Goal-based measurement in paediatric settings: implications for practice

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Contributions

JEC and JJ conceived the research, JJ, JEC, HF, TS and DL drafted and reviewed the manuscript.

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Competing Interests

JJ and DL have produced guidance on the Goal and Goal-based Outcomes tool (GBO). DL developed the GBO, trains people in its use and advocates for the clinical utility of idiographic tools. JJ and JEC currently work on the CORC project, which encourages the use of idiographic goal-based outcome measures.

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Abstract

There is an observed link between physical illness and mental health difficulties and an increased likelihood of mental health difficulties in young people with chronic health conditions. The main outcomes focus in paediatric settings is on physical health outcomes and functioning. In terms of emotional wellbeing, the focus is on quality of life, measures of wellbeing and perceptions of personal change, which is likely to be multi-faceted and vary between patients. To complement standardised and diagnostically based measures, goal-based outcome measurement may be considered. The aim of this paper is to build on previous research, to provide a reflective commentary based on the authors' clinical and research experience in the use and interpretation of goal-based outcomes, to address what using goal-based measures for outcome purposes in these settings means practically. Examples are provided to demonstrate the importance of considering meaningful outcomes of importance to young people and how professionals may presume that physical 'recovery' is the goal of treatment, but what recovery means to that young person may be very nuanced. Further key considerations and suggested phrasing are given to introduce and work with young people's goals.

Key words: *goals, outcomes, patient-defined outcome measures, goal-based outcomes, paediatrics, paediatric settings*

There is a UK central government drive to explore mental health and wellbeing in all elements of physical health care.[1 2] This stems from the observed link between physical illness and mental health difficulties[3 4] and indeed, research has shown an increased likelihood of mental health difficulties in young people with chronic health conditions.[5 6] Within physical health settings, the critical role of paediatric psychological professionals is to ensure high priority is given to meeting the mental health needs of young people, alongside specific physical health needs. To evidence outcomes in physical health, measures of progress are tracked in a multitude of ways, depending on the illness or presentation. For example, blood glucose and HbA1C in diabetes management; symptom and symptom burden measurement; pain inference measurement; blood pressure; weight; biochemical markers; magnetic resonance imaging and so on. Routine outcome monitoring for mental health mainly consists of standardised measures which seek to assess and monitor psychosocial factors young people commonly present with, such as anxiety, depression and behavioural difficulties (see Ruby et al., 2021[7]). These measures may be specific or general in focus. However, whilst some existing symptom-focused outcome measures may be useful in some cases, they may not align with young people's perception of outcomes that are of central importance[8 9], particularly in paediatric settings.[10] This in turn may lead to respondent fatigue[11] or may be time consuming for the patient and family with little perceived return. The current outcome focus in paediatric settings is on quality of life and measures of emotional wellbeing and perceptions of personal change, which is likely to be multi-faceted and vary between patients.[12-15]

To complement standardised and diagnostically-based measures, idiographic, or patient/client-defined measures enable young people to choose and track bespoke areas of change. One such patient-defined way of tracking mental and physical health needs is a goal-based approach. Goal-based outcome measures give a voice to patients, by allowing them to articulate outcomes of importance.[16 17] Research suggests that patient-defined outcome measurement covers areas of enquiry not otherwise explored by diagnostically-based measures, such as self-understanding, self-efficacy, confidence and help-seeking behaviour.[7 18] Whilst families usually help to complete standardised questionnaires, which may be key in some cases, goal-based work is conducted directly with young people. Such measures have demonstrated good face validity amongst young people and their representatives.[19 20] Goal-based measurement in paediatric settings may provide a way to ensure outcomes of importance for young people living with health conditions are captured. For

example, young people living with chronic health conditions, such as Type 1 diabetes consider outcomes of emotional well-being and social functioning to be important in addition to health outcomes.[21] The personalised nature of goal setting can help foster individualised patient-centred care, whilst also measuring progress, in ways that existing patient reported measures cannot.[13] The use of goal setting also fits well with the government call for more personalised care focussed on 'what matters' to people and their individual strengths and needs, with shared decision-making a central component.[22]

The aim of this paper is to build on the authors' previous discussion paper.[13] There, we presented the argument for meaningful mental health and wellbeing outcome measurement in paediatric settings, focused on goal tracking as a viable way to do this. Here, we will provide a reflective commentary based on our clinical and research experience in the use of goal-based measures, to address what using goal setting and tracking in these settings means practically. This includes discussion about incorporating of the perspectives of non-psychologists where the challenges they face might be quite different. Real life examples provided are in relation to specific conditions, given the authors' relevant expertise and experience.

