

Understanding and addressing the challenges of outcome measurement associated with differences in culture



This guidance is for professionals and practitioners that support children's and young people's mental health and wellbeing and engage with parents and carers. It aims to raise awareness of these issues, to identify good practice, and to promote effective ways of using measures that take into account differences in culture.

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Our use of language regarding race and ethnicity

Throughout this guidance, we use the terms ‘minoritised backgrounds and cultures’ to discuss race and ethnicity. The term ‘minoritised’ is used to recognise that individuals have been minoritised through processes of power and is dependent on context. Where research identifies specific ethnicities, we have included this within the guidance. We recognise that much of the research refers to wide racial or ethnic groups, which may not reflect how individuals identify themselves.

If you have any feedback on our use of language that would help us to refine our approach, please contact us at corc@annafreud.org. See more about our commitment to equity, diversity and inclusion [here](#).

About this guidance

CORC is committed to using feedback from children and young people to improve the care they receive. We believe everyone who offers support to children and young people should be using the best available tools and approaches to understand how to help them.

A lot of our work involves the routine use of standardised outcome measurement questionnaires. We have developed this guidance because, through shared learning and collaborations at CORC, we are aware of a range of barriers and issues that children and young people from minoritised cultures experience in engaging with outcome measurement.

While some of these are specific to particular contexts, there are common or overlapping issues such as: different meanings and concepts relating to mental health; distrust about the motive for asking for the information, or how the information might be used; the accessibility of the language generally. There are also some issues associated with the outcome measures themselves (how they were developed, in what contexts, and whether they reflect the diversity of lived experience) and how they are used in different settings. At Anna Freud we recognise that racism is deeply ingrained in the UK's cultural and social systems and has a major impact on the lives and mental health of children and families. Our commitment to being an anti-racist organisation is set out more fully on our [website](#).



Developing the guidance

As part of CORC's commitment to Closing the Gap in mental health support, in April 2023 we formed a working group of professionals from the NHS and voluntary sector organisations across the country to work with us to explore these challenges. We have developed this guidance from these discussions and in consultation with the CORC Advisory group and our wider Anna Freud networks.

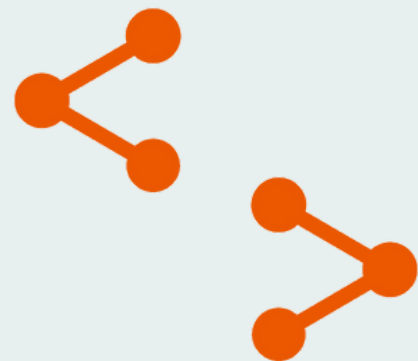
The aims of this guidance are to raise awareness of these issues, identify good practice, and to promote effective ways of using measures in all cultural contexts to enhance support for children and young people.

We do not have all of the answers, but we are committed to ongoing learning and further collaboration to update guidance and resources. Contact us at corc@annafreud.org if you would like to contribute to our ongoing work.

Quick summary

What are the challenges?

- **Accessibility of the language:** the text-based nature of many outcome measures can create challenges in accessibility for children, young people and families, especially for those that speak English as an additional language.
- **Different meanings and concepts related to mental health and wellbeing:** many outcome measures have been developed within a White Western context and may not accurately describe minoritised peoples' experiences and understanding of their mental health and wellbeing.
- **Measurement accuracy:** the applicability and accuracy of outcome measures across different groups has not been widely researched. In some cases, adaptations to scoring thresholds may need to be considered to reflect cultural variation in presentations of mental ill-health.
- **Stigma:** the stigma associated with mental ill-health can be a barrier to reporting difficulties and accepting support, and research suggests that this barrier may be greater for people from minoritised ethnic backgrounds.
- **Issues of trust:** there can be specific cultural challenges related to trust in services and institutions, from experiences of individual and systemic racism or discrimination. Fear around the purpose of outcome measurement, how the data will be used and who will see it may lead to inaccurate reporting, non-completion and disengagement.



How can these challenges be addressed?

- **Build trust and encourage positive engagement** by taking time to introduce the measure you would like to use and explaining why. Use the measure in a collaborative way as a tool for investigating what is happening and building shared understanding to support your work together.
- **Adopt a stance of cultural humility:** be open and curious and avoid assumptions, to help understand the influence that differences in culture may have.
- **Look at the language** in the measure you are using and consider whether using an interpreter or using a translated version of a measure would aid accessibility. If using a translated measure, review whether that different language version has been validated.
- **Consider the culture of the child, young person or family** that you are asking to complete the measure, and whether the questions may be stigmatising or not aligned with their understanding of their mental ill-health. You may want to focus on functioning, goals or quality of life rather than symptoms, and to think about important aspects of their lives that may be missed by some measures.
- **Consider how thresholds and norms might differ** when interpreting data, particularly when comparing between different cultural and ethnic groups.



