

PERSON-CENTRED CARE IN CHILDREN AND
YOUNG PEOPLE'S MENTAL HEALTH SERVICES

Setting the standard for personalised care

A guide for commissioners of mental health support for children
and young people



EBPU Evidence Based
Practice Unit

A partnership of



Anna Freud
National Centre for
Children and Families



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What do we mean by person-centred care?

Person-centred care places the individual receiving the service or support at the heart of their care.

The Health Foundation identifies four principles of person-centred care:

1. affording people dignity, respect and compassion
2. offering coordinated care, support or treatment
3. offering personalised care, support or treatment
4. being enabling

Why commission personalised care?

Personalised care involves a professional working together with the children and young people they are supporting – and their families and carers – to:

- understand their needs
- agree goals
- consider options for treatment and support
- put in place plans that take account of needs and preferences
- communicate on an ongoing basis about how things are progressing
- monitor progress and respond to feedback.

In this way providing personalised care is a collaborative process, which continues throughout the course of care.

Where people are involved in collaboratively planning their own care and support they are more likely to receive – and engage with – care or treatment that is appropriate to them. Evidence also suggests that personalised care planning plays a part in making the most effective use of resources.

Government policy and best practice guidance set out a clear case for personalised care, and as a consequence many commissioners are keen to promote personalised care both through explicit requirements within service specifications and contractual requirements, and through ways of working that will promote a person-centred approach.



This leaflet provides tips for funders in addressing some of the challenging questions in commissioning for personalised care.

What might I expect to see in a service that is personalising care?

There are a range of tools and approaches that you might like – or expect – to see in evidence in a service that is seeking to personalise the care it offers. The specific choice and mix of these (and other similar) elements will be guided by the purpose and context of your services and the particular groups of children and young people accessing support.

Examples of professionals working with children and young people, their families or carers in a collaborative way to:

	Types of evidence	Specific example
Understand needs	Using patient-reported outcome measures is a way of gaining feedback from a child or young person – or their parent/ carer – about their needs and the difficulties they are experiencing. These measures might relate to the individual's symptoms, functioning, or general wellbeing.	See the CORC website for a wide range of measures suitable for different purposes and age ranges. www.corc.uk.net

	Types of evidence	Specific example
Agree goals	Goal-based tools offer a way of capturing goals that have been collaboratively reached, and monitoring progress towards them over time.	Goal Based Outcome is a widely used tool in this area.

	Types of evidence	Specific example
Consider options for treatment and support	<p>The availability of accessible information about the different kinds of care, support and treatment on offer is an indication that a service is geared up to collaborate on this conversation.</p> <p>Decision-aid tools can be used to help consider the pros and cons of alternatives on offer. For example they might set out the evidence base for different interventions in an accessible way, alongside other considerations such as how, where and when the treatment is offered.</p>	<p>Websites and leaflets relating to your local provision.</p> <p>Booklets about the evidence base, like <i>Choosing What’s Best for You</i> published by the Anna Freud National Centre for Children and Families.</p> <p>Option grids, or tools like this Ottawa personal decision guide https://decisionaid.ohri.ca/docs/das/OPDG.pdf.</p>

	Types of evidence	Specific example
Plan interventions and support together	<p>Individual care plans should be used and structured in a way that facilitates the involvement of children and young people in decisions about their care.</p> <p>There are validated measures that assess the quality of service user involvement in shared decision making. The examples we are aware of have not yet been validated in child mental health settings.</p>	<p>The individual care plans used by the service.</p> <p>Example measures include CollaboRATE, SDM-Q-9.</p>



	Types of evidence	Specific example
Monitor progress and respond to feedback	Using patient-reported outcome measures and goal tracking tools on a regular basis, e.g. session by session, is a mechanism for finding out from children and young people if care is having the intended impact.	Session by session use of measures. See the CORC website for a range of measures suitable for different purposes and age ranges www.corc.uk.net .