Using goal-based measures in paediatric settings

Goals are defined as working on the existing gap between current and desired states[23] and 'intended changes in behaviour and experience to be attained by therapy'.[24](p. 354) Patients attending health settings are there for a purpose, which may be translated into goals; they want their lives to be different. These experiences of difficulties have motivated help-seeking behaviour, which may be led by young people, or by parents/carers. Goals may sit alongside usual clinical work[25], or particularly in psychological settings, goals might lead to shifts in clinicians' work to be goal focused.[26] It is the role of multidisciplinary teams including psychological professionals, to ensure that mental health goals are prioritised as much as physical health goals and incorporated into medical appointments.

Phrases used by clinicians to help facilitate goal setting include: *"what do you want to be different?", "where do you want to get to?",* and *"how do you want things to change?".* Tools such as the Goal-Based Outcome tool (GBO)[29], are considered effective measures of change during the course of therapy and provide useful information to facilitate clinical conversations.[27] The GBO allows

young people to set up to three goals, tracking progress on a scale from zero to ten where 'ten' signifies goal achievement. Goals may change over the course of care, and it is important to balance this with the complexity of tracking progress over time. Clinicians might instead work flexibly with patients and deviate from goals as required, perhaps treating them as guidance topics to remain on track.[19 28] However, in order to be effective, goals must be individually tailored and collaboratively used.[26]

Goals provide 'destinations' that young people wish to head towards: *"I want to go out with my school friends more"* may be a destination goal for a young person with anxiety, who may struggle to leave the house. The intervention, perhaps Cognitive Behavioural Therapy (CBT), is the 'vehicle', or method, to help them move towards their goal. The same could be true in paediatric settings: a young person with a medical illness or complex medication regimen, might similarly struggle to leave the house, to get to school or to socialise. This young person may have a similar destination goal to the young person with anxiety, but the 'vehicle' for reaching the goal will be a more physical intervention: surgery to improve mobility or a different way of delivering insulin to a young person with diabetes such as via a pump, instead of having to administer multiple daily injections, thus not needing to inject in front of peers.

Practicalities for paediatric settings

Goal-based measures could be integrated into paediatric settings' routine practice in initial assessments and throughout treatment. For some young people, the first assessment may not be the right occasion to discuss goals; there is a lot of information to gather in a short time and therapeutic alliance to establish. Young people may not be ready to think about goals yet and may still want their doctors to know how hard it is, thus may not be able to focus on recovery. There is increased recognition of the importance of seeing young people alone to undertake holistic assessments including psychosocial screening tools such as the HEEADSSS psychosocial interview[32]. The HEEADSSS is a semi-structured interview tool which gathers information about young people's lives, including home, education, activities, recreational drugs, mood and sleep and sexual and gender orientation. If such an interview is conducted as part of paediatric clerking clinic assessment, goal-

based discussions will follow on nicely, as the rapport will have been built through this process and the clinician will have shown an interest, and a better understanding of the young person's life.

We might assume when a young person presents with CFS/ME that 'recovery' is the goal of treatment, but what recovery means to that young person may be nuanced. It might mean returning to education full time, or conversely to stop going to school and access education online and hence have more energy to do other activities or socialise. It might be an improved sleep pattern or being able to go out for a full day with friends or to go horse riding, not as we may assume, to go to school. For a young person with functional neurological symptoms, the goal may be to get back to school in a wheelchair, not as we may assume, to be able to walk. Further, Other examples include: a young person with poorly controlled inflammatory bowel disease due to poor concordance with treatment. Identifying a goal such as starting puberty and growth and the vehicle is improved concordance with medication; in a young person reluctant to leave the house due to anxiety about the possibility of bowel accidents, the goal is to leave the house and the vehicles are medication to reduce stool frequency alongside talking therapy. Poor concordance is common in young people and strategies to identify barriers and improve this may be help achieve agreed goals. For example, previous research has highlighted the social stigma young people have experienced associated with diabetes and diabetes treatment, which may undermine attempts to treat their diabetes in social, school, or work environments.[30 31] See Table 1 for two real life case studies, to demonstrate goal setting and tracking in paediatric settings.