Context

There are reported differences in the prevalence of mental health problems between children and young people of different ethnicities. NHS Digital’s “Mental health of Children and Young People in England, 2021” survey identified that rates of probable mental ill-health were higher among 6 to 23 year olds in the White British (18.9%) and the mixed or other (22.5%) group, than in the Asian/ Asian British (8.4%) and Black/ Black British (8.3%) groups (NHS Digital, 2021).

These results may seem surprising given that those from minoritised ethnic groups may be likely to experience more stressors, such as racism or social disadvantage. Exactly why this pattern of findings occurs is not clear, though some studies point to other protective factors, such as social support, being more prevalent for some ethnic groups. Others suggest that cultural differences in mental health stigma, and in how mental health problems are described and reported, may also play a role (Evidence Based Practice Unit, 2023).

There are also reported differences in mental health treatment and outcomes for children and young people from minoritised backgrounds:

Outcomes: a recent study found that Mixed Race and Asian young people are less likely to report measurable improvement in mental health difficulties after receiving mental health support in the UK, when compared with White British children and young people (Ruphrect-Smith et al., 2023)

Case closure: in this study Black or Black British young people, Mixed Race young people, and those from Other White backgrounds were more likely to end treatment by non-mutual agreement than White British young people (Edbrooke-Childs et al., 2021)

Attendance: a study using CORC data found that Black children and young people, and those who did not provide information about their ethnicity, were more likely to attend services for a single session only (Edbrooke-Childs et al., 2021)

Pathways: this paper describes data that showed that children from Black and minoritised ethnic backgrounds were more likely to access children and young people’s mental health services through compulsory than voluntary care pathways (Edbrooke-Childs et al., 2016)

Laying the foundations

Obtaining meaningful information from an outcome measure involves the active participation of the child, young person, parent or carer who is filling it in.

Children and young people may be more willing and able to engage with the outcome measurement tools that practitioners ask them to respond to when they feel safe and supported and are confident that their responses will be used collaboratively and in their best interests.

Below we set two areas of good practice that lay the foundations for using measures with children, young people and families from diverse cultures.



Good practice in outcome measurement

The way measures are introduced and explained to a child or young person has a significant impact on how they are perceived and completed. It is natural for many young people, parents and carers to be fearful or confused by outcome measures and therefore practitioners should be considerate of these feelings when introducing measures for the first time. Introduce measures effectively by:

- taking time to **explain** the purpose and benefits of using a measure
- explaining **who** will see the information and **how** it will be used
- being **flexible** with how a measure is completed
- allowing time for the young person, parent or carer to ask questions
- familiarising, planning and practicing with the measure in advance, and **plan and practice** how you will introduce it.

Use outcome measures as a tool to explore and investigate the young person's feelings to get a better understanding of them and to prevent assumptions about their views or how they feel. Measures are part of support and it may take time to build trust within the therapeutic relationship and obtain accurate responses to the measure.

Helpful resources

- [CORC: Recommendations for using outcome measures](#)
- [CORC Training Module 4: Six steps to good practice \(video\)](#)
- Further resources on best practice, including training, can be found on the [CORC website](#)

A stance of cultural humility

Having an interpersonal stance that is other-oriented rather than self-focused, characterized by respect and lack of superiority toward an individual's cultural background and experience'

(Hook et al., 2013)

Taking a stance of cultural humility means that practitioners are **reflective** about the role and influence of culture in the experiences of the children and young people that they work with, in their own lives, and in the work they are doing. Similar concepts of cultural awareness and cultural competence are used within different organisations. The concept of cultural humility shifts the focus away from being aware or competent, to being self-reflective and curious. We believe that taking this stance supports practitioners to use outcome measures to best effect with children, young people and families from minoritised cultures.

Take a stance of cultural humility by:



- being **open** and **curious**
- striving to understand and **avoiding assumptions** about service users and their cultural identity
- being **attentive** to opportunities to explore aspects of a person's cultural identity in a **sensitive, non-judgemental** way.

Research involving adults has indicated that service users' perceptions of their therapist's cultural humility were positively associated with a strong working alliance and with improvement (Hook et al, 2013). Conversely, a lack of understanding of religious or cultural beliefs and obligations, and inadequate cultural adaptations to support outcome measurement, can be barriers to effective support (Faheem, 2023).

