposts to information about terms of use where possible.

Please note that NHS Digital have negotiated licences for a wide range of measures (although there may still be restrictions e.g. to a particular geographic territory): to find out more about a specific measure you may wish to contact NHS Digital (clin.licences@nhs.net).

Modifying standardised measures might affect your ability to flow data from that measure to the Mental Health Services Dataset or to CORC. It may also have an impact on how far your data can be meaningfully compared with data captured using the unmodified measure.



## CONFIDENTIALITY AND DATA PROTECTION

Considerations around confidentiality, informed consent and data protection apply in the normal way. Furthermore, when completing and discussing questionnaires with service users remotely, it may be helpful to suggest going to an area where conversations are less likely to be overheard. You may wish to discuss with service users any new potential risks to the confidentiality of information which you as a service will not be able to control or mitigate – for example:

- If questionnaires need to be saved or printed on devices owned by or shared with others (e.g. parents, carers, siblings)
- If you will be corresponding about questionnaires with both parents and young people using the same email address.

In thinking about any online data transfer (e.g. email, secure messaging app) or online data collection platform, you should consider similar data security questions as for other systems, for example what is the sensitivity of the data being collected, where would password-protection of documents be appropriate, how are user accounts set up and secured, who has access to what data, etc. These aspects should be reviewed regularly as part of your service's approach to data security. Useful resources include [ICO guidance](#), [Cyber Essentials](#), and the [Data Protection and Toolkit Standard](#).

We have received a number of queries relating to SurveyMonkey specifically: it may be useful to be aware that this platform stores data on servers in the U.S., which some Data Protection Officers may not be comfortable with, depending on the type of data being collected and local policies. However, SurveyMonkey does currently have certification for the Privacy Shield Framework, which is a scheme that places requirements on U.S. companies to process data in a way that is considered adequate by the EU Commission.





# RESEARCH RELEVANT TO USING OUTCOME MEASURES ONLINE

There are two aspects of research which may be helpful to bear in mind when you are working with outcome measures online.

## **If you are considering adapting questionnaires, or paraphrasing questions:**

Developers put a lot of expertise into developing measures and the psychometric validation of these – copyrights aim to protect the validity and reliability of the questionnaire:

- validity is the extent to which something measures what it is intended to measure, or how accurate it is
- the reliability is how consistent a measure is, for example, over time or between respondents.

If research shows the questionnaire is valid and reliable, we know it can be meaningfully used with multiple young people, and that we can compare responses across young people and across teams or services. Even small tweaks can mean the questionnaire it is no longer a valid or reliable measurement tool. It would no longer be sound to look at scores against clinical thresholds or norms, or to benchmark the data or to draw meaningful conclusions when looking at multiple scores together at an aggregate level.

## **When interpreting data from questionnaires completed online**

Even when the questions are not changed, research suggests different formats can have an impact on the way people respond to mental health and wellbeing questionnaires. For example:

- research using a quality of life measure found that there was little agreement between participants' responses when responding on digital devices and their responses when using a paper version of the measure (Juniper, et al., 2008; Juniper, Langlands & Juniper, 2009)
- research that compared computer and paper completed SDQs (Goodman, 1997) found that scores on the computer completed measures were significantly lower than the paper-based versions (Patalay et al 2016)
- in contrast, research using the YP-CORE (Twigg et al., 2009) found that young people's online responses were significantly higher than the published responses from face-to-face settings for that measure (Sefi and Hanley 2012)
- another research study points to the possibility of high concordance between paper-completed and telephone-completed quality of life measures (Hawthorne, 2003).

Some research looking at factors that might contribute to these differences have pointed to a possible disinhibition effect online, whereby respondents are more likely to rate measures more severely in an online format (Suler, 2004). Others suggest that there may be more agreement between responses online and on paper where the online measure (e.g. on a handheld device) looks very similar to the paper-based measure (Caro, Caro, Caro, Wouters & Juniper, 2001).

The variation in findings suggests that there is a need for more research in this developing area. When given a choice, the majority of adults and young people opt for electronic versions of measures over paper-based versions (Buchnell Martin & Parasuraman, 2003): there is a need to use these measures in as consistent a way as possible, in lieu of clear research findings as to how they function in different settings.

While we do not have this clear-cut understanding about how questionnaires function in different settings, we recommend that practitioners and services bear in mind, when they are interpreting questionnaire results, the potential for there to be a difference in the way that young people and others respond to measures remotely (compared to the paper-based versions).



## HELPFUL TIPS AND PRACTICAL POINTERS 2: FILLING IN A QUESTIONNAIRE TOGETHER, VERBALLY

We are keen to hear more feedback from children, young people, families and practitioners as to what makes this experience work well. We enjoyed [this video](#) from practitioners at the International Centre for Clinical Excellence in the US talking about what they find helpful in creating a culture of feedback. Based on our own trials, we hope others will find these four suggestions helpful:

1. **Go straight through all of the questions in order without stopping to discuss individual items. Then go back to any responses you feel are important or merit discussion.**

**Why?** This is partly for practical reasons: in our practice runs it was difficult to come back to the questionnaire after digging into individual responses – the discussion may take off into a different track. However this will also be a closer replication of a person completing the questionnaire on their own – the way in which it was designed/ researched as a measurement tool – discussing the items together is likely to influence the way the child or young person responds.

Explain at the beginning that you will be doing this. E.g. *“I am going to go straight through all of the questions without stopping first if that’s ok, even if you say something I really want to talk about some more. Then we’ll go back and discuss what seems important in what you have said.”*

**Why?** So the child or young person is expecting this and doesn’t feel that you are not listening or their response is not important to you.

