A national survey of current provision of waiting list initiatives offered by child and adolescent mental health services in England

Abstract

Background: Children and young people accessing child and adolescent mental health services (CAMHS) often report delays in receiving an assessment and commencing treatment. In 2018, the James Lind Alliance acknowledged developing CAMHS waiting-list interventions (WLI) as a top 10 priority.
Aims: This study aimed to examine the current provision of WLI in CAMHS.
Methods: During 2021, an online survey was sent to each National Health Service (NHS) trust providing CAMHS in England, to explore provision of WLI within their trust.
Findings: Of the 57 CAMHS trusts identified as meeting inclusion criteria, survey responses were received from 16 trusts, 12 of which had implemented WLI, a large proportion of these were digital interventions. Barriers and facilitators to WLIs were identified, particularly availability of staff.
Conclusions: WLIs are being used in some trusts but with limited evidence of evaluation, further research on the acceptability and effectiveness of WLI is warranted.

Key words

CAMHS, wait list initiative, children's mental health

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Once referred to child and adolescent mental health services (CAMHS), children and young people and their families often report long waiting lists for assessment, diagnosis, and treatment (Young Minds, 2022). The COVID-19 pandemic also brought an unprecedented mental health crisis (UNICEF, 2021), increasing the burden in over-stretched CAMHS. Although it is difficult to obtain an accurate assessment of mental health disorders, one survey study suggested probable mental health disorders increased from one in nine (12.1%) to one in six (16.7%) of 7–16-year-olds in 2020, although rates have remained stable since. In 17–19-year-olds, rates have continued to rise throughout this period from one in ten (10.1%) in 2017 to one in four (25.7%) in 2022 (Newlove-Delgado et al, 2022). It is likely that this increase has exacerbated waiting lists, with reports from clinicians suggest a subsequent influx of referrals post-lockdown, particularly with complex and crisis cases (McNicholas et al, 2021). Thus, it is perhaps more important than ever that we understand how best to support young people who are on a CAMHS waiting list.

Previous research indicates that waiting lists are detrimental to children and young people. For example, excessive waiting times are a barrier for accessing care and associated with negative outcomes such as deterring families from seeking help (Reardon et al, 2018), and could be a barrier to engagement in treatment (Sherman et al, 2009; Westin et al, 2014). Most research on 'waiting lists' focusses on how to avoid missed appointments or effectively manage booking/triage systems, there is less evidence on how to best support children and young

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people who are on waiting lists. In recognition of this, the James Lind Alliance (JLA) acknowledged developing CAMHS waiting-list interventions (WLI) as a top-10 priority (https://www.jla.nihr.ac.uk/priority-setting-partnerships/Mental-health-in-children-and-young-people/top-10-priorities.htm). Despite this, there are few published papers considering WLI (Thomas et al, 2021) highlighting a need to understand current WLI offered by CAMHS, to explore the barriers/facilitators and benefits/impact on services resulting from their implementation.

The aim of this research was to understand current provision of services for children and young people on CAMHS waiting lists. The study utilised a survey to explore the current provision of WLI in CAMHS, including barriers and facilitators to implementing WLI and the impact of the COVID-19 pandemic. The definition of WLI was co-produced with patient and public involvement (PPI) members, including children and young people and their families. As such, we define a WLI as 'an intervention that is offered to children and young people and/or their families following acceptance of referral, but before the first appointment to CAMHS. WLI could be workshops, psychoeducation, online-delivered interventions, signposting to charities which deliver a target intervention, social prescribing (e.g. arts, music, sports, volunteering, gardening). The provision of leaflets with brief advice, signposting to apps, websites or charities that do not provide an intervention would not be considered WLIs.'