Being curious about a child or young person and their experiences can help in acknowledging and exploring wider, intersecting aspects of a child or young person's life which may impact on their mental health and wellbeing or the support being offered.

Gathering feedback on cultural humility

'Measures of experience which focus on service users' experiences of practitioners understanding of their culture have been developed, primarily for adults to complete in the US. One example is the Cultural Humility Scale (National Council for Mental Wellbeing; Hook et al. 2013). This type of service experience feedback tool can be used as part of service improvement work in this area.

What are the challenges and how can they be addressed?

Research into the experiences of children and young people engaging with outcome measurement has identified a number of issues that arise from cultural differences. Some are specific to particular contexts, but many are common.

Common challenge 1: accessibility of the language

Outcome measures can be inaccessible for children, young people and families where they contain unfamiliar words or terms. Language barriers can impact on service users' understanding of questions on measures and therefore their ability to complete them accurately.

Analysis of commonly used outcome measures has shown that the **reading ability** required to understand a measure can be higher than the reading ability that would be expected for children in the age groups at which it is targeted, and for which it has been validated (Krause et al., 2022).

For children, young people and families who speak **English as an additional language** there are additional issues to address in translating mental health and wellbeing terminology accurately, as within many languages there are no equivalent mental health and wellbeing terms (McEvoy et al., 2017).

The text-based nature of measures may also present challenges for **neurodivergent children and young people, or those with learning disabilities**. The intersection between culture and additional learning needs requires careful consideration, particularly as children of ethnic minority groups are over-represented for some types of Special Educational Needs and under-represented for other types, compared to White British pupils (Strand et al., 2021).



A response: choose measures with care; consider an interpreter; consider a validated translation

Consider the cognitive and linguistic development of the children or young people you are working with when selecting a measure to use. It can be tempting to adapt measures to aid understanding, for example by using images or alternative wording. It is important to hold in mind however that this may affect the reliability of the measure (i.e. how consistent and accurate it is as a measurement tool). The CORC website has some guidance about using outcome and experience measures with children and young people who have learning disabilities which may also be useful to draw on (see Helpful resources below).

Give service users the option to use an outcome measure which is in the language they are most comfortable and fluent in. There are **translated versions** of many outcome measures that have been standardised through a process of translation, back translation, and trialling the translated measure. Not all translated measures have been validated in their translated form however (i.e. studied to ensure that they measure what they are intended to measure). Information on the validation of translated measures can be found on the [CORC website](#) or measure developers' websites.

Using an **interpreter** helps children and families communicate their experiences effectively. Where possible, consideration should be given to the gender, dialect and ethnic group of the interpreter, and whether this is acceptable to the service user. Practitioners have reported that being assisted by an interpreter can raise some challenges in building a therapeutic relationship, and in picking up on vital non-verbal cues. Effective interpreter training and collaborative working between the practitioner and interpreter can help to overcome these (Beck et al., 2019). This could include training on mental health and wellbeing, along with additional support if required (as interpreters may have similar personal experiences to the service users they support). Further practical information and guidance on working with interpreters can be found below.



Helpful resources

- [Chapter 3: Good practice models for support \(p.56\). Distress signals: unaccompanied young people's struggle for mental health care. The Children's Society.](#)
- Working with interpreters p.19. [Improving Access to Psychological Therapies \(IAPT\): Black, Asian and minority ethnic service user positive practice guide. British Association for Behavioural and Cognitive Psychotherapies.](#)
- CORC. [Gathering feedback and measuring outcomes and change with children and young people with learning disabilities.](#)

Common challenge 2: stigma

‘Language barriers rarely stood in isolation from other cultural factors, including stigma surrounding mental health’

(Mental Health Providers Forum and Race Equality Foundation, 2015)

Stigma surrounding mental health and wellbeing is well documented across society and is not limited to one particular culture or community. However, a recent systematic review suggests that mental health stigma is higher among ethnic minorities than majorities (Eylem et al., 2020). Some research suggests that anonymous online mental health services may have a higher uptake of young people who reported themselves as being from Black and minority ethnic groups, which may be due to the privacy and anonymity offered by the service (Rajgopal et al., 2021).

Stigma can be based on cultural beliefs, or on fears about the impact of having mental ill-health on a child, young person or family’s future prospects or standing within the community. Children and young people may experience this at home, in school or within community contexts (Li et al., 2020). Children and young people may not respond openly and honestly to an outcome measure where the language or the questions feel stigmatising to them (McEvoy et al., 2017), and this in turn may impact on the effectiveness of the support that is offered.