	Types of evidence	Specific example
Understand if care is personalised to a specific context	There are patient-report feedback tools that measure the extent to which a child or young person feels heard, understood or empowered in a particular session or relationship.	Session Rating Scale (therapeutic relationship) Session Feedback Questionnaire



	Types of evidence	Specific example
<p>Get feedback about how well the service overall is personalising care</p>	<p>Experience of service questionnaires can ask service users whether they felt they were listened to, and had their views and preferences taken into account.</p> <p>Service user involvement and participation groups may also offer opportunities to gather feedback from those who have accessed services.</p>	<p>Chartered Health Institute Experience of Service Questionnaire (CHI-ESQ) is widely used.</p>

What metrics could I use to monitor the quality of personalised care?

Where approaches and tools like those described are being used in a service, quantifiable metrics can be used to capture the extent to which they are being employed or the quality of interactions. Quantifiable metrics could include:

1. Indicators of professionals routinely drawing on feedback from children and young people as part of using outcome measures to understand their needs and symptoms.

For example:

The proportion of cases in which a child- or parent-reported measure of symptoms, functioning or wellbeing is used.

2. Indicators of professionals routinely enquiring about, and taking account of, children and young people's views, aspirations and preferences in planning care.

For example:

The proportion of cases in which a goal is being captured in a goal-based outcome measure.

The proportion of cases where personal care plans are being developed.

3. Indications that the professional and child/young person, and family where appropriate, are involved in reviewing and discussing progress over time.

For example:

Data from patient-reported outcome measures is captured at multiple time points for one episode of care.

Data on progress towards goals is captured at multiple time points for one episode of care.

4. Measures of the quality of the interactions between the child/ young person and professionals in the service.

For example:

Feedback from experience of care questionnaires.

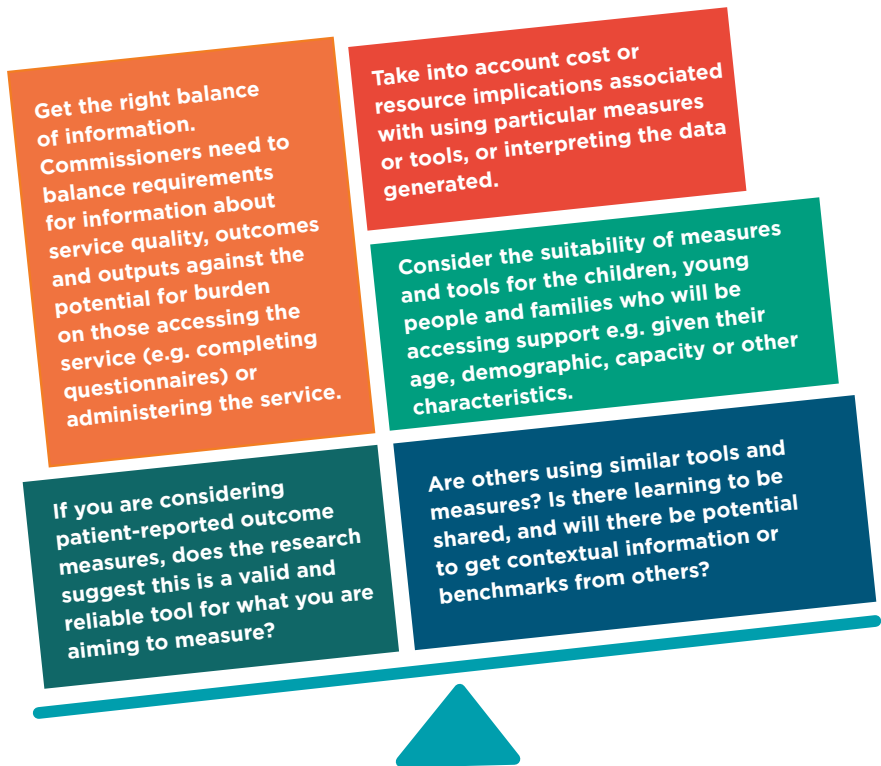
Feedback from questionnaires about the quality of shared decision making.