Methods

Participants

An email to participate in the survey was sent to research and innovation (R&I) departments in the 57 NHS trusts providing specialist CAMHS, eight trusts declined participation due to focusing on COVID-19 or portfolio adopted research only. The survey was therefore sent out to 49 CAMHS teams (survey available upon request). Overall, 18 responses were received from 16 trusts (two trusts covered multiple regional areas with distinct service provision). The response rate was 16/49 (33%). The survey was completed by a CAMHS Clinical Lead (*n*=7) or Director (*n*=2), Service Manager (*n*=3), Practitioner/Psychiatrist (*n*=3), and Head of Quality or Operations (*n*=3). Responses were received from at least one trust in each Health Education England region, however, exploration of regional differences was not possible due to the limited response.

Procedure

A survey was developed by the research team with support from PPI at Young Minds, a national mental health charity. Young people and/or their families were asked to provide information about the draft survey, additionally they were asked to provide any questions that they wanted to ask that were not covered by the survey, as well as providing comments about how to define a WLI. The R&I department of each NHS trust with CAMHS was asked (March-June 2021) to nominate one CAMHS staff member to complete the survey hosted via JISC (https://www.onlinesurveys.ac.uk/). The nominated CAMHS staff member was asked, via email, to read the participant information sheet and consent form online before responding to the WLIs survey questions. The survey was closed in September 2021. Data were extracted to Excel and analysed descriptively.

Ethics

Informed consent was obtained prior to the survey. The study was approved by the Health Research Authority (HRA; 20/HRA/5198 01.12.20) and the Faculty of Medicine and Health Sciences Research Ethics Committee, University of Nottingham (FMHS 109-1020 8.01.2021).

Results

The 18 responses reflect trusts that did (n=12) and did not (*n*=6) offer WLI, these are presented separately.

What waiting-list interventions are currently offered to children and young people?

The range of WLIs offered for different disorders varied considerably and can be broadly categorised as: digital interventions; face-to-face and/or telephone support; others.

Digital interventions included NHS approved apps such as Blue ICE and unnamed mindfulness apps used in 3 trusts (*n*=3) and online support or platforms provided by Kooth (*n*=5), SilverCloud (*n*=2), TogetherAll (*n*=1) and THRIVE (*n*=1). A trust-specific online digital platform was also used by one trust to reduce referral times, allow children and young people to self-refer, and provide assistance and support through digital technology. Digital waiting list support for parents/carers and/or teachers was provided by six trusts. This included: online parent support groups (*n*=2); referrals to online parenting programmes for ADHD (*n*=1) and behavioural/attachment difficulties (*n*=3); online workshops/webinars for condition specific psychoeducation and/or introduction to CAMHS (*n*=6); and online guided self-help (condition specific) including a slideshow/booklet (*n*=2).

Face-to-face or telephone support was provided by six trusts and included risk assessments and/or crisis support. These were mainly for generic use, suicide/self-harm and eating issues (all *n*=3). Brief low-level interventions delivered face-to-face were offered in three trusts, usually for mood disorders (*n*=2) or generic use (*n*=1). Another trust provided psychological well-being practitioner support but the specific intervention was not specified.

Four trusts mentioned signposting to charities/third sector organisations or other services, and two provided leaflets (it was not clear whether these met our criteria for WLIs). Although not mentioned in our definition of WLI, additional staffing was mentioned by two trusts.

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Table 1: Evaluation of main WLIs

				Informal evaluation	Formal evaluation				
Name of main WLI	**Aimed at**	**Duration of WLI**	**Type of therapy**	**Results**	**Cost effectiveness**	**Patient satisfaction**	**Patient symptoms**	**Further support**	**Time release for clinicians**
GBI	Both	5–8 sessions	CBT		NK	NK	NK	NK	NK
KOOTH	CYP	NDL	CBT		Cost effective	Pos.change	Pos.change	Pos.change	Pos.change
Thinking Differently	Both	One session	CBT			Pos.change		NK	
Silvercloud	CYP	5–8 sessions	Psychoed.		NK	NK	NK	NK	NK
Online workshops	Parent	2–4 sessions	No therapy			NK	NK	NK	NK
Signposting	Both	5–8 sessions	No therapy		NK	NK		Pos.change	
ED assessment	Both	2–4 sessions	Psychoed.	Manages risks, engages family, earlier care		Pos.change			
Risk management	Both	NDL	No therapy	Improve anxiety and sleep	NK	Pos.change	Pos.change	Pos.change	Pos.change
Support phone calls	Both	NDL	Psychoed.						
Band4 staff support	Both	NDL	Psychoed.	Improved patient satisfaction					
F to F support	Both	One session	Psychoed.	No change					
THRIVE	Both	NDL	No therapy	Improved patient satisfaction					