A response: consider using measures that focus on functioning, goals or quality of life

Consider using measures that focus on wellbeing, the impact of difficulties on quality of life or functioning to **build a full picture** of mental health and wellbeing. These measures use language which may be **less stigmatising** for children and young people because they focus on wider domains of psychological, physical and social wellbeing, rather than symptoms of mental ill-health.



Some examples of measures in these areas include:

Measures of wellbeing	Measures of functioning and quality of life
<u>Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)</u>	<u>Outcome Rating Scale (ORS) and Child Outcome Ratings Scale (CORS)</u>
<u>Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS)</u>	<u>KIDSCREEN-10</u>
<u>Stirling Children’s Wellbeing Scale</u>	<u>Students’ Life Satisfaction Scale</u>
<u>World Health Organisation - Five Wellbeing Index (WHO-5)</u>	<u>Personal Wellbeing Index -School Children (PWI-SC)</u>

Measures for setting and tracking goals

Goal-based measures **avoid stigmatising language** because goals are set by the young person collaboratively with support from their practitioner in their choice of language and phrasing. Goal-based measures give the young person the opportunity to take the lead in the setting of goals, which can create a sense of autonomy and choice.

The **Goal-based Outcomes (GBO)** tool focuses on outcomes that are important to the young person (Jacob et al., 2017) and can include items outside of the scope of many standardised outcome measures that may not accurately reflect the experiences of children and young people from diverse cultural backgrounds.

Goal setting is a vehicle for communication, as agreement on goals can lead to open communication, a shared understanding of difficulties and ways forward. Research suggests that goal setting is a helpful element of therapeutic relationships for young people with anxiety and depression (Jacob et al., 2022).

Building a trusting relationship can mitigate feelings of distrust which may be present in communities that have experienced discrimination and racism. For further information on issues of trust, see page 5.

Consider cultural factors when working with goals. The majority of research into goal setting has been conducted in high-income, Western settings and within some cultures, young people may not have the agency to agree goals, even when they can see the benefit of doing so (Jacob et al. 2022).



Helpful resources

- CORC. [Choosing the right measure for your service or intervention online training.](#)
- Goals in Therapy. [Working with goals online training videos](#)
- CORC. [Collaborative goal setting: what works for whom in therapeutic relationships? \(2021\).](#)

Common challenge 3: different meanings and concepts relating to mental health

Many outcome measures were developed within White, Western contexts and the way they describe and measure constructs of mental health and wellbeing may not reflect the understanding and experiences of children, young people and families from diverse cultural backgrounds.

In some cultures mental health is perceived in the context of spirituality and attributed to religious beliefs which are not routinely asked about in outcome measures (Mental Health Providers Forum and Race Equality Foundation, 2015).

Other cultures emphasise familial, social or community aspects of mental health and wellbeing that are not explored well in many commonly used outcome measures. Not considering these elements and being unable to measure them may limit the effectiveness of support.



The global picture

Globally, researchers have adapted outcome measures by identifying core, local conceptualisations of mental health and wellbeing. This can include internalising and externalising symptoms, but also reflects social and community aspects of mental health and wellbeing, some of which may differ from western outcome measures. For example, in northern Uganda the Acholi Psychosocial Assessment Instrument (Bentancourt et al., 2009) was developed using qualitative data and includes:

- I mutter to myself
- I don't greet people
- I sit with my cheek in my palm

A response: consider what is not being asked within the measure

Consider wider, intersecting aspects of a child or young or young person's life beyond the measure to build a greater understanding of their mental health and wellbeing.

The [Patient and Carer Race Equality Framework](#) encourages mental health providers to explore opportunities to take a **culturally informed approach** to outcome measurement that is tailored for diverse communities (NHS England, 2023).

One example of insight that can inform this kind of tailoring is found in qualitative research conducted for the development of the Centre for Mental Health's 'Culturally appropriate evaluation for young Black men' measure. This identified safe spaces, identity, relationships, levels of agency and control, employment and the role of religion and spirituality as key considerations when determining positive outcomes (Harris et al., 2020). These factors are not included in most commonly used outcome measures but they could play a role in support.

Taking a stance of cultural humility means being attentive to opportunities to explore aspects of a person's cultural identity in a sensitive, non-judgemental way. An example of this is the Cultural Formulation Interview that follows.