<Table 1 to go about here>

By regularly tracking goals, progress can be evidenced for young people but also for services, when often outcomes not pertaining to physical symptoms might be missed or lost to reporting because of a lack of suitable, quantitative measures. Integrating goal setting into practice could also help direct referrals and treatment approaches from paediatric multidisciplinary teams, possible 'vehicles' to reach goals. Conversations about goals with young people may help paediatricians consider whether referrals to psychology, occupational therapy, physiotherapy, mentoring or educational support might be most appropriate. A well-timed joint consultation with psychologist/occupational therapists and paediatricians may be helpful to bring the work together. If priority is truly given to the interest in whether interventions, biological or behavioural/psychological,

are having a positive impact on the lives of young people, it is imperative to listen to and understand what important change in their lives is. Asking young people about goals helps to provide a sense of agency and build trust, in a system in which young people can feel out of control, 'done to', and fearful; young people then become 'participants' and not just 'patients'.[34] It is this added agency that may explain the emerging evidence suggesting positive links between collaborative goal setting and good mental health outcomes. [35 36] Once young people's goals are understood, it is the job of professionals to explore what 'vehicles' might help goal achievement. These 'vehicles' can in turn be shared with young people and therefore improve the shared decision-making process. With support from adults, young people can weigh up the benefits and disbenefits of interventions, against its likelihood of helping them move towards their goals.[37]

Considerations

Goal setting might helpfully be seen as a process *and* a task. The 'process' of having goal-focussed conversations is a vital part of any intervention assessment, it facilitates a sense of agency and inclusion with young people by involving them in decisions about their care, and is the basis for informed consent. Even very young children or young people with cognitive impairments can, and should, be involved in discussions about what they hope to get from an intervention. More time and careful consideration of appropriate language may be needed, along with training and support to clinicians to facilitate goals that are genuinely privileging young people's own hopes for their future. The 'task' of setting genuinely collaboratively agreed goals that are safe, and fit with the context and remit of the service, is more challenging. Using goal-based measurement may be more challenging with some young people attending paediatric settings as it requires agreement on intended treatment outcomes. Clinician reservations may include concern about what to do when the young people and parent/carers' goals, or patient and clinician goals do not align, especially as poor adherence to medical treatment is common in adolescence for many reasons. [38 39] Take for example, a young person with Type 1 diabetes with a high Hba1c and poor adherence to their management regime. Their doctor's primary goal might be to improve diabetes control to reduce the risk of diabetic ketoacidosis admissions and long-term complications (physical goal), yet the risk may not presently concern the young person, and instead their goal is to not miss out on activities, or risk embarrassing hypoglycaemic episodes which are more likely with lower blood glucose levels (mental

health/wellbeing goal). Their goals to live without diabetes constrictions getting in the way (frequent injections and blood glucose measurements) are at odds with the paediatrician's goals of optimising HbA1C and preventing long term sequelae. There are also times when patients suggest goals that may be surprising to clinicians, such as *"to go to a football match and catch the ball"* ([33] p.14). The task then is to explore these goals in more depth; what is the meaning of this goal, what determines these goals which, on the surface, do not align with clinical work, and would not be captured on other types of outcome measurement. See Table 2 for examples of real clinical goals not associated with symptom reduction, and the associated underlying determinants.

Where seemingly unethical goals, or goals that do not fit with support clinicians can offer are suggested, more careful negotiation and exploration is required[25]. These divergent goals present challenges, but also opportunities to engage young people in their healthcare in meaningful ways, e.g.: *"If we were to work towards your goal of 'socialising more' what would ten out of ten look like? What would seven look like? What would need to be happening with diabetes to make this possible?".* You may then be able to find some areas of common goals. It is also important to be cognisant that goals belong to the young person, are important to them, and therefore any progress along the journey can be celebrated, not just the ultimate achievement of goals. This is also true when working on collaboratively agreeing goals with parents/carers in addition; further careful negotiation may be required here to find that common ground, with emphasis placed on the young person owning the goals.

<Table 2 to go about here>

When working with young people living with chronic health conditions, routine follow up appointments can be optimal moments to review goals and help paediatricians stay connected to the outcomes of importance to young people. Of course, goals might change with shifts in symptoms, management of conditions, or general life changes, and discussing goals can provide moments to review progress, the relevance of goals, and to set a focus for both a clinic appointment and ongoing support. Careful consideration of the appropriateness of goal setting when working in acute paediatric settings is needed, e.g., a young person in high levels of distress or in a medical crisis may not be able to set goals.

Tips for paediatricians

- Reviewing goals at follow up appointments can help keep track of progress and ensure you are working towards the outcomes of importance
- The GBO can be a useful tool for clinicians working with young people living with chronic health conditions to work towards meaningful markers of progress and support shared decision-making
- If goal-based work is being done by another member of the multi-disciplinary team, ensure those conversations also feed into your medical appointments, either by meetings or joint appointments
- Goals should be future-focused, positively framed and realistic
- Once you have identified goals, you can work collaboratively to identify vehicles that are most likely to achieve them.