Notes: CYP=children and young people, Both=parents and CYP, ED=eating disorders, GBI=group-based intervention, NDL=No defined length, NK=evaluated but not known, Pos.change=positive change

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Main WLI

Trusts described the WLI that was most frequently offered or most established in their service. There was no consensus in the main WLI across trusts (see *Table 1*). Interventions were aimed at both parent/carer and children and young people (*n*=9), children and young people only (*n*=2) and parent only (*n*=1). From those including children and young people as the recipient (*n*=11), guidance/support was provided to parents/carers at how best to get the children and young people to engage in the WLI in six trusts. The number of families supported by WLIs varied considerably across trusts (from 30–13 000 per year). Most trusts (8/12) stated that their intervention was suitable for a person with a disability, but only 4/12 were available in languages other than English. Funding for the WLIs was obtained internally (by the NHS) in five trusts, funded in partnership or commissioned in four trusts and not funded in two trusts. Trusts were asked if they had completed any formal (*n*=9) or informal (*n*=5) evaluation of their main WLI (see *Table 1*).

What are the barriers and facilitators to implementing WLI?

The implementation of the WLI was led by CAMHS managers (*n*=5), clinicians (*n*=5), commissioner (*n*=1), or a digital team (*n*=1). Most trusts decided to implement WLIs for multiple reasons, but primarily across all trusts to support patients and families (*n*=11), and because it addressed a clinical need (*n*=8). WLIs were implemented to be used as an initial management while waiting for support (e.g. online parenting programme) in six trusts. Only four trusts had developed a WLI as a result of the COVID-19 pandemic.

The factors informing the decision as to which WLI to implement included: recommended (*n*=6), patient demand (*n*=6), evidence-based (*n*=5), cheap to implement (*n*=2), and other (*n*=3). Other factors included:

> *'Recruitment difficulties, long waiting times, easier to employ more junior staff the service needed to provide something as some patients were left waiting far too long after an assessment with nothing offered other than wellbeing calls'.*

> *'The initiative came from the position that if we offered some low-level CBT & guidance on useful resources or support some clients may get better whilst waiting'.*

In terms of challenges to implementation, half the trusts reported that there were very few challenges to implementation (*n*=6), however, the other half reported that there were several (*n*=3) or many (*n*=3) challenges including managing family/children and young people expectations (*n*=4), funding (*n*=3), engagement (*n*=3), and location (*n*=3). To address these barriers staff had increased clinician support to help families engage and regularly reviewed provision. Another issue, reported by six trusts was 'Safeguarding, risk management, recording' issues, in response, staff had increased communication and developed robust recording systems and protocols.

One of the main challenges was staffing reported as an issue by 10 trusts. Qualitative comments relating to staffing included those relating to recruitment, resources, staff capacity and referrals. One participant reflected:

> *'Recruitment of generic posts is at its worst in the careers of many team leads and this has meant specialist staff stepping out of role to case manage and this increases the more hidden internal waiting lists'.*

Funding for preventative services to stop escalation of mental health difficulties was also raised:

> *'There is a real lack of funding for below-CAMHS interventions that could prevent people joining the waiting list and also to allow us to stepdown when the YPs are appropriate for discharge'.*

Other types of support staff felt that they needed included:

- National guidance on waiting lists
- Training and development for staff particularly in digital platforms
- Information about supporting children and young people to access education.