Cultural Formulation Interview (CFI)

The CFI (American Psychiatric Association, 2015) is an interview protocol designed to promote culturally competent practice and to include service users' perspectives in developing formulations of mental health problems. One of the supplementary modules to the Core CFI explores cultural challenges, stressors, and resilience for school-age children and adolescents (Lewis-Fernandez et al., 2015). Although there are limited studies using the CFI with children and young people (La Roche et al., 2020), it includes cultural questions that may be useful to explore from a stance of cultural humility and curiosity. For example:

“Sometimes people have different ways of describing their problem to their family, friends, or others in their community.

How would you describe your problem to them?”

“Sometimes doctors and patients misunderstand each other because they come from different backgrounds or have different expectations.

Have you been concerned about this and is there anything that we can do to provide you with the care you need?”

Helpful resources

- American Psychiatric Association. [Cultural Formulation Interview and Supplementary Modules to the Core Cultural Formulation Interview Module 9: School-age Children and Adolescents](#)
- The National Child Traumatic Stress Network. (2020). [Measures that are appropriate for refugee children and families](#)



Common challenge 4: measurement invariance across ethnicities

Studies exploring measurement invariance for outcome measures look at whether different groups of people interpret and respond to an outcome measure in a similar way (i.e. the responses to the measure do not vary across different responder groups).

CORC has reviewed research about measurement invariance across different ethnicities for some child and youth mental health and wellbeing outcome measures (see below). However the number of studies is relatively small, especially among UK populations and more research is needed.

Measurement invariance across ethnicities

CORC reviewed some studies exploring the relationship between outcome measures commonly used in child and youth mental health services and ethnicity or culture. Our review found that some studies suggest that the RCADS sub-scales were generally invariant, although this research did not use UK data (Ruby, 2020).

Studies investigating measurement invariance of the SDQ have been mixed. Several found it to be invariant, while others report that it may not allow for meaningful comparisons across ethnicities or countries (Ruby, 2020). One study suggested that using the SDQ alone may lead to underestimating the needs of unaccompanied children and young people seeking asylum, particularly in relation to the impact of trauma (The Children's Society, 2018). Another recent study of the parent-reported SDQ suggested that it is invariant for children aged between 5 and 14, but more consideration is required outside of these ages (Toseeb et al., 2022).



A response: be mindful about the limitations of measures

Research is limited in this area, and more work is needed to better understand strengths and limitations of different measures, and how they can be used to make meaningful comparisons across different contexts.

Meanwhile, it is appropriate to:

- be **curious** about the possibility that some groups of children and young people could be responding to the questions in the outcome measures differently
- use the data from the outcome measures alongside **other sources of information** to help create an accurate and rounded picture of a child or young person's mental health and wellbeing.

Common challenge 5: issues of trust

There may be a higher degree of distrust of services and institutions where people have experienced **individual** or **systemic racism** and **discrimination**. For example, specific examples of distrust towards services within the Muslim community around the use of the Prevent duty (Aked, 2020), and reluctance to access services due to discrimination towards the Travelling and Gypsy communities (ONS, 2022) were highlighted in consultation with our networks.

High levels of distrust can result in fear about the purpose of outcome measurement, how the data will be used and who will see it, and this may lead to non-completion and disengagement.

A response: communicate clearly the purpose of measures and give regular feedback



Explain the purpose of outcome measures before asking for them to be completed and build trust by listening to the concerns of young people and their families.

Young Champions at Anna Freud tell practitioners, when asking them to complete outcome measures, to:

1. Explain why you are asking me to fill it in, go through the results with me, and make the questionnaire feel part of our sessions together.
2. Think about what it will be like for me to fill it in, and be there to support or help me if that is what I need.
3. Explore my questionnaire responses with me and be clear that a questionnaire score can only be a part of building a bigger picture of who I am, and how I'm feeling.
4. You asking me to fill in the questionnaire is impacted by our relationship: if I trust you and understand where you are coming from, then it will be more meaningful.
5. Give me choice where you can, and don't make assumptions about how I will feel about the questionnaires.

(Child Outcomes Research Consortium, 2020)

Helpful resources

- [How do young people relate to completing outcome measures? \(video\)](#)
- [Outcome measures information leaflet for children, young people and families](#)

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The Child Outcomes Research Consortium (CORC) brings together organisations and individuals committed to using and improving evidence to improve children and young people's mental health and wellbeing. We are experts in measuring mental health outcomes.

Founded in 2002 by a group of mental health professionals determined to understand the impact of their work, today our network includes mental health providers, education settings, cultural and community services, local authorities, professional bodies and research institutions from across Europe and beyond.

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