2. **If you can, it is best if both of you can see the questionnaire you are filling in. You might do this by:**
  - If you are on videoconferencing software that allows you to share screens: by opening the blank questionnaire on your screen and then using the ‘share screen option’
  - If you can email: by emailing a copy of the questionnaire to the child or young person in advance and asking them to have it open for your session
  - If you are both online: ask the young person to open the measure on a website where it can be accessed. This may not be possible for all measures but a lot are available through the CORC website, <https://www.corc.uk.net/outcome-experience-measures/>

**Why?** This helps the child or young person follow you through the questions and empowers them as a respondent; it reduces the likelihood you will depart from the original questions; it is a closer replication of the measure as it was designed to be completed.





3. **Use the exact language in the questionnaire. This is difficult: when you are in a natural conversation with someone you know, it is natural, for example, to paraphrase, soften questions that may seem harsh, or rush over questions that might not seem relevant. We recommend you practice. Some tips and tricks we find helpful:**

- **Ask questions in a way in which it is clear that you are reading a question from a form, not asking a question as part of a natural dialogue.** You will still have your normal warm tone of voice, but ask the question slowly and deliberately and keep your tone level as you read out the statement and spell out each answer option. Pause between options. This helps you to be neutral in asking the questions, and avoid conveying a value judgement.
- **For the first two or three questions, read through all of the answer options.** This way the child or young person has a sense of the range or scale. After that (especially if they can see the questionnaire) they may go directly to the answer and that is fine – much in the same way as when you fill in a questionnaire on paper, slowly at first and then getting into the swing of it as you get familiar with the format.
- **Some questions are written in the first person.** It can feel strange to read these and tempting to paraphrase. Try to avoid naturalising the question by asking:

*“How often would you say you have no energy for things?” Often, sometimes etc*

Sticking with the original wording would be to say

So the first statement is *“I have no energy for things”*. How often does that apply to you? Often, sometimes...

**Why?** We recommend using questionnaires that have been researched so that we know they are reasonably good at measuring of what they aim to measure (e.g. ‘are these questions a valid and reliable way to understand how anxious someone is, how depressed they are..’). If the questions are asked using different words or in a different order, we can no longer be confident about this. For example it will no longer be robust to compare responses, or to aggregate them.

4. **Talk together about the responses given. If you are not already used to doing this, some suggestions to get you started:**

- *“It really stood out for me that you said xxx. Can you tell me a bit more about that?”*
- *“What was it like answering those questions? Are there any that you wanted to talk more about?”*
- *“I’m looking at what you said last time you did the questionnaire and I can see that you weren’t having as much trouble sleeping then. Has something changed there?”*
- *“I noticed the question about xxx was harder to answer and made you stop and think a bit. What was going on there?”*





## MEASURE CHOICE AND GUIDANCE ON SPECIFIC MEASURES

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A change in the way your service is delivered might cause you to review your choice of measure. If you are talking through a measure in a session you might want to consider:

- the length of the questionnaire: if you have been using longer measures, it is worth bearing in mind that research suggests briefer measures can also be psychometrically robust as well as simple to use (e.g. the Child Outcomes Rating Scale (Casey et al, 2019) or Young Person's CORE (Twigg et al., 2009).

In our practice runs we found that verbal completion worked for up to about 10 items – perhaps in some circumstances (for example if the young person is familiar with the questionnaire) this might be different: please share your experience of what works well with us.

- Goal-based measures may feel more natural to integrate into a remote session. Recent research on the Goals and [Goal-based Outcome tool](#) (GBO; Law, 2011) has found good levels of internal consistency between goals which suggests that even though goals vary in content, the goal ratings work together in a more cohesive way than previously thought - similar to standardised measures of mental health and wellbeing outcomes (Edbrooke-Childs et al., 2015).

You can find any information we have about specific measures recorded on the page for that measure in our [measures hub](#) including any guidance we may have on using it remotely, or any current relaxation in its terms of use. Helpful to note:

- CORE Systems Trust (YP CORE and CORE 10) has shared a [statement relating to Covid-19](#) and have shared versions of their measures to support practitioners working remotely at this time
- There are developer-approved video guides available discussing how to administer the [Outcome Rating Scale](#) and [Session Rating Scale](#) in remote work.

We encourage you to test out the questionnaires you use with a colleague and see if they feel like a good fit in your current service context. Choosing an outcome measurement questionnaire always involves balancing a number of considerations, bearing in mind for example:

- The cost and time involved in using it: how long does it take to complete? how easy it is to interpret?
- The purpose of using the outcome measure: what it is you want to understand, and how you want to use this information
- How robust the measure is: does the research suggest it is a valid and reliable tool?
- Whether it is right for your client group: is the language suited to those who will need to fill it out (e.g. the age, demographic or characteristics of children and young people you are working with)? Are the questions meaningful to them?

We welcome conversations with CORC members to review or talk through their outcome measure choices or options.



## SHARE YOUR EXPERIENCE AND KNOWLEDGE THROUGH CORC

Working with its members, CORC has built up lots of helpful knowledge, experience and guidance about using outcome measures to inform children and young people's wellbeing support – but we have had much less feedback about working with outcome measures remotely.

We are keen to hear directly from children, young people and practitioners so we can learn from your successes and failures, tackle the challenges collectively and pool the good practice. If you have information or experience you can share with us, please get in touch at [corc@annafreud.org](mailto:corc@annafreud.org).





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