Introducing goal-based measurement in clinic

Some example sentences (taken with permission from Law & Jacob, 2013):

"that has been really useful to help me understand a little about what has brought you here today; next it might be helpful for us to think together about what your hopes for the future might be"

then follow on with…

"so from what you have told me so far, what would you say your main goal is from coming to this service?"

"If we were to work together in a very helpful way, when we agree to stop meeting/ in six months' time, what things would you hope to be different by that time from how things are now?"

Conclusions

Whilst it is critical to monitor objective and clinical outcomes, it is of equal importance to track subjective, personalised and meaningful mental health outcomes. The challenges of using standardised outcome measurement in mental health settings are mirrored in paediatric settings, such that not all areas of interest and priority from clinical viewpoints are of equal importance to young people. It is therefore imperative that across all settings, professionals work collaboratively on tracking outcomes of value to young people. Previous research has demonstrated that these areas of importance may be associated with existential areas.[18 19] Through the examples given, we have demonstrated that there also may be more practical goals that are achieved through the 'vehicle' of clinical interventions that might not be immediately evident on first presentation. Where professionals in paediatric settings feel that the current focus on specific symptom improvement and quality of life may not be the right fit, the existing success of goal-based measurement in mental health settings may be replicated. We have demonstrated through lived examples, how goal-based measurement can be a worthwhile tool for use in paediatric settings. There will be young people for whom standardised measurement will feel appropriate; the key is to work with all young people to determine what their outcomes of importance are and how they may be tracked in the most appropriate ways. This may include some standardised measurement supplemented with goal-based outcome measurement.

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Tables

Table 1: Case Studies

Demographics	Case Study
Case Study 1. Chris 16 years old Living with severe ME/CFS	Chris has significantly reduced mobility, spending most of the day in bed, sensory sensitivity and mutism was seen for inpatient rehabilitation. Setting goals collaboratively with Chris was initially challenging. He could only manage very short sessions with his consultant and rehab team and was unable to speak. Using a communication board with words and images, Chris was able to communicate he wanted to focus on gaining mobility and strength, and he did not want to work on speaking. He was able to scale his progress through pointing at a drawn scale (0-10). As his strength built, he was able to communicate using a tablet that his goal was to gain independence, and a vehicle to doing this was through working on communication, as well as his mobility. As Chris's communication improved, he was able to share more nuanced goals to work towards, e.g., preparing his own food, and ultimately getting to the pub for his 18th birthday.
Case Study 2. Grace 17 years old Living with type 1 diabetes	Grace was struggling with managing the condition and her mother asked the diabetes service for more help. Initially Grace set a goal to improve diabetes management through more

	frequent blood glucose checks, and insulin blousing (a dose taken to handle a rise in blood glucose). Grace rated her goal progress as halfway, as her mother contacting the team had increased her motivation. However, through further exploration of what some of the barriers might be to more regular blood glucose monitoring, Grace was able to share that when she saw a high blood glucose level it left her feeling frustrated that her efforts to manage diabetes were not working and she experienced lots of self-critical thoughts, which then led to her avoiding checking. In collaboration with her consultant and psychologist, Grace changed her primary goal to self-compassion and agreed to additional sessions with the psychologist to work on negative thoughts that were connected with diabetes management.

Table 2: example goals and underlying determinants of the goals

Goal	Underlying determinant of goal
To go to a football match and catch the ball	Anxiety related to socialising in a large crowd. Goal achievement would mean that the anxiety had reduced enough to enable this activity
Stop going to school and access education online	Anxiety related to not being able to fully access in-person education/high levels of absence. Goal achievement would reduce anxiety and increase independence to adapt the learning environment for their individual needs
Being able to go out for a full day with friends	Anxiety/depression limiting their ability to socialise. Goal achievement would mean a reduction in anxiety/depression symptoms, leading to increased independence and ability to socialise
To go horse riding	Anxiety/depression limiting their ability to engage in hobbies. Goal achievement would mean a reduction in anxiety/depression symptoms, leading to increased independence and ability to engage in activities, which was not previously possible
To access education in a wheelchair rather than to improve walking	Self-esteem related to not being able to fully access in-person education. Goal achievement would increase independence and their ability to socialise

Learn to drive	Anxiety/depression limiting their ability to socialise. Goal achievement would mean a reduction in anxiety/depression symptoms, leading to increased independence through learning to drive