Please note that session-by-session feedback questionnaires about the quality of a therapeutic alliance are important tools in clinical practice but the information they generate may not be meaningful outside of this context or at a service level and we do not recommend their use in a performance management context.

What is an appropriate way to set a standard locally?

In agreeing on local metrics to use, commissioners should consider that any outcome and feedback data collected routinely in children and young people's mental health settings should be interpreted and used with care (see below). With this in mind, a recent report from the **Child Outcomes Research Consortium (CORC)** provides some contextual data for commissioners wishing to explore setting a benchmark in this area.

The best choice of metrics for personalised care in your area will relate to your local context and strategic priorities, and to the design of services and support locally. For this reason the decision should be made collaboratively, drawing on the expertise and knowledge of those who provide and use services, as well as commissioner requirements and insight from research and policy.



Working with messy data

The Child Outcomes Research Consortium (CORC) describes the information that we often get from patient-reported questionnaires in children and young people's mental health as flawed, uncertain, proximate and sparse – or FUPS:

Flawed, due to missing or erroneously recorded data.

Uncertain, due to differences in how data items (e.g. questions) are rated on a questionnaire, and/or variation in case mix.

Proximate, in that they are always a proxy for an indication of the impact of the service provided.

Sparse, in that even within complete datasets the low volume of cases within a given subgroup often limits the applicability of statistical inference.

Despite data limitations CORC argues that it is essential to examine the data we do have, and use it to inform thinking and decision making about what we can expect from personalised care in children and young people's mental health services. To support commissioners in this, there are several recommendations on working with FUPS data:

- **Focus on building a conversation around the data**, rather than expecting it to provide definitive answers.
- **Be open about the fact that analysis may be limited**, contain mistakes, or not account for subtle clinical points.
- **Be explicit if cases have been removed due to problems** with the data's completeness or quality.
- **Present data in a way that conveys any limitations on the interpretation of data**, e.g. include in reports the raw numbers that analyses are based on, not just percentages.
- **Provide a full definition of the metrics you are using**, and keep language precise and neutral.



- **Focus on accessible descriptive analyses**, and avoid terms like 'significance' or 'performance data' when making comparisons between groups.
- **Avoid 'black boxes'** – for example, complex statistics on very limited data – unless there is a clear reason.

How can I best work with messy data?

Using FUPS data to understand how well a service is embedding personalised care can raise some issues, with debates about the accuracy of data over-shadowing dialogue about what it might suggest and the actions it could prompt. To overcome this, CORC recommends facilitated stakeholder discussions that draw on expertise and knowledge from funders, those who provide services, and those who are using services. These discussions might include an exploration of the data under conditions which acknowledge the reality of data uncertainty, or triangulating different types of data from multiple perspectives. It would be advisable to give full consideration to the questions:

- If this data are a true reflection of reality, what would this mean?
- Is there action we would want to take?
- Are there actions we will take? How can we find out more?

Conclusion

Commissioners play a key role in supporting an open and progressive culture around personalised care. Thoughtful use of data to monitor the quality and extent of personalised ways of working can provide opportunities to build insight and collaborate on opportunities to improve services.



The Health Foundation Person-centred care resource centre

Information about person-centred care together with resources from The Health Foundation and recommendations from around the web.

personcentredcare.health.org.uk



The Child Outcomes Research Consortium (CORC) is the UK's leading membership organisation that collects and uses evidence to improve children and young people's mental health and wellbeing.

www.corc.uk.net

EBPU **Evidence Based** **Practice Unit**

Founded in 2006 as a collaboration between UCL Faculty of Brain Sciences and the Anna Freud National Centre for Children and Families, the **Evidence Based Practice Unit (EBPU)** bridges cutting-edge research and innovative practice in children's mental health. We conduct research, develop tools, provide training, evaluate interventions and disseminate evidence across four themes: risk, resilience, change and choice. Our vision is for all children and young people's wellbeing support to be informed by real-world evidence so that every child thrives.

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