Has the provision of WLI been influenced by COVID-19?

Three trusts had been using WLIs for a considerable time (starting in 2011, 2016 and 2019 respectively). The remaining trusts began using WLIs between 1/4/2020 and 1/5/2021. However, only four trusts implemented WLIs as a consequence of COVID-19, two of which were already in the process of being implemented.

Trusts which do not currently offer WLIs

From the six trusts that did not offer WLIs, none had active plans to offer WLIs in the future. The reasons given included insufficient staffing (*n*=4), unclear of benefit (*n*=2), no evidence based WLI (*n*=2), too expensive (*n*=1), no services available to offer the WLI (*n*=1). One trust also commented:

> *'Waiting time are below 2 weeks in all areas of referral, so WLI are currently not needed although would be considered in the future if waiting lists were to rise'.*

When asked about the type of help professionals need to offer further support to children and young people on waiting lists, four trusts mentioned more staff/human resources, one trust acknowledged the financial implications and energy needed to have a business plan for this, another the availability of specialist teams/agencies and the availability of materials.

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REFLECTIVE QUESTIONS

- What can CAMHS learn from this study?
- What further research is required to evaluate WLI?
- What other potential barriers may influence the provision of WLI?

KEY POINTS

- The survey showed that WLI were being used in some trusts, but there were variations in trusts need for WLI.
- The range of WLIs offered for different disorders varied considerably and can be broadly categorised as: digital interventions, face-to-face and/or telephone support, others.
- The main barrier to WLI was staffing.
- More research is needed to investigate WLI being offered within CAMHS, particularly focusing on the evidence base and cost effectiveness for these interventions.

Discussion

The aim of this research was to understand the current provision of services for children and young people on a CAMHS waiting list. From those that responded to the survey, 66% had implemented WLIs; however, this figure may not be representative of all CAMHS as it was limited by the poor response rate in the present study. It is possible that services with an interest in WLIs were more likely to respond to the survey. The findings are nevertheless important as there is so little information available about WLIs. There was no consensus in the main WLI across trusts but most interventions were aimed at both the parent/carer and children and young people. Staffing changes were also used in some trusts, for example providing a non-medical prescriber to enable clinicians to spend more time in assessment roles. This is consistent with the service delivery changes identified in previous research (Thomas et al, 2021). Although most trusts claimed to evaluate the impact of the WLI, the majority were unable to report the findings of the evaluation, however, from the few that did these were positive in terms of patient satisfaction, service efficiency, and cost effectiveness. The barriers and facilitators to implementing WLI were explored, the biggest barrier to implementation was staffing. Staff members felt that they would benefit from national guidance on waiting lists and training particularly in digital platforms and WLIs, this is currently lacking. The sharing of the evaluation of WLI across CAMHS would be useful to overcome these difficulties.

In terms of WLI, we found that the majority were digital in nature usually using online support or digital platforms, but also included face-to-face and telephone support. Although it is possible that the increase in remote methods of provision of WLI was influenced by COVID-19, only two trusts reported bringing the WLI forward because of the pandemic. However, this may reflect a sampling bias and it is important to consider the poor response rates in this research; trusts who were most affected by the pandemic may not have responded to the survey requests. The feedback from R&I departments was that CAMHS staff members were unable to complete the survey as they were overwhelmed with patient care. A further limitation is that there are potentially multiple waiting lists within CAMHS services, including as one trust commented 'hidden internal waiting lists', it is important to reflect on this in future research.

Conclusions

WLIs are being used in some trusts to help support young people on waiting lists, with limited evidence of positive evaluation. Further research on the acceptability, utility, and effectiveness of WLI is warranted. Interventions for children and young people and families on waiting lists for CAMHS may be used as a stepped-care approach being offered to all families initially, for some families this may be all the support that they need. How interventions for families on waiting lists are framed is therefore important and the term 'early intervention' may be more appropriate rather than WLI which implies that there will be a need for further treatment or support. **CHHE**

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